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## Clinical Ethics Committees and Pediatrics : an Evaluation of Case Consultations

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## **Clinical Ethics Committees and Pediatrics An Evaluation of Case Consultations**

*Tanja Ramsauer, Andreas Frewer*

### **Introduction**

Clinical Ethics Consultations in cases involving difficult moral issues are a comparatively recent development in applied medical ethics in Germany<sup>1</sup> and other European countries.<sup>2</sup> Although Clinical Ethics Consultations in the U.S. were introduced on a broad basis in the 1970s, with a few earlier starts, and are nowadays used in most hospitals, it is only since the mid-nineties that committees on the subject have been set up in Germany.<sup>3</sup> These were initially introduced in hospitals with religious affiliations.<sup>4</sup> Over a decade later with the increasing diversity and number of new areas of moral conflicts, this form of practical ethics has also been established in university hospitals. Until then, there was usually a hierarchical structure in these hospitals and a senior consultant made decisions on ethical questions occurring in clinical practice and this decision-making process was hardly questioned.

With medicine and clinical practice structured around evidence-based medicine (EBM) becoming ever more nuanced, almost from the beginning, the development of a professional consultation structure led to the question of scientific justification more than just pragmatic answers to the daily ethical conflicts of clinic life, research and politics. A decision-making process based on rank (“eminence based ethics”) needed to be replaced by “evidence-based ethics”. Analyses on the evaluation of clinical ethics consultation are of particular importance for scientific soundness and moral transparency. Another reason that the evaluation is necessary is the potential negative consequences of ethics consultations.<sup>5</sup>

The Clinical Ethics Committee at the Erlangen University Hospital was founded in 2002 as one of the first of its kind in Germany with more than 80 meetings of its approximately 20 interdisciplinary members.<sup>6</sup> It has more than 100

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<sup>1</sup> Cf. Frewer [2000], Dörries/Hespe-Jungesblut [2007], Frewer [2008].

<sup>2</sup> Slowther, Hope [2000], Salathé et al. [2008] and Frewer [2008].

<sup>3</sup> See Frewer et al. [2008].

<sup>4</sup> Steinkamp, Gordijn [2001].

<sup>5</sup> Tulskey, Fox [1996] p 110. Larcher et al. [1997].

<sup>6</sup> See Frewer et al. [2008].

documented larger case consultations carried out by a specialised working group (“AG Ethikberatung”). This paper concentrates on the ethical aspects of case consultations in pediatrics and its documentation.

### **Strategies for the Evaluation of Clinical Ethics Consultation**

In order to examine the quality of ethics consultation our aims first have to be defined. The obvious and most important task of Clinical Ethics Consultation is timely assistance in the decision-making process – the ethical grounds for the various therapies, consideration of their relative merits and help with communication in cases of disagreement – for health care teams or relatives in everyday clinical situations.<sup>7</sup> Among the previous evaluations there seems to be a consensus of opinion.<sup>8</sup> In many descriptions of the organizational structure of ethical consultations goals are to be found which are of only secondary importance, such as the development of guidelines and the fostering of ethical competence on the part of all those involved in the treatment.<sup>9</sup> At this point the main aims of an ethics consultation need to be examined more thoroughly.

How can we evaluate if, and in what measure, the goal of “assistance with decision-making” has been fulfilled? Which criteria should be used for this evaluation and are they ethically permissible? Previous empirical studies “measure” the most easily definable extent of resource use (costs based on length of stay, discontinuation of therapies which are not indicated, etc.), the “usefulness” in terms of “patient management”<sup>10</sup> (something which is much more difficult to record in terms of data), or the satisfaction of all those involved.<sup>11</sup>

In the first case it seems, even at a casual glance, there is the issue of the committee’s independence being endangered by economic interests. Exactly this independence is important for credibility and recognition. The last point can also be interpreted in different ways: should the patient and the relatives, the health care insurance, or those responsible for the treatment, be satisfied? Resource use, usefulness or satisfaction are not, however, ethical values and cannot therefore be used as targets. Further attempts to quantify and measure the ethical qualities of clinical consultations also involve considerable problems of methodology in research and practice. At a time of rapidly developing consultation services and offi-

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<sup>7</sup> On defining functions in CEC, e.g. Williamson et al. [2007] p. 221.

