

COMMUNITY ETHICS COMMITTEE REPORT to the
CHILDREN'S HOSPITAL DCD TASK FORCE

April, 2008

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INTRODUCTION

The Community Ethics Committee (CEC) is a group of fifteen members living in the general Boston area who are representative of the population served by the Harvard teaching hospitals. The need for such a consultative group has been evident for a long time since individuals currently serving as community members on hospital ethics committees are not able to be broadly representative of multiple communities. Solicitation for membership on the Committee has been cast widely through community, business, and church groups, with a specific application process to ensure selection of a diverse and effective working group.

The Community Ethics Committee is comprised of members within the geographic region of the Harvard hospitals who are diverse as to socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Of the fifteen members, nine are women and six are men; we range in age from our twenties to our seventies. Some of us have advanced degrees and some of us have high school diplomas. Among us are a high school administrator and two high school teachers; a rabbi and a minister of a large downtown Boston church; a manager of a residential facility for disabled individuals and parents with disabled children. Two of us have disabilities and two of us are retired, one from a large Boston law firm. We are students and writers and small business owners and volunteers. We volunteer at a local rape crisis center, on an Institutional Review Board, in health care facilities. We belong to eight different religious traditions, including atheism, and we speak seven different languages. We all attended the Harvard Bioethics Course in June of 2007, where we first met and began our conversation as the Community Ethics Committee.

PROCESS

The Committee met throughout the fall, winter and spring to educate ourselves about the issue of pediatric organ donation on cardiac death and to review the Children's Hospital DCD Task Force's Policy Report dated December 2006. (We confined our review to pediatric DCD and throughout this Report, we use the designation pDCD to note that limitation.) We corresponded by e-mail and shared articles we had found and information we had gathered. Our meetings were at a location on the Harvard Medical School site and, although scheduled to run from 6PM to 9PM, our discussions often continued much longer than that. We met in October with representatives of the New England Organ Bank where they described their business model and mission. Through a persuasive video, they presented the compelling need for organ donation and the scarcity

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of organs. Their materials contained a summary of the process of organ donation including differences in managing a dying patient's care in the cases of brain death and cardiac death. We had a lively period of questioning which included learning which organs and tissues are taken and that some tissues have a prolonged "shelf life".

We met in November with representatives of the Children's Hospital DCD Task Force and learned from them how the determination of cardiac death is made and how they came to the conclusion that five minutes was the best standard to use in making a determination of cardiac death. We also focused a great deal of time on the care given to the dying child and what supports the family received both in the initial presentation of the possibility of pDCD, occurring after a decision to withdraw life support, and in the physical, emotional and spiritual processes of the child's dying and death. We all spoke about these issues with family, friends and colleagues – the community. Based on our group discussions and in order to obtain everyone's viewpoints, our committee leadership developed a survey that solicited individual Committee members' thoughts on the questions asked by Children's Hospital's Task Force and related concerns discussed during our meetings. Lastly, we met in January and March to review the survey responses and to focus our thoughts regarding the proposed pediatric DCD Policy. Some of the comments from that Survey are included in this Report.

RESOURCES and SURVEY

A Bibliography of articles and resources distributed to the CEC is attached as Attachment 1; and the Survey that was distributed to the CEC members is Attachment 2.

RESPONSES and COMMENTS

The CEC was presented with four questions (see Attachment 3 for the detailed questions submitted by Charlotte Harrison, co-chair of the Children's Hospital DCD Task Force). In brief, those questions were:

1. To what population of pediatric patients should pDCD be available?
2. To which parents should the possibility of pDCD be broached?
3. What safeguards within the proposed pDCD policy are most important?
4. Should Children's Hospital accept organs from hospitals having a protocol which declares cardiac death as occurring less than five minutes after acirculation?

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The responses set forth below are necessarily condensed and cannot completely reflect the richness of the Committee's discussions or the care with which we wrestled with these issues.

1. To what population of patients should pediatric DCD be available?

Most of the Committee felt comfortable making DCD available to any dying child of any age, if the parents gave consent. The CEC unanimously supported making pDCD available to mature minors who had completed donor cards or registration statements - in other words, to those who had given first person consent to organ donation. It is important to note that two members of the Committee wanted to allow pDCD for mature minors without donor cards only if they were able to articulate their desire to donate organs or if they had parents who could report that the minor had previously stated their wishes to donate.

The CEC spent considerable time discussing the concept of "best interests" - the decision-making standard applied to parents deciding on behalf of minors who do not have the maturity or ability to speak for themselves. The discussion focused on the fact that the dying child's best interests are to be treated with dignity and respect, with a focus on minimizing both physical and psychic pain and suffering during his or her last moments. The CEC recognized that the concept of "best interests" also extends to the dying child's family and that the family's cultural, religious and social tenets are central in determining what are the "best interests" to be considered in making a good decision.

