World Health Organization

Assessing and supporting adolescents' capacity for autonomous decision-making in health-care settings

A tool for health-care providers

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Contents

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Abbreviations and acronyms

HCP	health care provider
WHO	World Health Organization

Glossary

Adolescent. WHO defines adolescents as people aged 10–19 years *(1)*.

Adolescent-friendly health care and services. The WHO "quality of care" framework *(2)* sets five criteria for health services to be considered adolescent friendly:

- accessible: adolescents can obtain the available health services;
- acceptable: adolescents are willing to obtain the available health services;
- equitable: all adolescents, not just selected groups, can obtain the available health services;
- appropriate: the health services are those that adolescents need; and
- effective: the right health services are provided in the right way and make a positive contribution to health.

To be considered adolescent friendly, services must adhere to the eight WHO global standards to improve the quality of health-care services for adolescents *(1)*.

Anticipatory guidance: Generally defined as discussions and counselling to anticipate and prepare parents or legal guardians, children and adolescents for significant developmental changes (physical, psychological, emotional, social) that may occur between health care visits. Includes all actions to promote progressive autonomy and self-management by adolescents and to help parents or legal guardians to support the autonomy of their child or adolescent. The capacity to express one's point of view and to make decisions requires specific skills. Every health professional has a duty to support children and adolescents in the acquisition of such skills from an early age. Each contact with a child or adolescent is thus an opportunity to provide anticipatory guidance.

Attitude: A person's values and beliefs about a process or person, which influence their behaviour *(1)*.

Competence: A legal concept referring to the right to make an autonomous decision (i.e. a decision taken without authorization by a third party, e.g. parents or guardian). The age of competence depends on the national legal framework. In some high-income countries, minor adolescents are considered competent as long as, in a given situation, their health-care providers consider that they are capable of decision-making. In many other countries, competence is defined legally according to age.

Confidentiality: The right of an individual (e.g. adolescent) to privacy of personal information, including health-care records. Adolescents have the right to privacy during consultations, examinations and treatments. Thus, confidential care is an essential component of the health care of adolescents and supports their autonomy. Health-care providers (HCP) should be able to inform adolescents and their parents or legal guardians about confidential care and its limits. In applying confidentiality, it is also essential to ensure effective communication with parents or legal guardians, as appropriate.

Decision-making capacity: While competence is a legal concept, capacity is a clinical concept that refers to the individual psychological or cognitive ability to make a decision. Usually, four dimensions are considered to contribute to the capacity for making decisions *(3)*: how people understand information about their condition and the available options, how people compare the options by balancing risks and benefits and can discuss the potential consequences of a decision, how people discuss the relevance of the options for their own situation and how people can express a choice and argue it in the light of previous discussions.

Evolving capacity: The capacity of an adolescent to understand matters that affect changes in their life and health with age and maturity *(1)*. The more an adolescent **knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for him or her can transform direction and guidance into reminders and advice, and later into exchange on an equal footing** *(4)*.

In health care, evolving capacity means that, as the adolescent matures, his or her views have increasing weight in choices about care. The fact that the adolescent is very young or in a vulnerable situation (e.g. has a disability, belongs to a minority group, is a migrant) does not deprive them of the right to express their views, nor does it reduce the weight given to the adolescent's views in determining their best interests *(5)* and, hence, choices on aspects of care.

Informed choice: A choice made by an adolescent on the elements of his or her care (e.g. treatment options, follow-up options, refusal of services) as a result of adequate, appropriate, clear information for understanding the nature, risks, alternatives to a medical procedure or treatment and their implications for health and other aspects of the adolescent's life. If there is more than one possible course of action for a health condition or if the outcome of a treatment is uncertain, the advantages of all possible options must be weighed against all possible risks and side-effects. The views of the adolescent must be given due weight according to his or her age and maturity *(5)*.

Informed consent: A documented (usually written) agreement or permission based on full, clear information on the nature, risks and alternatives of a medical procedure or treatment and their implications, before the physician or other HCP begins the procedure or treatment. After receiving this information, the adolescent (or a third party authorized to give informed consent) either consents to or refuses the procedure or treatment. The procedures and treatments that require informed consent are stipulated in national laws and regulations. Although many procedures and treatments do not require informed consent, the adolescent should be supported to make an informed choice and give assent if they wish.