<sup>8</sup> Vollmann, Weidtmann [2003] pp. 232-233, Salathé et al. [2008].

<sup>9</sup> Dobrin [2003].

<sup>10</sup> Kobert et al. [2008].

<sup>11</sup> Schneiderman et al. [2003]. See also Schneiderman et al. [2000].

cial recommendations for this development,<sup>12</sup> e.g. within the framework of the certification processes<sup>13</sup> – is the goal formal certification of the hospital rather than a good consultation? – it seems that an evaluation is urgently required.

The consultation process reveals a complex and multi-stage procedure whereby various criteria have to be fulfilled within its individual phases. At the beginning the question has to be raised: Who asked for the ethics consultation? What do the data on the initiation of the consultation reveal about the hospital structure? Is the possibility of a “consultation” known to be available in the entire establishment? Is it considered to be uncomplicated, available and timely?

Basically, the consultation consists of the following: a case description, initial information, an account of the various evaluations made by the team, definition of the ethical problems involved, options available, when necessary, explained within the framework of normative limitations, and the justification of these, the search for a solution and, finally, a summary of the various positions and procedures. As far as the documentation is concerned, an important question is whether the contents of the report fully reflect the consultation.<sup>14</sup> Afterwards, it would be worthwhile examining to what extent decision-making would have been simplified by better-founded justifications, use of any new insights, and more consensus within the team.

In the concluding discussion in the ethics committee any necessary further actions could be planned, or standards for quality assurance could be established.

Since the quality of the consultation process is very dependent on the qualifications of the counselor, the counselors themselves could be required to undergo an examination of their “moral competence” (tolerance, sympathy, openness, self-evaluation, courage, etc.) which is very difficult to evaluate. Further intellectual abilities (abstract thinking, etc.) and certain core competencies<sup>15</sup> should also be a prerequisite. The staff could be questioned about their qualifications for specific areas, or appropriate training for them.

Since an examination of all these aspects could quickly develop into an endless undertaking, the focus of the following comments is exclusively on the *ethics consultation* and its *documentation*. In a critical analysis of our university’s consultation reports their contents should be examined, not only with regard to the quality

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<sup>12</sup> Cf. Zentrale Ethikkommission [2006].

<sup>13</sup> Vollmann [2008] p. 34.

<sup>14</sup> Towards contents of summary see: Wernstedt, Vollmann [2005] p. 45. Orr, Moon [1993] p. 50.

<sup>15</sup> According to Simon: the ability to recognize an ethical problem, to analyse it, to organize and supervise a counselling process. Cf. Simon [2008] pp. 58-75.

of the documentation (completeness, clarity, etc.), but also the comprehensibility of the ethical conflicts and transparency of ethical grounds or considerations.

Furthermore, answers must be given to more specific questions, such as the most important areas of conflict within pediatrics, the composition of the consulting team in terms of specializations, and the structure of the conversations which have taken place. As a source, the consultation documents, by their very nature, present a certain limitation, since the content quality of the consultation can only be ascertained by adequate documentation of the sessions.

### **Method and Contents**

Here presented is an evaluation of 16 pediatric consultation reports of the more than 100 cases of the larger and explicitly documented<sup>16</sup> clinical ethics consultations at the Erlangen University Hospital between 2002 and 2008.<sup>17</sup> These cases are considered on the basis of their formal and non case-related documentation elements, and also on the specifically case-related contents.

