MEDICAL
ETHICAL
GUIDE-
LINES

Ethics support in medicine

Recommendations

Ethics support in medicine

In various guidelines issued by the Swiss Academy of Medical Sciences (SAMS), it is recommended that ethics support[1] should be sought. In recent years, numerous services of this kind have been developed in Switzerland, ranging from the provision of ethical opinions in individual cases to assistance with the elaboration of ethical guidelines or the organization of continuing education events on ethical topics.

However, ethics support structures (ethics structures) are only useful if they fulfil their functions in an appropriate manner. The Introduction to „Ethics support in medicine" defines the aims and tasks of such structures, while also drawing attention to their limits and to associated risks and misconceptions.

The Recommendations emphasize the wide variety of possible structures and methods, and explore key aspects of the activities concerned. When is it advisable to seek ethics support? What points are to be considered with regard to decisions on individual cases, the development of general ethical guidelines, or undergraduate, postgraduate and continuing education? Guidance is also offered on the establishment of ethics structures. What structural conditions need to be met? How can the independence of an ethics structure be guaranteed? What basic attitudes, knowledge and skills are required on the part of the members? How should such a structure be made up, and how can its visibility be enhanced? Finally, a checklist of practical considerations is given (Section 3.6) in order to facilitate the choice of an appropriate structure in particular cases and the organization of consultation processes.

To date, ethics structures have been established primarily in major acute-care hospitals, but they are increasingly also being developed in other areas, both in inpatient and outpatient settings. The requirements applicable for ethics structures in different types of setting are therefore reviewed in this document. Various methods of ethics support are described (and further references given) in the Annex.

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1 The term «ethics support» (for which no exact equivalent exists in the French or German literature) covers the development and promotion of ethical knowledge, skills and attitudes in the practices of healthcare institutions. It encompasses all types of support: consultations, opinions, etc.

I.   INTRODUCTION

Ethical problems are frequently encountered in medical practice. These include, for example, decisions concerning the maintenance or withdrawal of life-support measures in cases where the prognosis is poor, respect for – and limits to – patient[2] autonomy and the equitable allocation of resources in the face of rising healthcare costs; in all of these situations, conflicts of values arise in relation to important issues. Guidance and support for healthcare professionals confronted with such situations are provided by medical-ethical recommendations and guidelines, such as those of the SAMS. However, such recommendations and guidelines can only contain considerations of a general nature. In individual cases, reflection and decision-making will need to be adapted to the context and to the specific features of the situation. Here, the various forms of ethics support can offer assistance.

As in many other countries, ethics support structures (ethics structures) are developing rapidly in Switzerland. In several SAMS guidelines, it is recommended that ethics support should be sought.

In view of these developments, the SAMS carried out a study of the ethics support services available at healthcare institutions in Switzerland[3]. In this document[4], the basic requirements to be met by activities of this kind are defined. While ethics support cannot replace the kind of ethical reflection which is typically required in day-to-day clinical practice, it may offer additional aid in dealing with ethically difficult situations; it must however be structured in such a way as to provide real support.

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2   Throughout the text, for the sake of readability, the masculine form is used in a gender-neutral manner.

3   Cf. Salathé M, Amstad H, Jünger M, Leuthold M, Regamey C. Institutionalisierung der Ethikberatung an Akutspitälern, psychiatrischen Kliniken, Pflegeheimen und Einrichtungen der Rehabilitation der Schweiz: Zweite Umfrage der Schweizerischen Akademie der Medizinischen Wissenschaften. Bioethica Forum. 2008; 1(1): 8–14.

4   SAMS recommendations are less binding than SAMS guidelines, which – once they are incorporated into the Code of the Swiss Medical Association (FMH) – have to be complied with.