Rights: Adolescents' health-related rights include at least the following *(1)*:

- Care that is considerate, respectful and non-judgemental of the adolescent's unique values and beliefs. Some values and beliefs are commonly held by all adolescents or community members and are frequently cultural and religious in origin. Others are held by the adolescent alone. Strongly held values and beliefs can shape the care process and how adolescents respond to care. Thus, each health-care provider must provide care and services that respect the different values and beliefs of adolescents. Also, health-care providers should be non-judgemental with regard to adolescents' personal characteristics, life-style choices and life circumstances.

- Care that is respectful of the adolescent's need for privacy during consultations, examinations and treatments. Adolescent privacy is important, especially during clinical examinations and procedures. Adolescents may desire privacy from other staff, other patients and even family members. Staff members must appreciate the needs of adolescent clients for privacy and respect those needs.

- Protection from physical and verbal assault and other forms of degrading and inhuman treatment. This responsibility is particularly relevant to very young and vulnerable adolescents, those who are mentally ill and others who cannot protect themselves or signal for help.

- Information that is confidential and protected from loss or misuse. The facility respects information as confidential and implements policies and procedures that protect information from loss or misuse. Staff respect adolescent confidentiality by not disclosing their information to a third party unless legally required and by not posting confidential information or holding client-related discussions in public places.

- Non-discrimination, which is the right of every adolescent to the highest attainable standard of health and quality of health care, without discrimination of any kind, irrespective of the adolescent's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status of his or her parents or legal guardian.

- Participation in care. Unless decision-making capacity is delegated by law to a third party or the adolescent lacks decision-making capacity as assessed by the relevant authority,[1] the adolescent decides on all aspects of care, including refusing care. The adolescent also decides which family member and friends, if any, participate in the care process. Adolescents' involvement in care is respected, irrespective of whether the adolescent has the legal capacity for decision-making. An adult's judgement of an adolescent's best interests cannot override the obligation to respect all rights of adolescents as stipulated in the Convention of the Rights of the Child *(6)*. This includes the right of an adolescent who is capable of forming his or her own views to express those views freely in all matters that affect him or her and having those views given due weight in accordance with their age and maturity *(1,5)* (see also *Evolving capacity*). The facility supports and promotes adolescent involvement in all aspects of care through related policies and procedures.

Shared decision-making: Based on the premise that both the patient and the HCP are experts and work together in making a medical decision. This concept, which moves away from a unilateral, paternalistic view of decision-making, is now widely acknowledged as an essential component of patient-centred care *(7)*. There are many models of shared decision-making. Most include the following components: describing treatment options, tailoring information, exploring patient preferences (concerns, goals, beliefs and values) and deliberation (seeking a consensual decision) *(8)*.

1 In many countries, health-care providers have the authority to assess whether an adolescent has decision-making capacity; in some circumstances, a decision is taken in court.

1. Introduction

Background and purpose

The right to participate is a fundamental right stated in the International Convention of the Rights of the Child. The definition of “child” in the Convention is children aged 0–18 years. Therefore, all adolescents should be able to participate and freely express their views on any decisions regarding their health, no matter their decision-making capacity. The weight given to their views and their degree of autonomy depend, however, on their decision-making capacity, which in turn depends on their biological maturity (for which age is a proxy measure) and their social, psychological and cognitive maturity, which depends to some extent on age but is also shaped by factors such as social networks, access to education and family context. Evaluation of decision-making capacity is therefore not straightforward for HCPs, many of whom lack training and tools in conducting such evaluations, and age is often used as the sole indicator of maturity.

The Global Accelerated Action for the health of adolescents: guidance for country implementation *(9)* recommends that informed consent be sought from a child when he or she is deemed mature enough to make an informed decision and that decisions on maturity be made case-by-case. This recommendation should be translated into a practical tool for use by professionals in adolescent health to support changes in the practice of youth participation, enhance their capacity and offer care that is in the best interests of adolescents.

