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Editor's Forum

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The three papers in this issue of *Health Ethics Today* deal with very different subjects but have in common a focus on the borderline/interface between the health care professional and society. The actions of health care professionals are guided by internal self regulating principles to maintain standards and ensure public trust in the professions. Formal codes of ethics uphold the traditional aims of promoting the patient's welfare. In the diverse clinical world of today's health care system, physicians and nurses will encounter situations where their actions have direct social and legal implications for themselves and those they serve. This situation is highlighted by Bailey and Penney as they discuss how to deal with information about patients relating to criminal activity. The health professional's ethical responsibility is to respect confidentiality with very few exceptions. The authors suggest that recent changes in the law may put physicians and nurses in a difficult position by requesting such information without patient consent at the "discretion" of the health care professional. Confidentiality of information is also compromised when the health of a newborn baby is endangered due to maternal drug abuse. In specific cases the detection of drug metabolites in the newborn does assist in proper diagnosis and treatment of

serious illnesses due to maternal drug abuse. But does the occasional necessity justify screening a population of babies thought to be at risk of complications? This question is discussed in Byrne's paper with a view to remind health professionals of the wider social and legal implications of decisions made in acute care

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settings. For example, organ transplantation has evolved from an experimental practice to become a common clinical choice of treatment for many diseases. Most organs are donated as a result of another person's death.

A common decision making process prior to organ donation is to attempt to declare brain death in the person. This occurs most frequently in the intensive care unit or emergency room setting. Brain death is

commonly accepted as equivalent to body death in terms of irreversibility and survival but was never required as a category prior to organ transplantation becoming real. Joffe questions the legitimacy of the concept of brain death as being equivalent to total death. Once again the wider implications for society from a common clinical practice are highlighted by Joffe's questions about the nature of dying and death. ■

Should Health Care Professionals Heal or Squeal? Disclosure to Police under a New Section of Alberta's Health Information Act

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An oncology nurse is watching news on television at home when he learns of an armed robbery at a local bank. A man reportedly approached a teller for cash, revealing a gun and stating that he was dying and had 'nothing to lose'. Shots were fired although no one was injured. Footage from the bank's surveillance equipment was shown and the police asked the general public for assistance identifying the robber.

The nurse believes that the robber is a patient he recently treated at the oncology clinic. The next day, the nurse seeks advice from his manager. Together they determine that the nurse should contact the police and disclose the identity of the individual. The key factors to the decision are that (1) the nurse reasonably believes that the information relates to an offence (the bank robbery) and (2) that disclosure would enable the police to further investigate the crime – the nurse fears that if he does not disclose the patient's identity to the police, the

patient will engage in further violent crime and endanger other members of the community. The nurse and the manager are not required to inform the patient of a disclosure made (Alberta Health and Wellness, 2007, s. 37.3) and do not plan to do so.

This is the scenario used by Alberta Health and Wellness to illustrate when health care professionals (HCPs) governed by Alberta's *Health Information Act* (HIA) may decide to disclose confidential information about their patients to police without consent under a newly added section to the Act (HIA, 2000/2006, s. 37.3). Prior to the recent amendments to the HIA, information could be disclosed to police if served with a subpoena, warrant or court order (s. 35(1)(i)), if the disclosure was to avert or minimize an imminent danger to a person (s. 35(1)(m)), if it was in the best interests of an individual who lacked capacity (s. 35(1)(n)), or if police were investigating an offence involving life-threatening injuries to an individual (s. 35(1)(j); this last section has now been repealed).