Comments from the Survey include the following:

- Parents' interests are obviously very important, but by themselves, they are not sufficient to justify such consent. A risk exists that the child will be used as a means to an end – his/her dignity being thereby undermined.
- The obligation of the institution is to the patient in the bed and not to an abstract person elsewhere.
- I tend to think that the Children's Hospital Ethics Committee should have a mechanism to review all such surrogate "best interests" decisions.
- I think the life that's being saved is more important than the life that's being lost. The only best interest to work towards is that of the life that donated organ(s) are meant to save.
- The best interest standard should apply to the process associated with the withdrawal of life support and organ removal, such that this process ensures that the patient does not experience pain and suffering in death.

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2. To which parents should the possibility of DCD be broached?

The Children's Hospital DCD Task Force expressed concern about broaching the subject of pDCD to parents who had already been presented with the difficult decision to withdraw life support from their dying child. The phrase "don't ask, do tell" came to represent the Task Force's conclusion that, to protect the bonds of trust and confidence in the dying child's care team, the possibility of an organ donation through the DCD process would not be discussed unless the parents asked about it. In other words, a dying child whose organs might have been donated upon cardiac death would be denied that opportunity if the family did not know to ask the care team about the possibility before the child's death. This approach was unanimously, thoroughly and resoundingly rejected by the CEC, with the Committee concluding that pDCD should be a subject that is presented to families uniformly and, if at all possible, early in the course of their hospital encounters.

Although both the CEC and the Task Force were concerned about the possible loss of trust that families might experience when the issue of pDCD was discussed, the CEC's concern was different. The CEC was convinced that the breach of trust would be significant if a family learned that their deceased child might have been able to donate an organ under the pDCD policy but, because they did not know to ask, the opportune moment had passed. The obligation to inform as many families as possible in as unobtrusive a way as possible became paramount to the CEC members.

The CEC suggests that an informative brochure be made available to families, if not with the packet of materials presented upon admission, then at least among materials available to families in the lobby areas of the ICUs. In this way, families could have access to the information in a non-threatening and individualized way, not tied directly to the medical care their loved one receives.

Comments from the Survey include the following:

- The more people know about pDCD in advance, the less difficult it would be to raise the issue in the midst of a tragedy
- The informed consent process is most important – what information is communicated, when, by whom, and to whom. I believe we should be specific about this.
- The stuff we read [encouraging the use of presumptive consent language in organ solicitation] was creepy.

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3. What safeguards within the proposed DCD policy are most important?

In addition to the recommendation that Children's Hospital provide information regarding the organ donation process openly and early on, three safeguards were especially important to maintaining the Committee members' comfort with supporting the pDCD policy. Those three safeguards have to do with the language and approach used to discuss pDCD with families; the pre-mortem medical interventions that should be prohibited; and the necessary inter-relationship of Children's with NEOB and ensuring a coordination of policy implementation over time.

The Committee was concerned about both the language and the approach used in discussions of pDCD with families. In that regard, the use of "presumptive consent language" was viewed as highly suspect and tended to increase distrust of the organ procurement process. The people who are discussing pDCD with families should pay close attention to the words they use and must be meticulous about maintaining the primary obligation of care to the dying child, that being the highest good in this particular situation. Most of the Committee members expressed the belief that someone from the dying child's primary care team who had already established a trustworthy relationship with the family should be the person responsible for beginning the conversation with the family about the possibility of pDCD. In addition, some CEC members thought that a person from Children's Hospital should be present with the NEOB representatives when they discussed organ donation with families.

The Committee was protective of the dying child's bodily integrity and wanted to ensure that no potentially burdensome medical interventions would be initiated prior to death for the sole purpose of enhancing the viability of organs. In particular, the insertion of cannulas and the administration of heparin were seen to have no medical benefit to the dying child and should not be done prior to the declaration of cardiac death. The medical interventions that the Committee viewed as necessary were those to ensure the dying child's last moments were free from psychic and physical pain.

Lastly, the Committee was particularly concerned about two aspects of the proposed Children's Hospital DCD policy as it relates to NEOB. The first is a concern about genuinely informed consent. As representatives of the community, the members felt that the general community does not have a real awareness about what organ donation actually involves and, in particular, the extent of the organs that are taken and how they are used. In particular, the fact that tissue may be stored by NEOB for long periods of time post-mortem and subsequently sold as a commodity was disturbing and a significant concern to the Committee members. To protect families' cultural and religious views about burial and respect for remains, the informed consent for organ donation must include what organs and tissue are taken, how they are stored and what

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happens to those organs and tissue afterwards. Related to that issue, the Committee was concerned about the standard "blanket consent" presented to families, and we suggest that informed consent include the possibility of a limited donation of specific organs.