1. Aims

Ethics support is designed to facilitate decision-making for individuals and institutions facing ethically difficult situations which involve value conflicts. It should also enhance the transparency of decision-making processes, promote the recognition of conflicting values or interests and indicate ways of resolving such conflicts. Any opinions offered are of a consultative nature: the legitimacy of ethics support is based solely on the arguments put forward. Responsibility for decision-making rests with the physician and the care team, and the role to be assigned to patient autonomy remains unchanged. The idea is not to make ethics structures irreplaceable or to absolve care teams of their responsibility, but to offer systematic support for care teams and management in dealing with ethical problems and conflicts. Ethics support thus also helps clinical teams treating and caring for patients to tackle ethical problems themselves. Ethical reflection methods can help to inform routine measures and specific decisions, and to define structures and procedures in hospitals, clinics and other institutions, as well as in outpatient and community care. Such methods should promote:

– due consideration of the patient's wishes throughout the treatment process,
– the quality of decisions and practices, and depth of reflection,
– conscious assumption of responsibility and interprofessional collaboration,
– transparency and traceability of decisions.

Ethics structures should thus make a significant contribution to the quality of treatment and other services. While ethical reflection may also be implicitly involved in other contexts, the present recommendations are exclusively concerned with structures which are explicitly devoted to ethical reflection.

2. Tasks

Ethics support may include (retrospective or prospective) consultation in individual cases, support for institutional management, the development of general ethical guidelines and contributions to undergraduate, postgraduate and continuing education in ethics, as well as research in ethics and other activities.

3. Limits, risks and misconceptions

To avoid any misunderstandings, it is important that the aims and role of ethics structures should be clearly defined:

– Ethics support cannot replace legal advice or mediation in cases of conflict.
– Ethics support is not indicated in all difficult situations, but only where value conflicts are involved.
– Ethics structures are not intended to restrict the decision-making authority of physicians or nursing staff, but to provide methodological support. Ethics structures play a consultative role and should not come to be regarded as exercising a control function.
– Ethics structures must be independent: to serve a useful purpose, they must be able to formulate recommendations and opinions freely within healthcare institutions.
– An ethics structure must aim to provide practical support, rather than being a body established purely for administrative reasons. Accordingly, the SAMS does not support the idea of ethics support services being a prerequisite e.g. for hospital accreditation, as is the case in the United States.
– Ethics structures do not serve the same function as Cantonal Ethics Commissions, which are responsible for the evaluation of research projects and thus have decision making powers.

4. Target audience

These recommendations are addressed in particular to clinical ethicists[5], members of ethics structures and any other persons explicitly involved in the provision of advice or opinions concerning ethical issues arising in medicine.

They are also addressed to inpatient or outpatient institutions (regardless of size) which plan to establish or have already established an ethics structure, as well as to healthcare professionals[6] who require ethics support in a particular field of medicine.

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5 «The terms ethicist, clinical ethicist, ethics consultant and bioethicist refer to a specialist in bioethics, i.e. a person with an academic background in the humanities/social sciences or in biomedical or health sciences who has been trained in the methods of bioethics (analysis of ethical problems in biomedicine from a multidisciplinary perspective). The ethicist›s tasks are generally twofold: acting as a hospital ethics consultant in efforts to resolve difficult clinical cases and providing instruction in bioethics for healthcare professionals.» (cf. Hottois G., Missa JN. Nouvelle Encyclopédie de bioéthique. Brussels: De Boeck Université, 2001)

6 The term «healthcare professionals» covers physicians, nursing staff and other therapists.

1.   Structures and methods

The type of ethics structure chosen will depend on the tasks it is to perform. At present, no particular type of structure stands out as superior to others, either in theory or in practice. It is important to decide whether ethics support is to be provided by a group (committee or team), by an individual, or by both. An ethics structure may be maintained by an organization (e.g. hospital, nursing home, home care provider) or a network. It may also be jointly maintained by a group of such entities.

Different methods exist for the provision of ethics support in individual cases. It is not currently possible to recommend one method in particular, either on philosophical or on empirical grounds. The SAMS welcomes research in this area. The choice of a method or methods should be determined in the specific context and on the basis of the tasks to be performed by the ethics structure. The present recommendations define minimum requirements which are to be met irrespective of the approach(es) adopted.