This includes an ethical analysis of the cases described, taking into account the disciplines involved in the treatment and consultation team, the frequency of issues within pediatric medical ethics, the occurrence of additional questions and reasons for involving clinical ethical consultation. Is it uncertainty when making decisions primarily due to an unquantifiable prognosis, or rather due to uncertainty when arriving at ethical judgments? Or is it a legal safeguard? What are the dynamics of the consultation? Are there changes in focus and new insights in the case? What is the situation as far as having an open dialogue? Do all parties involved have a chance to express themselves? Are all opinions accorded the same weight? Were new courses of action formulated? Are there questions which can already be answered with reference to guidelines? Have the consequences or conclusion been clearly explained, or the need for further meetings stated?

### **Formal Evaluation of the Consultation Report**

In total there were reports for 16 patients (siblings twice) and 15 conversations took place. One case required two sessions. The length of the discussions varied between 60 and 120 minutes (purely for statistical purposes: mean 82 min.).

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<sup>16</sup> Besides various other just verbal (e.g. on the phone) consultations.

<sup>17</sup> The cases for this article were reviewed by a pediatric specialist (Tanja Ramsauer) and professor of medical ethics (Andreas Frewer) both working in clinical ethics and responsible for ethics consultation, before 2006 as is Dr. Thela Wernstedt and beyond 2006 Dr. Uwe Fahr. We would like to thank Dr. Thela Wernstedt (Erlangen/Hanover) and Professor Wolfgang Rascher (Erlangen) for their support.

Once, two conversations of 60 and 30 min. respectively took place. For one of the conversations no time was recorded. In the literature times range from 45-60 to an average of 60 min. so that consultation length here seems to be somewhat longer than in other places. Since in many investigations into acceptability and practicality the considerable shortage of time in clinical work has been pointed out, time requirements should be examined critically.<sup>18</sup>

The age of pediatric patients ranged from 11 days to 19 years, with an average age of just over seven years (85 months). It was rather surprising to note the lack of cases of immediately post-natal children and only two pediatric cases during the first month of life. According to the literature most of the case consultations occur during this period. This could be related to the noticeable underrepresentation of various specialist groups, such as neonatology and pediatric cardiology, in which ethically problematic decisions usually occur in the postnatal phase (please refer to the paragraph on Specializations Involved). The “adult” cases (two cases of 19-year-olds) are not surprising, inasmuch as these were typical cases of patients who had been treated for many years in the Pediatric Departments for multiple physical and/or mental illnesses. For this reason they continued to be treated by the same departments after reaching adulthood, simply because these were familiar to both the patients and their families.

Regarding the persons of the ethics team involved in the consultation sessions there was one full-time ethicist always present during the consultation sessions with the exception of one case. She or he also produced the report in the majority of cases. In half of the ethics consultations doctors and caregivers respectively, as professional groups, were represented. In 36% of the cases a chaplain was present and in one case a psychologist was there. This combination of professional groups is to be welcomed as the consulting process can only benefit from the introduction of various perspectives from those in interdisciplinary fields.<sup>19</sup> This corresponds with the composition of other ethical consultation groups to be found in the literature.<sup>20</sup> In a few other groups references can also be found to administrators and legal representatives.<sup>21</sup>

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<sup>18</sup> Doerries [2003].

<sup>19</sup> Neitzke [2003].

<sup>20</sup> Interdisciplinary CEC members, see Fox et al. [2007] p. 17.

<sup>21</sup> See Guo, Schick [2003].

### Documentary Elements Related to Specific Cases

In total there were eight different specialisations represented in the case discussions, five of which were specialised areas within pediatrics: nephrology, intensive care, cardiology, oncology and metabolic disorders.