The new section provides HCPs with discretion to disclose information to police if they reasonably believe that:

- The information relates to a possible commission of an offence under a statute of Alberta or Canada, and
- The disclosure will protect the health and safety of Albertans

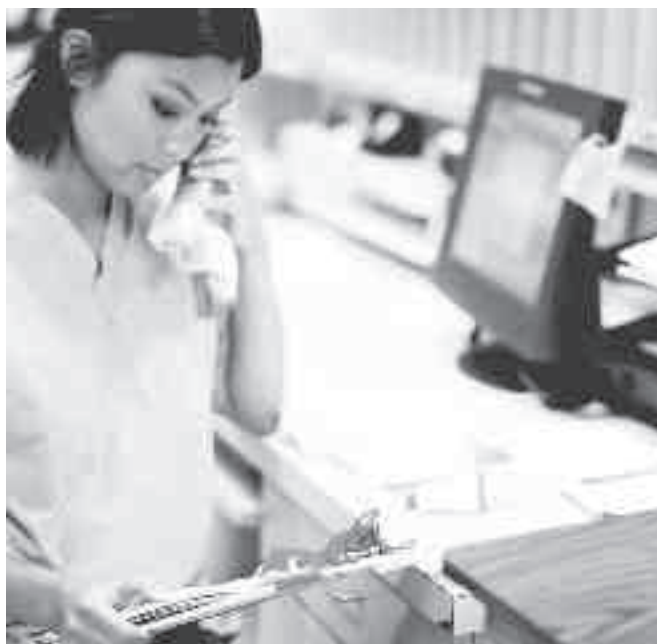
HCPs can decide to provide police with the following information:

- Name
- Date of birth
- Nature of injury or illness
- Date on which a health service was sought or received
- Location where health service was sought or received
- Whether any samples of bodily substances were taken from the individual

At first glance, the example used above may seem like a reasonable scenario in which a HCP ought to exercise discretion to disclose. This nurse believes he recognizes the individual on the video as his patient. However, there are several parts of this example which will send shivers up the spine of anyone who believes in the protection of patient confidentiality unless there is a justifiable basis in both law and ethics for its breach.

To provide good care to patients, HCPs must establish a relationship of trust with their patients. If trust does not exist, information that may be crucial to proper treatment may not be forthcoming. The assurance of protecting confidentiality may be necessary to acquire full and accurate information from a trusting patient to provide good care. The potential of disclosing sensitive confidential information may deter patients from seeking care at all.

It is a HCP's ethical and legal obligation to protect the confidentiality of a patient's information¹. A HCP should not disclose confidential information without consent unless the law and ethics provide for this under exceptional circumstances.



Case law and codes of ethics have made it clear that while HCPs may owe obligations to others, their primary duty is to their patient. “Consider first the well-being of the patient”, for example, is the primary ethical obligation of physicians in Canada according to the Canadian Medical Association (CMA, 2004) Code. A breach of confidentiality should only occur in those cases where it has been demonstrated to be legally and ethically justifiable (for example, to prevent future serious harm to an individual).

Canadian case law has also made it very clear that while police and HCPs each have important roles in our society, they are distinct and there are good reasons for them to remain so². Health care professionals should provide competent care; they should not be part of the law-enforcement machinery of the state.

The nurse in our example must have a reasonable belief that information about his patient relates to a possible commission of an offence. Clearly, an offence has been committed, but is there sufficient basis to believe it has been committed by his patient? Eyewitness evidence is notoriously unreliable. In this case, the nurse was not even at the bank. He saw a few seconds of what was likely a low quality surveillance clip on the television. Is this enough to say that he has a reasonable belief that the robber is

his patient? At best, this is a long stretch. Reasonable belief means much more than a suspicion.

He must also have a reasonable belief that his breach of patient confidentiality and subsequent disclosure will protect the health and safety of Albertans. In the example used, it seems to say that because the nurse has a belief that his patient will engage in further violent crime that this criteria has been satisfied. But on what basis does he form this belief? There is nothing to suggest that this nurse has any information which would lead him to form such an opinion.

The example ends with the comment that the nurse would not need to tell his patient that he had breached his duty of confidentiality. While it is true that under the HIA there is no such requirement, there is a duty in the Act to consider a patient's wishes before disclosure is made (HIA, 2000/2006, s. 58(2)). As well, and likely more significant in this example, are the ethical obligations that exist. At least for physicians, the CMA Code of Ethics states:

Disclose your patients' personal health information to third parties only with their consent, or as provided for by law, such as when the maintenance of confidentiality would result in a significant risk of substantial harm to... In such cases, take all reasonable steps to inform the patients that the usual requirements for confidentiality will be breached.