2.   Ethics support

2.1.   Requests for ethics support

Any requests concerning a situation which is felt to pose ethical difficulties (manifested e.g. by a sense of unease, disagreement or uncertainty as to how best to proceed) may fall within the remit of an ethics structure. The topics may include, for example, uncertainties regarding treatment decisions, resource allocation, the duties of physicians or nursing staff, uncertainties arising in an intercultural context, end-of-life decisions, or the application of restraint measures. Ethics support for an individual case may be requested by anyone who is directly involved in the situation.

All requests are to be recorded, with confidentiality being maintained. A decision will then be taken on whether a request is be dealt with by the ethics structure itself or referred to other bodies (e.g. ombudsman, legal department). Requests arising from a value conflict are to be dealt with by the ethics structure.

2.2. Ethics support in individual cases

Ethics support in individual cases should be provided in an interdisciplinary manner, with all the members of the care team being involved as far as possible. Various methods may be adopted and members of the care team may be involved in different ways. For example, a member of the ethics structure could act as a facilitator in the care team's decision-making process. Alternatively, the ethics structure could offer a recommendation concerning a problem submitted by the care team. These two methods could also be combined. It is important to clarify the participants' values and to draw attention to the relevant ethical guidelines and legal foundations, as well as positions represented in the literature. Questions submitted to an ethics structure frequently require a rapid response. The ethics structure should therefore be organized in such a way as to enable it to respond appropriately to urgent requests.

Ethics structures should also determine how patients and their relatives are to be involved in the ethics support process. If an ethics support process involves members of a clinical team who are also members of the ethics structure, they are only to participate in their capacity as clinical team members.

If no consensus is reached, it is preferable to set out the arguments for each of the positions adopted, rather than seeking to convey an impression of unanimity (e.g. by means of a vote).

At minimum, the situation, the issue, the participants, the solutions proposed and the justifications offered are to be documented; if a member withdraws from the process – e.g. owing to a conflict of interest – this should also be recorded. The way in which the conclusions are to be communicated and implemented is also to be recorded. The minutes should be dated and, if necessary, a date set for a review. The person responsible for this procedure is to be specified. The fact that a clinical ethical consultation has taken place and any points relevant to the management of the patient should be noted in the patient's records; the patient will thus have access to this information.

Ethics support in an individual case may be provided either prospectively or retrospectively. Discussion or presentation of an ethical case may be included in a continuing education event. All the participants should be made aware of the didactic purpose.

2.3. Development of general ethical guidelines

Ethical guidelines deal with recurrent problems or value conflicts, such as the implementation of advance directives, resuscitation, restraint, end-of-life nutrition, or blood transfusion in Jehovah's Witnesses. They are developed in response to questions arising in an inpatient or outpatient setting or at long-term care institutions. They are prepared by the ethics structure in collaboration with other professionals concerned and with members of management. If necessary, additional experts may be consulted.

Ethical guidelines comprise substantive recommendations, a detailed ethical justification and explicit reflection on values, addressing the specific problems of the organization concerned. They must be in accordance with legal requirements and the medical-ethical guidelines of the SAMS, taking account of current scientific knowledge. When a draft version of the guidelines has been prepared, it should be reviewed by the departments and users most closely involved in the practices in question.

Such guidelines can only become binding if they are adopted by the managers responsible. Their applicability and binding force should then be clearly indicated within the organization. Information on new guidelines is to be provided at introductory events, internal briefings, and undergraduate, postgraduate or continuing education sessions and/or disseminated via internal publications (magazines, intranet, etc.).

Ethical guidelines are to be updated regularly and, if necessary, adapted to ensure that they remain applicable in practice.

2.4. Undergraduate, postgraduate and continuing education

Ethics structures can make a significant contribution to undergraduate, postgraduate and continuing education, thanks to their experience in dealing with the problems which arise within the institution.

Ethics structures should provide undergraduate, postgraduate and continuing education for their members. The undergraduate, postgraduate and continuing education provided by an ethics structure for members of the institution to which it is attached should include both theoretical knowledge and practical skills.

Members of an ethics structure can also help to educate the public on issues in clinical ethics, e.g. by taking part in lectures or discussions.