From this perspective, the purpose of this tool is to help HCPs in assessing adolescent capacity and to support them in making autonomous decisions about various aspects of their care. The tool is based on shared decision-making and thus considers the perspectives of the individual, families and communities to assess and support adolescents in making decisions about their health. Its aim is to move from a vertical, paternalistic, unilateral view of assessment to a much more horizontal, integrated process, with the adolescent as a partner at the centre of the process.

Target audience

The tool is designed for use by any health professional who is involved in the care of adolescents.

Development of the tool

This guidance is based on an evidence review undertaken by a group of international experts in adolescent medicine, adolescent gynaecology, nursing, epidemiology, public health, law, developmental, forensic and clinical psychology, psychiatry, sociology and bioethics *(10)* and was developed by an panel of 13 professionals representing different contexts and geographical regions with expertise in primary and referral-level paediatric and adolescent health care, children's rights, bioethics, developmental psychology and research in competence and decision-making capacity. Subsequently, a panel of international experts representing United Nations agencies and experts in the field of adolescent health care reviewed the tool for validation and finalization.

Links with other WHO resources

This tool operationalizes recommendations from other WHO documents on adolescent rights-based care, confidentiality and informed consent (Fig. 1).

Fig. 1. WHO documents that address the issues of adolescent rights-based care, confidentiality and informed consent

WHO document	Messages related to adolescent decision-making capacity
Global accelerated action for the health of adolescents: guidance for country implementation	Provides recommendations for policy-makers on addressing consent and assent to health treatment or services in national policies (p. 94)
WHO, UNAIDS. Global standards for quality health-care services for adolescents: a guide to implement a standards-driven approach to improve the quality of health care services for adolescents. Vol. 1. Standards and criteria	Sets standards for rights-based care for adolescents, which require that adolescents be involved in decisions about their own care, that HCPs explicitly respect the adolescent's decision on preferred options and follow-up and that the health facility builds adolescents' capacity in certain aspects of health-service provision.
HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV: recommendations for a public health approach and considerations for policy-makers and managers	Countries are encouraged to examine their consent policies and consider revising them to reduce age-related barriers to access and uptake of care and to provide linkages to prevention, treatment and care after testing. Young people should be able to obtain health care without parental or guardian consent or presence.
WHO recommendations on adolescent sexual and reproductive health and rights	Recommends removal of mandatory third-party (e.g. parent, guardian or spousal) authorization or notification for the provision of sexual and reproductive health services, including information on contraceptive services.

2. Use of the tool

Fig. 2.
The tool has three parts:

1. **The first part** describes situations in which this tool is applicable and gives an overview of the tool at a glance.
2. **The second part** describes the context of which the health care provider should be aware before applying the assessment algorithm described in Part 3.
3. **The third part** describes the four steps in assessing and supporting adolescents' capacity to make decisions on their own care.

Before applying the tool, the user is encouraged to become acquainted with parts 1 and 2. The tool is useful in any situation in which adolescents wish to make an autonomous decision about their health and when either an HCP or parents or legal guardians disagree with their decision. This may include, for example, taking or stopping medication (including contraception), undergoing surgery, undergoing examinations, laboratory tests or other investigations and being admitted to hospital. Further, an adolescent may ask for confidential care in relation to parents or legal guardians. In these situations, the tool can help professionals to decide, with the adolescent, whether they can agree to offer confidential care, partially or fully. In all cases, the social and legal context of the country must be considered.

The tool is designed for assessment of minor adolescent clients. The legal definition of the term "minor" differs among countries. In most, minors are individuals under the legal age of majority (usually 18 years), and the lower age limit is that at which adolescents show significant cognitive capacity to make certain independent decisions, usually from 10–12 years. Although the tool is applicable mainly to individuals aged 10–18 years, younger children should also be involved in their care and invited to express their views, regardless of their age.