The HIA also requires the HCPs to disclose information only that is necessary for the recipient's (the police's) intended purpose (HIA, 2000/2006, s. 58(1)). To fulfill this statutory obligation, what questions should the HCP ask the police officer prior to disclosure? Are they seeking enough information to obtain a warrant? Something more? A HCP is hardly in a position to assess the amount and type of information necessary. Neither are they as insulated from police influence as a court would be. It is likely that in those situations where a HCP is faced with a request or demand from police, many HCPs may feel pressure to comply and may not have time to consider all of the relevant conflicting duties they face.

In addition to these concerns, we believe this new section of the HIA to be unconstitutional³. As a result, if information is provided to police under this section in an attempt to assist police with an investigation leading to charges being laid, disclosure under this section could lead to the information being excluded as evidence in court.

This new section of the HIA gives HCPs the discretion to disclose without the consent of their patient. But does not require it. We have called for the repeal of this section. We have also recommended that regional health authorities and others who are currently working on guidelines interpret this section narrowly. We urge HCPs to recall their ethical and legal duties to their patients, and the effects of such disclosure, before deciding whether to breach confidentiality under a section aimed not at the health and well-being of patients, but at law enforcement. We hope they keep in mind the many Albertans whose health and safety may be threatened by the knowledge that their once-trusted HCP may rat them out. ■

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Notes

- ¹ Canadian Medical Association. (2004). *Code of Ethics*, s. 31 – 37. See, for e.g., Ellen I. Picard & Gerald B. Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 3rd ed. (Scarborough, Ont.: Carswell, 1996). See also *McInerney v. McDonald*, [1992] 2 S.C.R. 138.
- ² See, for e.g., *Canada (Solicitor General) v. Ontario (Royal Commission of Inquiry into the Confidentiality of Health Records)* [1981] 2 S.C.R. 494.
- ³ See Tracey M. Bailey & Steven Penney. (2007). Healing, not Squealing: Recent Amendments to Alberta's Health Information Act. *Health Law Review*, 15(2), 3-14. See this paper, as well, for a more in depth look at the competing legal and ethical obligations with respect to disclosure under s. 37.3 of HIA.

Neonatal Drug Screening; Is It Justified in Babies of Drug Abusing Mothers?

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On morning ward rounds in the neonatal intensive care unit (NICU) the attending physician is asked to order a “drug screen” on a full term baby girl admitted during the night with respiratory distress. The respiratory problem has improved and she is now clinically stable. She will only require NICU care for 48 hours of intravenous antibiotics after which she will be ready for discharge. A “drug screen” is a common request in babies with a history of suspected maternal substance abuse. How should the physician respond to this request? This paper will discuss this question from an ethics perspective.

The purpose of any screening test is to detect a problem before clinical symptoms occur. By detecting an abnormality in the pre-clinical stage, later adverse consequences can be prevented. Universal newborn metabolic screening is one example of a very successful screening program. This program prevents life-long physical and mental illnesses by detecting rare metabolic conditions soon after birth before symptoms occur. The recognition of the clear benefit of metabolic screening to the newborn population has resulted in it becoming legally mandatory in many jurisdictions. This well established clinical practice of universal metabolic screening of newborns is accepted as beneficial even though the vast majority of test results will be normal and therefore of no benefit to those babies. The traditional clinical and ethical requirements for a population screening program include the following; First, the tests are used for serious conditions which cannot be diagnosed clinically at the time of testing. Second, the tests benefit susceptible individuals by early detection and treatment of the condition. Third, the tests themselves are safe and individuals will not be harmed by testing. Fourth, the accuracy of the tests



is in keeping with required standards for low false positive and false negative results. Fifth, competent individuals are informed about the tests and consent must be obtained before testing. For some population screening programs the tests are mandated by law and consent is not required but individuals must be informed that they are being screened.