3. Establishment and maintenance of ethics structures

3.1. Structural conditions and independence

Ethics structures should be firmly established within the host organization; management should support them and provide them with the necessary resources. The human and material resources made available (e.g. administrative office and resources for training of members) should reflect the tasks assigned to them. This also implies that, as far as is reasonable, the members of an ethics structure should be able to carry out their duties during working hours.

The profile and mission of ethics structures should be clearly defined. Interfaces with other units dealing with related questions (e.g. legal department or mediation services) need to be defined.

The provision of ethics support presupposes an organizational culture which is open to discussion of issues that may be controversial, to possible ethical conflicts, to interdisciplinary exchanges and to the possibility of drawing practical conclusions. It also requires a critical mass of commitment to clinical ethics among employees. Where sufficient interest is lacking, it can be fostered by undergraduate, postgraduate and continuing education.

Ethics structures must be accessible. Management should ensure (e.g. by making sufficient time available) that ethics support can in fact be sought. It should be possible to seek ethics support at any time without first obtaining the approval of superiors. This will be facilitated if ethics support is perceived not as a threat, but as a source of assistance.

The value of ethics structures is based on the independence of their function and on their structural links to the host institution. They should operate as independently as possible, reflect critically on any dependencies – including the effects of socialization within the institution – and ensure that any interdependencies are managed transparently so as to guard against instrumentalization. They should be able to act on their own initiative. Independence can be promoted e.g. by part-time work, participation in networks and the specification of independence in contracts, etc. A sufficient degree of independence is to be guaranteed by the by-laws.

3.2. Establishment of an ethics structure

The establishment and development of an ethics structure within an organization requires effective coordination of bottom-up and top-down initiatives. A unilateral process will have little chance of succeeding: requests, or even demands, made by practitioners will be to no avail if an ethical sensibility is lacking on the part of management. Conversely, an offer of ethical support resources for which staff see no need will be equally fruitless.

Initially, if an institution wishes to establish an ethics structure, a proposal should be prepared by a small, interdisciplinary group whose members are drawn from various hierarchical levels and include at least one person with appropriate qualifications in ethics. This group should agree on a definition of „ethics support", gain an overview of existing methods (cf. Annex) and elaborate a concept and by-laws in which the function and form of the ethics structure are specified. Initial awareness-raising – e.g. through training events or seminars – may be useful. It is also important to clarify from the outset the tasks of the ethics structure and the limits to which it is subject.

3.3. Composition

If an ethics structure comprises a number of people, it is essential to ensure a degree of diversity in its composition. It should include at least the following:
– representatives of various professional groups and disciplines;
– people from different hierarchical levels within the organization;
– an ethicist[7] or other individual with advanced training in clinical ethics. The ethicist may also act as a consultant to the structure.

It is also recommended that the members should include:
– one or more external representatives of a medical profession;
– a lawyer, psychologist, social worker, chaplain, etc.;
– other external lay members[8].

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7 Cf. footnote 5.

8 These may be patients, patient representatives, relatives, or other individuals not attached to the institution who are interested in serving as a member of an ethics structure.

3.4. Basic attitudes, knowledge and skills

All ethics structures should meet the requirements specified below, regardless of whether the structure consists of a committee or an individual. In the case of a committee, certain requirements may be fulfilled by one or more members.

As regards basic attitudes, the members of an ethics structure should be:
– prepared to reflect on their own values;
– able to formulate and defend their own views;
– prepared to reconsider their initial opinion in the light of group discussions;
– prepared to play an active part;
– open to discussions with people who have different viewpoints;
– open to other disciplines and professions;
– prepared to gain a realistic picture of day-to-day clinical practice;
– prepared to undergo continuing education in ethics.

As regards knowledge and skills, the members of an ethics structure should, as soon as possible:
– be able to distinguish between ethical reflection and moral judgement;
– be familiar with the various ethical theories and capable of applying theoretical arguments to practical cases;
– be capable, in a concrete situation, of distinguishing the key values from the key facts, i.e. aware of the difference between the normative and the descriptive;
– be capable of distinguishing ethics from law and seeing how the two are interrelated;
– be aware of the main issues in medical ethics;
– be aware of the main sources in medical ethics (SAMS guidelines, WMA International Code) and nursing ethics (SBK/ASI, ICN Code);
– be aware of the organizations responsible for professional ethics (e.g. SAMS, NEK/CNE, FMH, SBK/ASI).