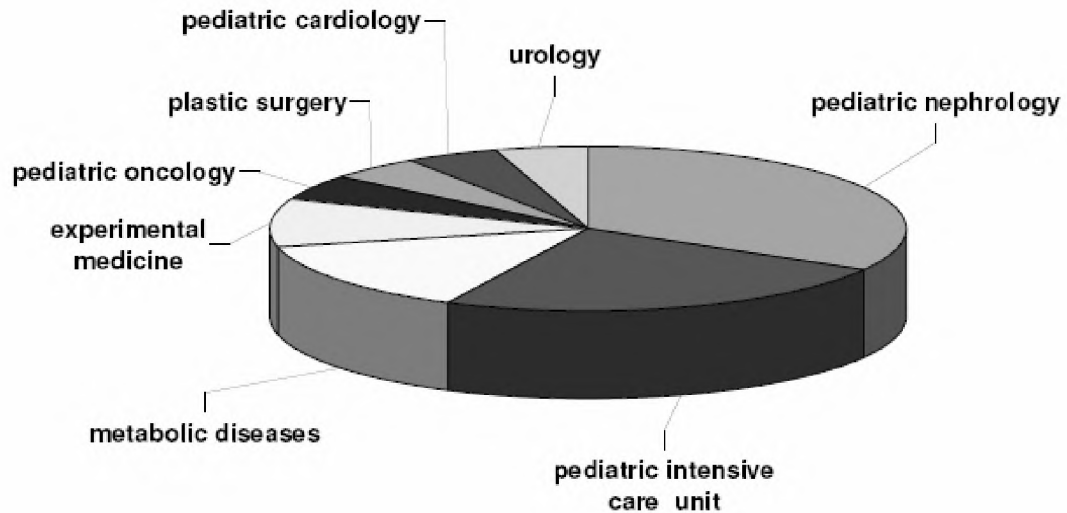


Fig. 1: Specialisations involved in the clinical team

This distribution seems unusual and perhaps only portrays the University Children’s Hospital which is being examined here. The frequent participation of the nephrology department is very noticeable, and even for a university hospital which specializes in this area still seems unusual at first glance. This is also not reflected in the literature.<sup>22</sup> On the other hand, other ethical problems frequently mentioned in the literature are almost completely absent, for example, from pediatric oncology and pediatric cardiology (only one case with a secondary cardiac problem). It is a little speculative to try to explain this, but it should be attempted anyway.

On closer inspection many children’s nephrology cases fall into the category of a dilemma which occurs frequently: starting or not-starting dialysis in cases of considerable physical and/or mental retardation, with the onset of kidney failure, or the expected onset in the short term. The discussion then centred around the issue of “quality of life” (with, e.g. the use of force, “tying the patient to the dialysis machine”) and practical matters related to compliance and other necessities when dealing with handicapped children. Considering the frequency of

<sup>22</sup> Kliegman et al. [1986], Edens et al. [1990].

these cases, it is rather surprising that more about guidelines on the subject, or experience with treating these cases has not been reported in the literature.<sup>23</sup> From this point of view, that issue has perhaps been under-represented in other reports, unless internal guidelines are available in these hospitals.

That both the other specializations (pediatric oncology and pediatric cardiology) do not appear, may have something to do with the fact that a well-organized system of interdisciplinary “case conferences” (regular intern case conferences on the more complex patients) has frequently already been established within these departments. In this regard, it would be of interest to see a breakdown, for example, of withdrawal of life-sustaining treatment in the period being observed, but without an ethical case consultation. This information has been considered in other studies.<sup>24</sup>

The neonatal departments only appear once as the unit requesting the consultation.<sup>25</sup> These numbers are also low if it is assumed that there have also been cases with ethics as an issue, in which no ethics consultation was requested due to a unanimous decision of all concerned. This is surprising, especially since the neonatal departments are *always* involved with decisions at the very beginning of life, and since all premature and newborn babies with relevant clinical problems, independent of the later specifics of the illness, are usually in these departments.

This is why the share of cases discussed in most publications<sup>26</sup> is largest in the neonatal departments. However, it should be pointed out that, with the cases considered here, despite the time period of five years, the low number of case consultations could have led to distortions.