3. Context

3.1 Adolescents' rights

According to the United Nations Convention of the Rights of the Child (1989) *(6)*, adolescents should be able to express independent choices, access services and assert their rights. The Convention cites four general principles for guaranteeing the enjoyment of all rights:

- Article 2: Non-discrimination
- Article 3: Best interests
- Article 6: Right to life, survival and development
- Article 12: Participation / Right to have one's views expressed freely (in accordance with the age and maturity of the child)

Although the experience of adolescents differs by region and context, most meet a number of challenges to respect for their rights. These include stigmatization and a negative perception of adolescents, lack of understanding of their developmental needs and the difficulty of balancing a need for protection with their emerging capacity for participation *(5)*. In many places, adolescents are too often presumed to be incompetent and incapable of making decisions about their lives. All countries should move from a paternalistic approach and promote developmentally appropriate participation in accordance with the social and cultural context of the region. This is a fundamental step in respecting the best interests of adolescents, which is predicated on participation, their right to be heard and their opinion given due weight.

In a clinical setting, adolescents' participation is best enhanced through shared decision-making, which is a key component of patient-centred health care. It is based on the concept that both doctors and patients are experts, one on health issues and the other on their health needs. The life context in which those needs arise should be met. They thus work together towards a consensus decision *(8, 11)*. To ensure effective participation of adolescents in all decisions on their health, HCPs must consider many factors, including the influence of developmental stage and brain maturation, which imply consideration of evolving capacity *(1)* rather than having or not having the capacity for decision-making. Moreover, in order to make an informed choice, adolescents should be given developmentally appropriate information in adolescent-friendly language. Other important considerations are ensuring privacy during consultations, examinations and treatment and an attitude that is respectful and non-judgemental of the adolescent's unique values and beliefs *(12)*.

3.2 Developmental perspective

Adolescence is a stage of development in which key milestones are achieved. These include formation of identity, exploration of sexual orientation, evolving autonomy and progress towards adult roles. This life phase is a time of both opportunities and vulnerability due to brain changes and maturation, increased emotional arousal and impulsivity and exploratory behaviour that could lead to risk-taking. The most significant changes in the brain are associated with processing rewards and risks, self-regulation and sensitivity to the influence of peers on decision-making. Adolescents tend to develop intellectual maturity before emotional and social maturity *(13)*. The capacity of human beings to foresee the consequences of a decision may be influenced by their emotional state, which is stronger among adolescents, whose brains are maturing, implying strong emotional arousal and weak pre-frontal control. Thus, reasoning capacity for making decisions may be altered in situations of emotional arousal ("hot cognition") *(14)*. HCPs must be aware of these aspects and provide a safe, calm environment for optimal reasoning to enhance decision-making capacity.

Parents also undergo a transition during their child's adolescence and should learn how to encourage self-management and empowerment of their child in all decisions on their health in order to foster their autonomy. This requires a progressive change in parenting, from an active role in decisions to helping them make their own decisions. Health professionals have a duty to empower children and adolescents in making decisions from an early age. Each contact with them and their parents or legal guardians is an opportunity to provide anticipatory guidance *(15)* on these aspects, supporting parents or legal guardians as well as adolescents in this transition through the therapeutic triangle (adolescent–carer–provider) to create a trustful relationship with both. Seeing the adolescent alone for at least part of the consultation while ensuring inclusion of the parents or legal guardians also enhances the transition.

A significant challenge is reconciling evolving capacity during developmental changes in adolescence with concrete evaluation of decision-making capacity at a specific time for a specific situation. In line with adolescent rights, HCPs should move from a vertical view of an "assessment" of decision-making capacity to a more participative, integrated process in which adolescents and their parents or legal guardians are seen as partners, at the centre of the process. In this approach, the practitioner's role is to support the adolescent in making decisions while involving parents and legal guardians as much as is necessary in the best interests of the adolescent.

3.3 Assessment of decision-making capacity

The concept that people are capable of making their own decisions about their health is based on the Nuremberg Code *(16)*, which states that consent to participation in research should be voluntary, which implies that a person has adequate understanding and mental capacity *(17)*. After the Second World War, the duty of clinicians to inform patients properly and not override their autonomy became a central theme in health-care legislation. In 1982, Appelbaum and Roth *(3)* identified four legal standards for evaluating decision-making capacity: the ability to understand the information provided, to engage in reasoning when deciding, to appreciate this information as relevant to one's own circumstances and to express a choice.