Ethically, neonatal metabolic screening is justified on the basis of preventing harm to a tiny minority of babies who test positive. By allowing the vast majority of babies to have needle pokes done which will have normal results, ethical importance is given to the seriousness of the risk (i.e., life-threatening or life-long disabling illness), even though the numeric

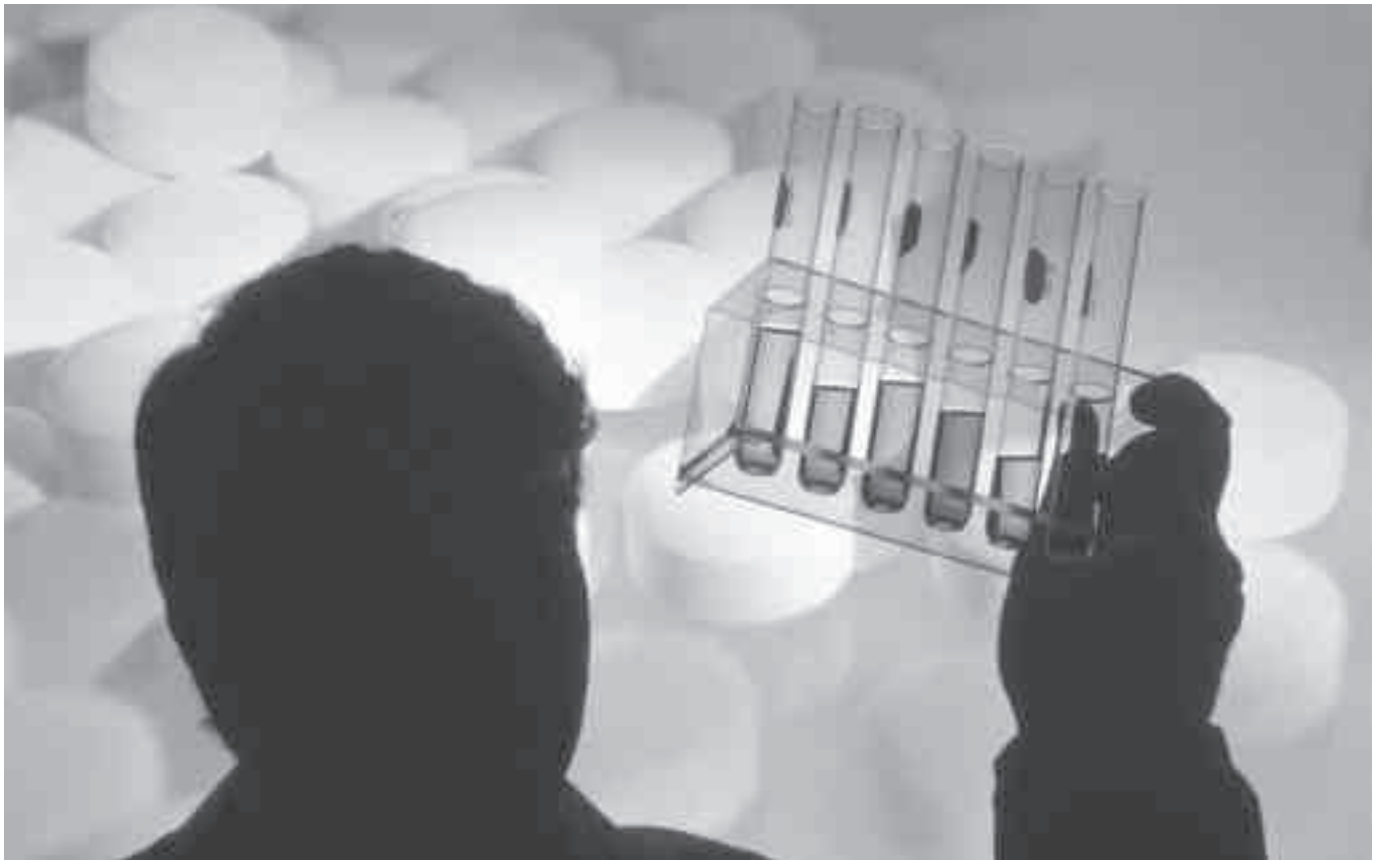
risk is very low. Justification of “small pain” for all babies rests on the avoidance of developing the condition being beneficial to the few. It may be argued that other benefits for the normal population include prevention of disability and death, and decreasing personal and societal costs for long term illness and disability in affected infants. How does this view of universal neonatal screening apply to our hypothetical request for a “drug screen” on this baby? There are several aspects of the request that need clarification before the physician can give an answer. How valid is the maternal history of substance abuse used to identify a baby or a population of babies to be tested? What is the purpose of the test – screen or diagnostic? What consequences are likely to result from testing or not testing newborns for drug metabolites?