### Consultations – Top Down or Bottom Up?

The composition of the case conferences in the Pediatric Hospital or counseling facilities proved to be astonishingly variable, i.e. the ratio between supervisors/managers and non-supervisory or trainee staff, seems relatively well-balanced.

Individual cases are, however, dominated by single groups within the hierarchy, e.g. Cases 3 and 5 with only consultants participating. Also in Case 12 the six caregivers compared to three doctors (two consultants and one senior house

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<sup>23</sup> Reichwald-Klugger et al. [2000].

<sup>24</sup> Kliegman et al. [1986].

<sup>25</sup> NICU and PICU = neonatal/pediatric intensive care unit have been grouped together here under “Pediatric Intensive Care Unit”.

<sup>26</sup> Kliegman et al. [1986].



officer) were in the majority. In Case 14 with one representative from care-giving staff, Psychology Department and assistant doctors respectively, there was no chairperson present. Cases 3 and 5 are linked as they concern the same fundamental illness of the patients. The dominance of supervisory staff can easily be explained in this instance, since it was a rare condition and the question of using an “experimental” therapy thus involved the borders between an attempt to cure, experimental treatment, and the clinical trial of a new therapy. This requires experience in dealing with scientific classification and research projects. The dominance of care-giving personnel in Case 12 could be explained in this case as it primarily concerned the care-givers’ disagreement about the treatment requested by the patient and his surrogates. In Case 14 it can only be speculated why no supervisory member of staff is present. From the psychological and social perspective it appears to involve particularly difficult circumstances, which should for that very reason favour the presence of supervisory staff to take responsibility. On the other hand the participating senior house officer is a very experienced specialist. No conclusions can be drawn from the reports as to whether other duties prevented further persons from participating in the consultations.

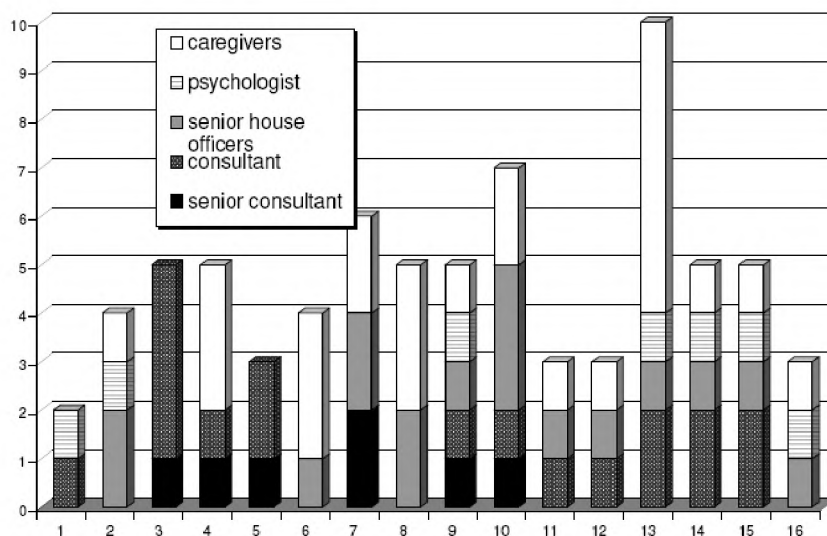


Fig. 2: Composition of Treatment Teams Participating in Conferences

### Breakdown of Consultation Content into Ethical Criteria

If the contents of the consultations are approached from the perspective of the formulation of the problems which lead to the consultation, these contents can be categorized into various types. These are question formulations typical to medical ethics such as “from which point, and based on which clinical criteria, is a withholding or withdrawal of therapy indicated?” or “what is the presumed *best*

*interest of the patient*".<sup>27</sup> The "question of justice" is found less frequently in individual consultations in other places (contrary to resource distribution in health care system). "Should siblings with the same original illness be treated in the same manner if the illness progresses differently, and therefore has a different prognosis? For example, should they have equal access to a kidney replacement procedure?"