There are three situations in which evaluation of decision-making capacity may be required: in the clinical setting, for research purposes and for legal reasons. To understand the issues associated with each situation, *competence* must be differentiated from *capacity*. The former is a legal concept that refers to the right to provide an opinion or make an autonomous decision and the latter is a clinical concept of individual psychological and cognitive ability to understand information, reason and reflect to make a decision *(10)*. Competence and capacity are task- and context-specific. The potential difficulty with regard to children and adolescents is that capacity for autonomy is a continuous variable (evolving degree of capacity), but determination of competence is dichotomous (yes or no).

In evolving capacity, the capacity of an adolescent to understand matters that affect his or her life and health evolve with age and maturity. The more an adolescent **knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for him or her can transform direction and guidance into reminders and advice, and later into exchange on an equal footing** *(4)*.

As adolescents mature, their views have increasing weight in choices of health care. HCPs have the duty to support their views and choices on aspects of care and advocate for their choices in their best interests. Nevertheless, as capacity is specific to each task and context specific, adolescents may have adequate capacity for a given decision but diminished or absent capacity for another medical decision *(18–20)*.

3.4 Legal considerations

Translation of legal logic into clinical reality may be inherently problematic. The legal paradigm is more dichotomous than the clinical reality, as it places less weight on interpersonal differences. In the field of health, diagnoses, treatments and prognoses are constantly influenced by the personal circumstances of the patient. Legally, adults are presumed to be competent unless proved otherwise, whereas children and adolescents are still too often presumed not to be competent, and their competence must be assessed in order to be recognized. National legal frameworks are highly heterogeneous *(21)*. Some countries or states have defined in law the age at which minors can make decisions about their health, but age limits are not defined in most countries, and the task of assessing their competence is left to HCPs and their teams.

The human rights of children and adolescents imply the right to consent and access to confidential care. In its General Comment no. 20 on the implementation of the rights of the child during adolescence, the United Nations Committee on the Rights of the Child *(5)* recommends that States review or introduce legislation recognizing the right of adolescents to take increasing responsibility for decisions that affect their lives. It also states that the right to confidential medical counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit. Adolescents can therefore access counselling and advice without the consent of a parent or guardian, irrespective of age, if they so wish (Art. 39). Consideration should also be given to a legal presumption that adolescents are competent to seek and have access to preventive or time-sensitive sexual and reproductive health commodities and services.

3.5 Ethical considerations

From an ethics perspective, individuals are competent if they are able to make decisions based on understanding and rational reasoning *(22)*. Their decisions thus represent informed, free, self-determined (autonomous) choices that must be respected. The corollary is that informed refusal should also be honoured. This is more difficult to respect in the clinical field, and HCPs tend to conclude that decision-making capacity is lacking when children's legal guardians have other views and express different choices from those of their children *(23, 24)*. This is a thorny issue in adolescent medicine, because adolescents sometimes do not share the view of the health professional or their parents or legal guardian, not because of a lack of discernment but because of different values. In some situations, adolescents are unable to make free, informed, autonomous decisions and require support from adults *(14)*. This ethical dilemma in the field of adolescent health is related to the tension for HCPs of having to make some decisions to protect the adolescent's well-being, even against their will, and the importance of supporting the autonomy of adolescents to make their own decisions.

The principles of medical ethics – beneficence, non-maleficence, respect (autonomy) and justice *(19)* – remain applicable, mainly in the context of clinical care, in addition to the numerous aspects of the assessment and improvement of decision-making capacity in adolescent patients. Although these principles are powerful guides in clinical medicine, they are not considered absolute *(25)* but rather "prima facie duties", i.e. to uphold each principle. As the principles are not hierarchical, even though two or more principles may conflict, no one principle is more important than another. Application of the principles should therefore be based on the context of each situation. In this sense, the principles can be applied in clinical medicine and research to identify moral problems that may arise in different situations. This does not imply that ethical principles are not relevant but rather that they should be complemented by other analytical frameworks, which can resolve conflicts among the principles as an essential element in decision-making.