Each of the following should be possessed by at least one of the members[9]:
– knowledge of different ways of structuring ethical reflection in concrete situations and for other specific questions;
– the ability to facilitate ethical deliberations;
– the ability to identify the moral perspectives of all parties concerned;
– detailed knowledge of the structure of ethical arguments;
– knowledge of key stages in the historical development of medical ethics;

9 Meeting these requirements would be demanding, given the human and material resources currently available to ethics structures; however, they are appropriate to the function of these structures and thus represent goals to be aspired to, even if they are not immediately attainable.

- familiarity with earlier and current debates on bioethical issues;
- detailed medical knowledge and the ability to communicate this in a lay-friendly manner;
- contacts with the clinical ethics research community, e.g. via affiliation to a university bioethics institute;
- detailed knowledge of health law.

Depending on the area of activity of the ethics structure, it may also be useful to be able to draw on skills in other fields, such as organization theory, intercultural relations, sociology, psychology and pastoral care. However, knowledge in these specific areas may also be obtained by consulting experts.

The relevant knowledge and skills may be acquired in different ways (e.g. undergraduate, postgraduate or continuing education organized by the ethics structure). The modalities should be defined in the by-laws, which should also specify what is to count as evidence of undergraduate, postgraduate or continuing education. It should be possible for members of an ethics structure to undergo undergraduate, postgraduate or continuing education during working hours.

3.5. Visibility of an ethics structure

A communication strategy plays an important role in raising awareness of an ethics structure and thus making it more accessible. The channels available may vary from one institution to another (e.g. in-house newspapers, web or intranet sites, brochures for staff or patients, posters). Contact details should be provided so as to facilitate requests for ethics support.

3.6. Practical considerations

Three questions need to be addressed:
- What type of structure is appropriate for ethics support in individual cases?
- How should the consultation process be organized?
- What method(s) of deliberation should be used?[10]

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10 Various methods exist, and it is difficult to recommend one unequivocally. Examples of methods are given in the Annex to these recommendations, which is available (in French and German) on the SAMS website.

What type of structure is appropriate for ethics support in individual cases?

Ethics support may be provided by a committee, a small group or an ethics consultant.

– A committee will be able to include a wide variety of viewpoints and specific expertise in ethics, but it will be difficult for it to respond promptly to requests for support in urgent cases.
– An ethics consultant will have expertise in ethics but will need to ensure that the consultation reflects the diverse views held within the team in question.
– A small group will allow for greater flexibility than is possible with a committee, and greater diversity than is possible with a single consultant.

Combinations of these various structures are also possible.

How should the consultation process be organized?

The following practical points need to be addressed:

– How patients and healthcare professionals are to be informed of the existence of the ethics structure.
– The conditions under which ethics support may be requested.
– The procedure(s) for requesting ethics support in individual cases.
– The procedure to be followed if a member of the ethics structure receives an informal request for an ethical opinion.
– The procedure for providing a rapid response in urgent cases, and the minimum period required for issuing an opinion.
– The composition of the group offering ethics support or, if appropriate, how this is to be determined on a case-by-case basis. Also to be clarified is how those who have not requested a consultation are to be involved – i.e. the patient when support is requested by a team, or the team when support is requested by a patient or his relatives.
– How ethical opinions are to be communicated.
– How the conclusions of ethics support are to be documented and archived.
– How confidentiality is to be maintained.

A number of administrative questions also need to be addressed[11]:
– How sufficient ethical expertise is to be assured for each consultation.
– Whether the term of office is to be limited for members of the ethics structure.
– How and according to what criteria new members of the ethics structure are recruited.
– How administrative support is to be assured and what budget is available.
– What resources are available for undergraduate, postgraduate and continuing education for members of the ethics structure.
– If members of the ethics structure participate outside their working hours or if external persons are engaged, how they are to be remunerated.