Unfortunately maternal history about substance abuse during pregnancy is very unreliable due to the frequency of under-reporting and denial. Targeting a specific population of babies for screening on the suspicion of maternal drug abuse *alone* is not justified for several reasons; the wide margin of error involved in drug abuse history, the risks of racial and socio-economically disadvantaged women being screened without supporting evidence, the lack of obvious benefits from screening to most babies with positive results.

There may be clinical evidence of prenatal substance abuse in some mothers making the likelihood of a positive drug test very high in the baby. In such cases the request to “screen” the baby is not truly a screen but a diagnostic test based on suspicions from clinical maternal assessment and history. In this scenario the purpose of the test is to confirm drug metabolites in the baby and to infer substance abuse by the mother. In addition, if the baby develops drug withdrawal symptoms consistent with Neonatal Abstinence Syndrome (NAS) or shows other symptoms of prenatal drug exposure, the presence of drug metabolites adds weight to the diagnosis. However, if the baby does not show NAS or other symptoms what does the positive drug test mean?

A common purpose and consequence of the neonatal drug test is to inform social welfare agencies of a positive result as evidence of prenatal exposure to drugs and “flag” the file for child protection agencies. The risk for the baby of serious neglect after discharge from the hospital is very high in the social setting of severe maternal substance abuse. In keeping with the ethical standard of promoting the *best interests* of the baby, health care professionals (HCPs) have a responsibility to prevent future harms. This ethical duty to protect the baby may result in a necessary breach of confidentiality of the mother’s health record concerning drug abuse. The most likely consequence will be a court-ordered apprehension removing the baby from the mother and family. But does a positive drug test result assist HCPs in carrying out this duty to protect and promote the *best interests* of the baby?

The ethical dilemma faced by the physician involves the conflict between a duty to promote care for the baby and mother together and a duty to prevent later harms. The practice of selective newborn screening for drug metabolites implies that this diagnostic approach will assist in treating early clinical problems and will also prevent later neglect or abuse of the baby. For example, it is argued that a positive drug screen will allow early treatment for NAS. But NAS scoring systems were developed precisely to identify early clinical signs of NAS to facilitate early treatment, thereby making the drug screen for narcotic metabolites somewhat redundant. However, as NAS does not occur after prenatal exposure to many non-narcotic drugs we are left with the problem of how to identify babies at risk for other complications. Surprisingly, when we consider the severe teratogenicity of alcohol, the majority of babies exposed prenatally to “street drugs” do not develop serious medical complications. Babies who develop complications can be diagnosed and treated based on history, clinical findings and investigative drug testing included. By focusing attention on the baby’s immediate and long term needs a “drug screen” can be seen as of little use unless the baby is symptomatic.



Mothers with chronic substance abuse may be highly dependent and intoxicated during labor and delivery. In such cases the mother cannot provide infant care after birth. If a decision is made to test the baby for drug metabolites because of symptoms, the mother should be informed that a drug test is being done. The mother should not be asked to consent because the test is indicated in the infant's *best interests* even though her confidentiality and right to privacy are being placed at risk. Because of the inference of a positive drug test the results must be kept strictly confidential and initially only discussed with the mother. If necessary, child protection services will be made aware of the test results by being brought into the future discharge planning. A problem for HCPs is that they now face a breach of trust with the infant's mother by seeking this "proof" of prenatal drug exposure. While this decision is based on the *best interests* of the baby it negates the mother's self-respect and autonomy, and should be restricted to cases where neglect and serious harms are likely.