The second aspect of NEOB involvement that is of concern to the Committee has to do with the recognition that policies change over time. The Committee wants to ensure the coordination of the Children's Hospital DCD policy with any changes that NEOB might initiate later. The Committee's comfort with the proposed pDCD policy is expressly based upon representations of current NEOB policies and practices and should those policies or practices change, then the Children's Hospital DCD Policy would need to be re-examined.

Comments from the Survey include the following:

- I would like to know how the pDCD process fits with particular religious views and that, where appropriate for the family, religious counselors participate in the process.
- Part of educating the public would include discussing the rate of success – short term and long term. The commercialization of the process is a concern, as well as the potential to mislead the public into thinking transplanting organs is like transplanting a muffler. In other words, allowing the public to think one can just pop an organ in and expect the recipient to run on forever.
- I think people should be told about organ procurement in as much detail as they request, i.e. about the process and harvesting of tissue including skin, bone, etc., even if that reduces the rate of donation.
- Someone from Children's should make the initial contact and must absolutely provide disclosures before NEOB is called. NEOB is not to be trusted to provide a realistic, fair, transparent description of the organ donation process. Children's is obligated to tell the family about: (1) how some body parts are never buried; (2) some body parts are sold by NEOB; (3) pDCD could likely abbreviate the time with the child at the end of his/her life; (4) how the harvesting must occur within minutes of the heart stopping which may have cultural/religious/spiritual constraints; (5) that a child is not the likely organ recipient; (6) that organ donation may be right for some people, but it's not automatically the "right thing to do" and that Children's fully respects the decision of the donor/family. The key is a transparent policy!
- I believe the spiritual or existential needs of a patient are just as critical as his or her physical ones. One's person's need to live doesn't outweigh categorically another's right to die with dignity.

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4. Should Children's Hospital accept organs from hospitals having a protocol which declares cardiac death as occurring less than five minutes after acirculation?

The Committee members acknowledged the disturbing dilemma posed by the situation which might arise when a viable organ is offered from an institution that declares death on a shorter time-frame than that established by the Children's Hospital DCD Policy. Nevertheless, the value of consistency in upholding the time-frame set, after lengthy and careful deliberation, by the Children's Hospital DCD Policy was viewed as paramount. Most of the CEC believes that organs available from institutions that declare death using a shorter time-frame than five minutes should not be accepted for transplant at Children's Hospital.

Comments from the Survey include the following:

- If the five minutes (instead of a shorter period) is to support staff feelings/comfort with pDCD, or to encourage public support with more conservative waiting times, or to respect medical information that auto-resuscitation is absolutely not possible, then I don't think CHB could/should be accepting organs from hospitals who wait less time.
- CHB is a model for the nation and the world. If a strict protocol for pDCD is developed and it is violated, we damage the Hospital's integrity, which will hinder its mission and effectiveness in the long run.
- I do not see any point in letting an organ "go to waste" and passing up an opportunity to help another child, just based on differences in policies and principles. However, at the same time . . .

ASSUMPTIONS Leading to our Decision to Support pDCD

The members of the Community Ethics Committee are grateful for the opportunity to contribute to the Task Force's development of a policy on pediatric organ donation after cardiac death at Children's Hospital Boston. Our understanding of the complex issues surrounding pDCD would not have been possible without the due diligence of the Task Force and the thoroughness of its report. We were impressed by the Task Force's extensive research and analysis of the issues, the clear level of caring and sensitivity that was evident throughout the report, and the high standards of excellence at Children's Hospital Boston.

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We find that pDCD is far too complex to warrant a universal approval. That is to say, we are in favor of pDCD, but wish to convey that there were several underlying assumptions we made when formulating our responses to the report, largely based on our positive impressions of the Task Force. These assumptions are:

1. That the primary care team/hospital staff is committed to providing the highest quality of care, with respect and sensitivity to the dying child.
2. That all decisions surrounding the care of the dying child (including the decision to withdraw LST), are made independent of any consideration for organ donation.
3. That no measures are taken that would potentially cause psychic or physical pain for the dying child, for the sole purpose of organ procurement.
4. That the family is provided with all the information needed to give informed consent to DCD.
5. That the hospital has a task force dedicated to ensuring continuing evaluation and oversight of the pDCD protocol.
6. That there are safeguards in place to protect against abuses or violations of the protocol (including appropriate avenues for reporting violations or ethical breaches, i.e., in situations where conflicts of interest are perceived and/or there is a perception that the family is being pressured to donate).

We understand that pDCD is being discussed and becoming a mode of organ donation in hospitals nationwide, and believe that hospitals and their associated communities should engage in dialogue on such policy decisions.

Finally, we agree that Children's Hospital Boston may share this report with other hospitals and respectfully ask that Children's Hospital Boston not exclude these assumptions when sharing CEC feedback with internal and external parties. We thank you for the opportunity to engage with you in such interesting and important deliberations.