The initiation of the kidney replacement procedure, when a mental handicap is diagnosed, was a frequent reason for requesting an ethics consultation in the reports under consideration here. This has already been discussed under specialised disciplines. Interpersonal conflicts are also basic problems surrounding the pediatric sick bed and often lead to an ethical consultation. Although they are not in the strictest sense a problem of medical ethics, they are always mentioned in regard to consultation issues.<sup>28</sup> It seems they are also particularly easily solved during an open-format discussion focusing on mediation, as is the case with ethical consultations.<sup>29</sup>

Also in reports from other consultation teams, subjects can be found which belong rather to an explanation of legal issues (e.g. why is "active" extubation, when therapy goals are changed to palliative medicine, not automatically considered illegal assisting someone to die). This problem could be seen twice in the case documentations. The occurrence of two cases where the application to begin an individual attempt to cure illustrates the confusion in jurisdiction between the Clinical Ethics Committee and the Institutional Review Board, or at least the grey area between those jurisdictions. An unusual ethics consultation already took place in the first year of those cases being examined here: a legal, moral position taken by the doctor treating a female patient dependent on medical help and threatened with deportation to a country where therapy possibilities were not guaranteed.

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<sup>27</sup> See also Edens [1990].

<sup>28</sup> Orr, Perkin [1994] p. 324. Michaels, Oliver [1986].

<sup>29</sup> Agich [2003].

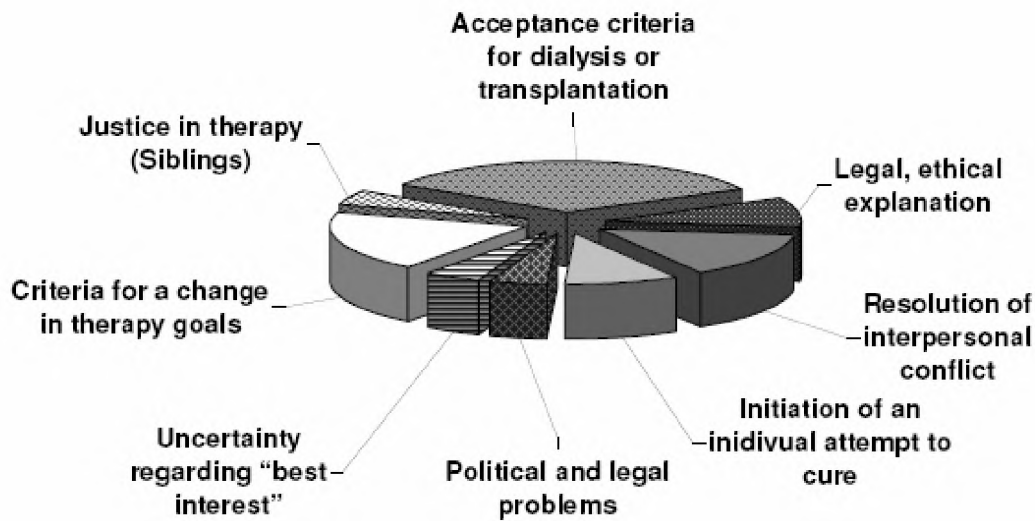


Fig. 3: Consultation Contents

### Methods and Completeness of Documentation

Written documentation was provided in general by a report writer from the working group on Ethics Consultation (mostly an employee of the Professorship for Medical Ethics). In one case it was done by a participating doctor in the form of a report to the ethics consultant. Of the 16 pediatric ethics consultations there were only hand-written notes for two of the sessions. Since these could not be evaluated they were not included in this analysis. In two cases there were corrected, hand-written draft reports, in which all the essential contents were included, and in one case there was an almost complete, uncorrected draft. These three reports seemed usable for evaluation purposes and were therefore included. The report comprises details of the people participating, the date and place of the consultation and a short summary of the medical situation. However, sometimes it was assumed that the exact medical facts of the case were known and, for example, a case summary is alluded to, but is not included in the report. In all of the reports the ethical question is formulated with different levels of explicitness.