The possibility of assisting the mother with her own serious drug related problems will be enhanced by having her involved directly in the baby's care. This can be implemented cooperatively with others being the primary care providers for the infant until such time as the mother shows herself capable of doing so. It is important for physicians, nurses and social workers to avoid judgmental decision-making and to remember that there is a broad spectrum from the extreme to less serious degrees of drug dependence. Childbirth and newborn nurturing present a rare opportunity for women to break out of a chronic substance abuse lifestyle. Recognizing the mother as a person with a chronic life-threatening illness rather than a "junkie" is the first step in helping her to be involved in her baby's care. Eventually this respect as a mother and ability to care for her baby may help her in her own rehabilitation. Sadly the opposite scenario is all too often the case with mothers viewed as villains who deliberately harm their babies.

It has been argued that a positive drug test result in a baby indicates actual prenatal neglect and inevitable abuse of the infant after birth.

So why do we not simply test any baby with a suspicious history on this basis? This question is often asked by NICU staff after a baby is admitted for observation when the mother has absconded shortly after giving birth (usually to get a drug “fix”) and does not return for days if at all. The mother may have a history of pre-

vious pregnancies where babies have been neglected and apprehended by court order. These examples present support for drug testing of individual babies at high risk but do not justify population screening. Unfortunately newborn drug screening programs have all too often been established with the sole goal of protecting babies by removing them from their mothers soon after birth. This approach has not been shown to improve outcome for the majority of mothers or their babies. By targeting the babies of specific ethnic groups or socio-economically deprived mothers for drug screening we run the serious risk of discriminatory profiling in a coercive and judgmental manner. One of many reported attempts to “help” such infants, which involved cooperation of a university based medical center and local police, resulted in punitive legal actions against mothers during labour or immediately after giving birth without any community supports in place. Clearly this coercive approach is not ethically sound either and does not help the mother or the infant’s point of view.



It may be that a research based program of selective population drug screening on newborns of drug abusing mothers, with community based supports in place, would achieve improved outcomes for both mother and baby. Such a program would require enrollment of substance abusing mothers during pregnancy and would entail specific discharge planning involving the mother in the baby’s care. The utility of baby drug testing would then be

subject to assessment as part of the study analysis. Beyond this scenario attempts to use drug screening of newborns as a “one fits all” solution to this social tragedy are doomed to fail. Specific clinical situations in newborns will require drug metabolite testing but should remain the exception to the rule. Protection of these newborns from neglect or abuse after birth is best achieved by comprehensive care planning to ensure a safe nurturing environment. ■

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What is the Current Understanding of Brain Death in Canada?

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Brain death (BD) is legally and medically accepted as death of the patient. This was recently confirmed by a multidisciplinary forum in Canada, which also clarified clinical and ancillary tests used to confirm BD. However, the conceptual justification for BD being the death of the patient is problematic. The standard argument is that the concept (or definition) of death is the irreversible loss of the integration of the organism as a whole, resulting inevitably in cardiac arrest in a very short time. There are two criteria for this state of death: BD and circulatory death. With BD, it is said, there is irreversible loss of the integration of the organism as a whole, and this *is* death. Bedside tests (often called “the criteria” for BD) are used to determine and confirm that the brain is dead.

Problems with the Brain Death Concept

This paradigm for why we should accept BD as being death requires scrutiny. There are many reports of patients with confirmed BD, who have “survived” for weeks, months, and even in some cases for years. These patients demonstrate ongoing functions such as growth, sexual maturation, resisting infections, cardiovascular stability, and fluid and electrolyte balance. Some reports describe BD pregnant women who have been able to support a fetus to viability. These findings suggest that the theory that there has been irreversible loss of integration of the organism with BD is not tenable. The longest “survivor” reported after BD “lived” at home, with a ventilator and tube feeds, for 20 years after meningitis.