When an ethics structure is established, these questions should be clarified and the key points set down in by-laws.

3.7. Requirements for specific settings

Existing ethics support methods and structures have developed in response to the needs of acute-care hospitals in particular. But ethics support has to be adapted to meet the needs of different settings. Specific adjustments are proposed below for the following settings: acute care in large hospitals, psychiatry, paediatrics, long-term care, outpatient medicine and community care, prison medicine, and ethics support for the management and administration of healthcare institutions.

Acute care in large hospitals

The first ethics structures were developed in the acute-care setting, and most of the existing models have been tailored to this context. However, it is important to define the specific features which distinguish acute-care hospitals from other settings where ethics structures may operate:
– Relations between employees at a large institution are frequently less direct and less clearly defined than in a smaller hospital. Depending on the size of the institution, different approaches and measures will be required in order to make people aware of an ethics structure, to build confidence and to gain the support (formal and informal) of management.
– Because of the wide variety of cases submitted, members of an ethics structure at a large institution will more often be confronted with situations which go beyond their day-to-day experience, even as healthcare professionals.
– The relatively rapid turnover of hospital staff may jeopardize the minimum degree of stability required for an ethics structure.

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11 Cf. Slowther AM, Johnston C, Goodall J, Hope T. A practical guide for clinical ethics support. Oxford: The Ethox Centre, University of Oxford; 2004.

- The transfers and changes of care team which are typical of a patient's stay at a large hospital may not only themselves raise ethical issues but also complicate the work of an ethics structure.
- In some cases, a number of different ethics structures operate independently of each other.
- A university institute may also be active in the field of medical ethics.

In view of these specific features, the following points should be considered:
- A systematic communication strategy will be required to make people aware of the ethics structure within the hospital.
- Regular rotation of members of the ethics structure may help to raise awareness and ethical sensibility, while also increasing the number of former members in different departments.
- To ensure diversity of clinical experience, the members of the ethics structure should be drawn from different professional groups and medical disciplines within the hospital.
- When members are recruited, it is recommended that preference be given to people who will be working at the institution for some time.
- Because of the high turnover of staff, efforts to raise awareness of ethical issues will need to be repeated periodically.
- The existence of several independent ethics structures should be justified by specific needs, and their respective roles should be clearly defined. Coordination and cooperation is required between the various structures.
- At a university hospital, cooperation should be sought with the institute of medical ethics.

Psychiatry

Patients with psychiatric problems are cared for in both inpatient and outpatient settings. Some of the issues with which ethics structures are confronted are therefore also encountered in other areas of medicine (applicability of advance directives, refusal of treatment, alternatives to restraint measures, requests for assisted suicide, etc.).

Ethical difficulties specific to psychiatry include the following:
– the influence – sometimes fluctuating, sometimes permanent – of the psychiatric disorder on the patient's mental capacity, which is itself a matter for psychiatric assessment;
– the relatively high frequency of cases where a patient may pose a danger to himself, his environment, or nursing staff;
– the important role played by those close to the patient, such as informal caregivers (family), or a legal guardian or tutelary authority, often partners in the provision of care;
– the individualization of treatments (in general, disorders are less amenable to standard treatment protocols).

Accordingly, ethics structures should consider the following points:
– Special efforts are sometimes required to ensure that patients with psychiatric problems are not treated differently from other patients with regard to ethics support (e.g. involvement of the patient and, with his prior agreement, his relatives).
– Recommendations developed for other areas often need to be adapted to the specific requirements of psychiatry. For example, advance directives have become increasingly common in psychiatry. Advance directives, sometimes prepared by the patient and his care team in the outpatient setting or after emergency hospitalization, allow the patient to state therapeutic preferences for possible future crises and to establish a therapeutic alliance.
– Patients with psychiatric problems are more likely to wish to access their records. Documentation of the ethical consultation must – as ever – ensure that the confidentiality of information provided to physicians by third parties is maintained.

In psychiatric practice, the ethical consultation may also represent an opportunity to resume the dialogue between the patient and therapists or to place it on a new footing, so as to better accommodate the patient's needs. This is to be strictly distinguished from an appeal against deprivation of the patient's liberty.