In the main paragraph, the "ethics consultation", the actual discussion is recorded and various aspects of the problem are summarized. A conclusion about various opinions (of the participants) or even changes of opinions during the course of the conversation are, however, hardly ever discernible. Examining the reports seems to be more problematic in statements on "patient's opinion" (or with patients unable to give consent [e.g. infants, severely mentally-handicapped patients] the parents' opinion). Here, at any rate in six cases out of fourteen, no explicit description of the patient's position or opinion is given. In a further case on a

10-year-old patient it is recorded extremely briefly. Even when the ethical consultation has taken place before the parents are informed of treatment recommendations, it is reasonable to assume that the opinion/position of family members is known in concrete terms; it should be ascertained in a detailed manner and documented.<sup>30</sup>

An essential component of the documentation of a consultation is a clear presentation of the available options which are implicit in the problem, and their respective ethical grounds. This sometimes imposes too rigid a structure on the report, but can be effective as a measure of the quality of the consultation.<sup>31</sup>

In the reports at issue options are stated, mostly even explicitly listed. However, in two cases it remained unclear which options should be weighed against each other on the basis of justification. In total three cases are not comprehensible from a medical content viewpoint. Otherwise, the medical information is also in rather brief, even though in some cases the symptoms were highly complex. In these cases it would certainly have been helpful to attach the case summary which had been prepared by the treatment team. Of course, it could well be that the various options and their justifications had been thoroughly worked through during the consultation. However, for an evaluation of the consultation, as well as any further scientific uses for that documentation, a more structured formulation would be desirable.

In the majority of the reports no conclusions can be drawn on the quality of the "free discussions". Who spoke and how each person's contribution was weighted, would, however, certainly exceed the limits of an approximately three-page report. Attributing specific opinions to the various participants certainly seems important when these positions diverge within the team, or when the consensus of opinion is not shared at all by some individuals. In one of the reports there is a comment on this point, in which reservations based on conscience are referred to. The "active" part of the withdrawal of life-sustaining treatment (in this case extubation) should therefore be carried out by a team member who agrees with the decision.

If the ethical questions are looked at again in light of guidelines already available, these are not able to answer them. However, the question of inclusion or exclusion criteria for a kidney replacement therapy occurs so frequently that the development of a guideline which could at least offer a support structure for individual decision-making seems obvious.<sup>32</sup>

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<sup>30</sup> Orr, Shelton [2009].

<sup>31</sup> Bramstedt et al. [2009].

<sup>32</sup> See also Kliegman et al. [1986].

Employee training was expressly not considered of primary importance for this evaluation. Nevertheless, the uncertainty shown in some of the reports, and very often prevalent in practice, as shown by the misuse of terms like “active or passive assistance in dying”, throws up the question as to what extent such instruction would not greatly benefit the patient and would therefore be also a criterion for an evaluation.

Finally, in each report there is a summary (with the exception of the uncorrected draft) of the positions taken during the conversation (those persons present were in agreement or not, argument convincing, etc.) and the most important conclusions of the consultation. Details about procedures and the need for further discussions are noted only in exceptional cases.

## Conclusion

Overall these reports give a lot of detailed information about the presentation and ethical reappraisal of moral questions in pediatrics. Regarding the documentation elements which were not case-related, the balance in composition of the participating treatment teams was quite astonishing – at any rate considering at what short notice the consultations were set up. The evaluation as to which specialization each of the cases belonged revealed a noticeable accumulation of cases involving questions of kidney replacement therapy. The development of criteria for the initiation of kidney replacement therapy should therefore be considered. With regard to the completeness of the documentation being considered, more detailed information on the medical facts would seem to be of value. Primarily, more attention should be given to matters of patient autonomy and therefore to more exact descriptions of the patient’s – or the parents’ – opinions.

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