Thus, while ethical principles are important in decision-making, they do not always provide answers to all the questions or conflicts that may arise. When principles conflict, deliberative balancing *(25)* may provide reasons for considering one value more important than another. The tool described here integrates the perspective of rights, ethics, context, social determinants and vulnerability into the decision-making process.

4. Four steps in assessing adolescent capacity for autonomous decision-making in health-care settings

The step-by-step process described below is based on the principles of shared decision-making and people-centred care *(26)* from the perspectives of individuals, their family and their community. The tool is designed to be used to assess and support adolescents in making decisions about their health. It includes elements of assessment of cognitive capacity for decision-making and adds a broader evaluation of risks and resources and the emotional state of adolescents, all of which influence their health and decision-making. It is therefore a fully integrated part of care rather than a separate process.

4.1 Overview

The tool is summarized in Fig. 3.

Fig. 3. Practical steps for assessing and supporting adolescent capacity for autonomous decision-making

The four steps are:

1

Joint exploration of the situation and options: Explore with the adolescent the important elements of decision-making and the overall situation, including the adolescent's psychosocial life, risks and resources. The role of the professional is to provide all the necessary information in appropriate language on the framework of care, the medical condition and the options to help the adolescent in making a choice.

2

Common synthesis of the situation: Summarize the issues raised in step 1 and ensure common understanding. The HCP should be particularly attentive to elements that are likely to alter a decision and address them as appropriate to allows deliberation with the adolescent and any relevant partners in order to reach a consensual decision. The involvement of parents or legal guardians and other relevant people should be discussed with the adolescent.

3

Decision point: Decide whether the adolescent has the capacity to make an autonomous decision in a given situation at a given time.

4

Follow-up: Outline guidelines for follow-up, whether or not consensus is reached on a decision.

Although the process has four steps, it is not designed as a rigidly linear process. An integrated, dynamic approach should be used, with reiteration of the different steps as necessary. Clinicians need not go through the steps in a single consultation. Unless an urgent decision is required, the HCP is invited to plan at least two consultations.

As not all situations have the same degree of complexity, less complex situations might not require all the steps in detail. An evaluation of the complexity of a situation is left to the discretion of the HCP.

4.2 The four steps

The assessment steps are summarized in an algorithm (see Web Annex) and described below.

The HCP should create an empathetic, trustful, respectful environment and thus have the necessary attitude and communication skills. He or she should be aware of the general framework for adolescent-friendly health care. The HCP should also be aware of the framework of care that supports autonomous decision-making according to local legal and social norms and recognize the importance of the fundamental rights stated in the Convention on the Rights of the Child as the normative and legal foundation for providing services. The HCP should understand how the Convention has either been incorporated into domestic legislation or can be invoked by the judicial system.

Early in the process, adolescents should be given all the necessary information on their health-related rights, in particular their right to participation and confidentiality, in developmentally appropriate language. This includes information on the extent to which their rights are respected and protected under national law. Adolescents should also be informed about support for their shared decisions.

4.2.1 Joint exploration of the situation and options

This first step helps HCPs to explore the overall situation and available options with an open mind, jointly with the adolescent.

Exploration of the psychosocial context, including resources and vulnerability factors

Decisions, especially complex decisions, cannot be made without exploration of the adolescent's overall and psychosocial situation. They may be vulnerable in a number of ways that could either alter their decision-making capacity or threaten their healthy development if they make a particular decision. It is also essential to identify the resources that can help the adolescent in making decisions.

The HCP could use examples of questions adapted from the "home, education/employment, eating, activities, drugs, sexuality, suicide/depression, and safety" (HEEADSSS) questionnaire for adolescent psychosocial history *(27)*. They should be attentive to the adolescent's emotional state and provide a safe, calm environment for optimal reasoning, to enhance decision-making capacity.