Problems with the Brain Death Tests

The bedside tests used do not confirm lack of all functions or destruction of the entire brain. Electroencephalography (EEG) activity is detectable after BD in 20%, brainstem evoked potentials remain in about





5% after BD, some hypothalamic functions remain in up to 50% after BD, and case reports describe breathing above the current cutoff (PaCO_2 above 60mmHg) for lack of breathing on the apnea test. Once confirmatory cerebral blood flow studies are done, 5% have brain blood flow when they are BD. When cerebral blood flow is measured by computed tomographic (CT) angiography, over 30% have brain blood flow after BD. The solution offered for these problems is that any remaining functions of the brain are due to “nests” of neurons not needed for integration of the organism. This is problematic for two reasons. First, as discussed above, there does not always seem to be irreversible loss of integration of the organism in BD. Second, how these “nests of neurons not required for integrating function” differ from other functions tested (such as a pupil reflex to light, an ineffectual breath at a PaCO_2 of 60mmHg, a slight withdrawal of a limb, a movement of an eye to cold water injected into the ear canal, etc.) which are stated to be critical for integration of the organism is unclear.

Other Brain-Based Concepts of Death

An attempt to justify BD being death itself is the so called “higher brain death” definition. By this rationale, definition of death is the irreversible loss of the capacity for consciousness. This has not been accepted as death in any country, probably because it would mean that breathing is irrelevant, and a patient that has irreversibly lost consciousness, could be declared dead despite ongoing breathing, circulation, and movement.

Another suggestion is to accept brainstem death as death. Brainstem death is said to mark the time when the “conscious soul” leaves and the “breath of life” is gone. However, in rare cases of brainstem death the higher brain may be relatively spared, and the capacity for consciousness may not be lost (in one series this occurred in 3.6% of BD cases). Brainstem death suggests Cartesian dualism, implying that we can know when the soul departs (coincident with the time that the capacity for *demonstrating* conscious-

ness has irreversibly been lost). By the brainstem death rationale, the patient in a permanent vegetative state has also lost the “conscious soul”. This “breath of life” rationale means that a person with a high cervical-spine injury with permanent inability to breathe, has loss of the “breath of life” and is defined as dead while fully awake on a ventilator.

Canadian Neurosurgeons and Pediatric Intensivists

We (Joffe et al., in press) recently surveyed Canadian pediatric intensivists and neurosurgeons to determine their understanding of these issues. We found that there is limited awareness of the conceptual problems with both the BD concept, and with current tests used to determine BD. For example, when faced with a BD patient with no brain blood flow, yet a family that insists on “life support”, >30% would continue life support. I suggest that as similar requests by family for life support continuation after circulatory death are not accepted in clinical practice, this means that BD is thought by these doctors to be different from death. Canadian neurosurgeons when asked directly “are brain death and cardiac death the same state (i.e., are both death of the patient)?” 45% answered “no”. When the physicians were asked to explain why brain death is equivalent to death, only <40% chose a loss of integration of the organism concept, and many chose a prognosis (i.e., quality of *life* was not acceptable, cardiac arrest was inevitable). Most of the physicians answered that BD is not compatible with EEG activity. Over

one third said that BD is not compatible with some cerebral blood flow. These results are concerning when one considers that a recent forum of experts in Canada affirmed that BD *is* death, and clarified the clinical tests used to diagnose BD.

Conclusions

Brain death is entrenched in clinical practice, and is accepted as death by legal and medical culture and by many in our western society. Surprisingly, no one has been able to explain exactly why BD *is* death. Given the problems described above, I suggest that it is more honest to claim that BD is a state of neurological devastation with an extremely poor prognosis. It is a state where withdrawal of life support may be in the patient’s best interests, and if withdrawn, death will result within minutes. This is however a very different claim from the assertion that BD *is* death. ■

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Upcoming Events

Dossetor Centre Health Ethics Seminars:

Please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ for an updated seminar schedule.

Health Ethics Week 2008:

Health Ethics Week will take place from 3 – 9 March 2008. The theme: *Creating Space for Moral Reflection*. More information available at: <http://www.phen.ab.ca/ethicsweek/>

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