Paediatrics and neonatology

In paediatrics, and particularly in neonatology, a pressing need for structured support in dealing with ethical problems was perceived relatively early; consequently, various models have already been developed in Switzerland. Compared to the adult acute-care setting, the following distinctive features should be noted:

– urgent treatment decisions (e.g. regarding intensive care for extremely premature infants) may have very long-term consequences;
– the prognosis for mortality and long-term morbidity is highly uncertain;
– there is no indication of the patient's presumed wishes in newborns, infants and preschool children;
– the patient's mental capacity develops over time;
– parents act as legal representatives and are at the same time directly and permanently affected by all decisions.

In view of these specific features and the well-established tradition of working in multidisciplinary care teams, ethics structures in this setting should consider the following points:

– It is essential that a sufficient number of members of the ethics structure should have professional experience in the field of paediatrics.
– A certain degree of independence from ethics structures for adults may be advantageous, even if a paediatrics department is part of a general hospital.
– Each structure should determine how parents are to be involved in treatment decisions.
– At least one member should be familiar with the principles of child protection.
– Interfaces should be defined with the child protection groups which exist at all paediatric hospitals and clinics.

Long-term care

Most of those who receive long-term care also reside at the institution which provides it. Here, ethical decisions regarding medical treatment and nursing care arise almost on a daily basis and concern a particularly vulnerable group of patients:

– For physical, mental and/or psychosocial reasons, these patients are largely dependent on other people and particularly in need of protection and support.
– In many cases their capacity for autonomy is limited or their mental capacity is restricted to certain areas or is difficult to assess.
– They often lack the strength or ability to express or assert their wishes without assistance.
– The coexistence of various forms of dependency, as well as relations between patients, relatives and carers, may give rise to tensions or even violence.
– Respect for privacy is difficult in a place where life is lived in a community.

– Residents at a long-term care institution are at increased risk for under- or over-treatment, particularly if they suffer from dementia or some other psychogeriatric condition.
– Many people who work at care homes lack specific professional training or have different cultural backgrounds.
– With long-term care and management, personal relationships may develop between staff and patients; these in turn may have a positive or negative influence on the emergence, perception and resolution of ethical problems.

For everyone involved in long-term care (physicians, nurses, other therapists, social services, pastoral carers), ethical sensibilities and skills are thus indispensable, as ethical decisions need to be taken on a daily basis.

Ethical questions of a more general nature – e.g. ethical guidelines on the deprivation of liberty, assisted suicide, or the development of foundations for ethical decision-making – can be dealt with by an ethics structure composed of different professional groups and hierarchical levels (including representatives of management and the body responsible for the institution). An ethics structure may also be established jointly by a number of institutions.

Outpatient medicine, Spitex (home care), community care

Situations requiring difficult ethical decisions are no less common in outpatient settings than in hospitals or long-term care institutions. However, in most cases, given the lack of explicit ethics structures, these questions are discussed by primary care physicians in Balint groups or quality circles.

A wide variety of ethically difficult situations are encountered in this setting. They include situations where disagreements arise on the nature or proper limits of medical care, or involving patients who are particularly vulnerable, dependent and/or incapacitated, or who exhibit behavioural disorders. Particularly challenging in this setting are situations involving alcohol abuse, violence or neglect, or cases where dependent patients live alone.

If ethics structures are to be established in the outpatient setting, the following points should be considered:
– Care is provided within the patient's home, where personal standards in daily life often differ from professional standards. Management problems with an ethical dimension frequently concern the structure of the patient's (and/or his relatives') daily life.
– Patients often have a personal relationship with the people who provide care. This may facilitate ethical decision-making, but it may equally impede the recognition of problems.

- The quality and continuity of outpatient care often depends on the patient's relatives, who are frequently responsible for contacts with primary-care and other physicians, Spitex and other care providers.
- Ethical problems are more likely to arise as a result of poorly defined responsibilities.
- Financial problems, which are more directly apparent in the outpatient setting, may lead to tensions between patients and professionals.
- It is difficult to offer ethics support in an emergency. The number of professionals involved and a lack of continuity may lead to fragmentation of care. Meetings between professionals and relatives are difficult to organize. As well as raising ethical issues, this may complicate the work of an ethics structure.