Exploration of the decision and options with the adolescent – understanding, reasoning, comparison of options, appreciation, expression of choice

This step addresses the decision itself. It allows adolescents to reflect in depth on their medical situation and the options available in the light of information provided by the professional. It represents an opportunity for the professional to evaluate the adolescent's ability to understand their situation, to consider the options and to appreciate them in relation to the situation in order to express a choice. HCPs are encouraged to use motivational interviewing techniques *(28)* to explore the reasons for and against a certain decision with the young person. The steps of understanding, reasoning, appreciation and expression of choice reflect the four standards proposed in 1982 which are included in the MacCAT-T tool for evaluating the decision-making capacity of adults *(29)*. The HCP may apply these standards during the joint exploration. At the end of this step, the adolescent expresses a choice.

The tool provides examples of questions related to each of these standards to help the HCP in guiding the discussion and reflection. The HCP should also assess the emotional state of the adolescent and ensure an optimal environment for them to reflect on their decision ("cold cognition").

4.2.2. Common synthesis of the situation

The second step is to synthesize the overall situation with the adolescent, with or without their parents or legal guardian, and reach a consensus.

Summary of the main issues

The HCP should summarize the key issues raised in previous discussions and ensure common understanding of them with the adolescent and other relevant persons, as appropriate. The HCP should observe the influence of the beliefs, values and representations of everyone involved and also the influence of their own experience, beliefs, values and representations on their perception of the situation. The professional should assess the extent to which the adolescent is free to express their own choices and opinions and to maintain them in the face of conflicting views (e.g. from the HCP, parents or legal guardian).

Consensus-building

A discussion takes place to reach consensus on the decision. The HCP and the adolescent will determine who else should participate in the discussion, such as the adolescent's parents or legal guardian, another trusted adult or other professionals who know the adolescent well (e.g. teacher, educator, mental health provider, social worker). During the discussion, the HCP may include a bioethical perspective, at least in their own reflections. Depending on the complexity of the situation, the HCP may also consider discussing it with another professional who is less emotionally involved or within their team. When available, an expert in bioethics could be involved.

4.2.3. Decision point

At this stage, the HCP decides whether the adolescent has or has not the capacity to make an autonomous decision. If a minor adolescent is considered to have the capacity, the HCP should further reflect on the situation to determine whether protection is necessary according to the legal context of the country. In some countries, for example, the law states that health professionals are obliged to report a minor in danger to the protection authority.

If the decision puts the adolescent's development at major risk, the decision should be deferred if possible, even if the adolescent has the capacity, to consider with the adolescent solutions to minimize the risk. If the adolescent is considered not to have the capacity to take decisions or their capacity is questionable, the decision should be deferred if possible to determine how to support the adolescent.

4.2.4. Follow-up

Adolescent's autonomous decision and organization of follow-up

Decision-making capacity and medical conditions evolve over time. Therefore, any important decision must be followed up, planned in consultation with the adolescent, with or without the parents or legal guardian and any others. The HCP should describe the conditions and framework for follow-up. The extent to which parents or legal guardians are to be involved and the feedback that they will receive are of particular importance and should be discussed with the adolescent.

Follow-up visits should be scheduled as appropriate. At each subsequent visit, the discussion should address the following elements: barriers to and impact of implementation of the decision, whether the decision should be reconsidered, evolution of the medical condition, the needs of the patient and the parents or legal guardian and psychosocial context and well-being.

Professionals have a duty to support children and adolescents in making decisions from an early age. Each contact with a child or adolescent is thus an opportunity to provide anticipatory guidance on these aspects. To ensure that anticipatory guidance empowers adolescents, HCPs should practise self-reflection and self-management and avoid a paternalistic explanatory approach. The HCP may use concrete examples of how this can be done.

Deferral of a decision for further exploration

When an adolescent does not have the capacity for decision-making, if their capacity is questionable or if a consensus is not reached because of concern that the adolescent needs protection, the decision should be deferred, if possible, to explore the reasons. The steps of the process should therefore be repeated to find solutions with the adolescent (with or without the parents or legal guardian) to reach a new consensus. Most of the time will be spent in determining why consensus was not reached previously and how it could now be reached.

The HCP should remain alone in this step but should discuss the situation with at least one other professional who is less emotionally involved.

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