Ethics structures should also consider the following points:
- Undergraduate, postgraduate and continuing education in ethical reflection and deliberation should be offered for professionals in outpatient care (Spitex, primary-care physicians)
- In urgent cases, an outpatient ethics structure should be readily and rapidly accessible, if necessary by telephone.
- For more complex home care cases, participation in interdisciplinary meetings should also be possible.
- When relatives assume responsibility for the care of a patient, they should also be involved in ethical deliberations.
- Ethical discussion needs to be coordinated in cases where several institutions participating in clinical care each have their own ethics structure.

Prison medicine

Specific problems arising in prison medicine have been dealt with in SAMS guidelines published previously[12]. As regards ethics support, the specific features of this setting include the following:

– It is difficult to establish and maintain a level of care equivalent to that provided in other settings.
– In certain situations, prison staff are involved, without being either care providers or relatives of the patient.
– The independence of the ethics structure needs to be assured not only vis-à-vis the hospital or outpatient institution, but also vis-à-vis the prison.

The following points should also be considered:

– It is preferable for an ethics structure to be established within the healthcare system. It is more difficult to guarantee the independence of an ad hoc structure established within a prison.
– The members of the ethics structure must be able to visit the site.
– To ensure that the necessary knowledge of the specific medical situation is available, prison medical staff should be involved in ethical deliberations.
– A process should be defined for deciding under what conditions, and how, one or more employees of the prison should be involved in ethical deliberations.

Ethics support for institutional management and administration

Ethics support should also be available for the management and administration of healthcare institutions.

However, the provision of such support for management may give rise to dependencies and conflicts of interests (involving economic, institutional and political factors), which need to be carefully managed. Thus, it must be possible for an ethics structure to decline requests for support without suffering any adverse consequences, especially in cases primarily concerning questions of business or environmental ethics, for example. Accordingly, support for the management of an institution should be provided by a team (e.g. the internal ethics committee) rather than by an individual ethicist. In certain circumstances, it may be preferable to engage an external consultant so as to ensure greater independence.

Ethics structures which provide support for management should have the necessary economic and legal knowledge and be familiar with the latest developments in national health policy.

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12 Cf. «The exercise of medical activities with respect to detained persons.»
SAMS medical-ethical guidelines.

4.   Quality

It is important that ethics structures should have the resources required to evaluate the quality of their activities. However, it should be stressed that evaluation of the quality of ethics support is a delicate matter – one cannot simply apply the quantitative tools used in other areas. The SAMS would welcome research relating to the quality of clinical ethics support structures.

To evaluate the quality of ethics support, it would be important to define objectives and assess the extent to which these are attained. This would require extensive reflection on the appropriateness and validity of the evaluation criteria selected. For example, the number of consultations requested is not necessarily a good indicator of quality, as it could reflect either ease of access to the structure or the failure of training efforts designed to facilitate the resolution of recurrent problems.

Sharing of experience and expertise within a network of ethics structures should therefore be promoted; this could include, for example, a peer-to-peer review system. Feedback can also be requested from users.

In the worst case, should an ethics structure fail to function effectively, it must be possible to make adjustments while at the same time preserving its independence.

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Information on the preparation of these guidelines

Mandate
On 20 June 2008, the Central Ethical Committee (CEC) of the SAMS appointed a sub-committee to draw up medical-ethical recommendations on ethics structures.

Responsible sub-committee
Professor Samia Hurst, Geneva (Chair)
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Dr Charles Chappuis, Spiegel
Dr Carlo Foppa, Morges
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Experts consulted
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Tanja Krones, Zurich
Professor Roberto Malacrida, Lugano
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Consultation procedure
On 24 November 2011, the Senate of the SAMS approved a draft version of these recommendations, to be submitted for consultation.

Approval
The final version of these recommendations was approved by the Senate of the SAMS on 29 May 2012.