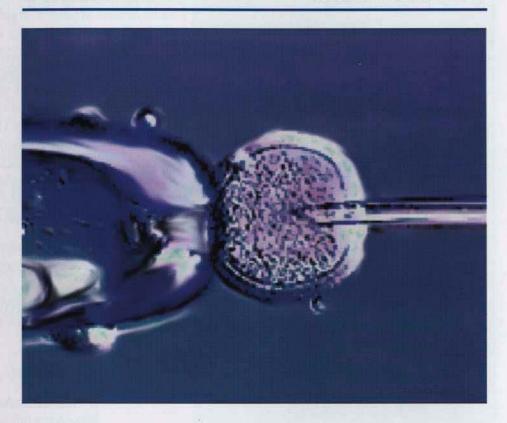
The Interdisciplinary Journal of Health, Ethics, and Policy

December 2001

Volume 1 Number 2



Original Articles

A New Lens: Arguments for a Conceptual Shift in the Debate Surrounding the Use of Cloning Technology for Stem Cell Research

Jayme Dowdall

HIV and Harm Reduction: A Case Study of Cambridge Cares About AIDS, Inc.

Rachel Jervis

A Publication of TuftScope, a Student Organization at Tufts University http://www.tuftscope.com

The Interdisciplinary Journal of Health, Ethics, & Policy

> Editors-in-Chief Bradley Crotty Katharine McGinigle

Editorial Staff
Mauricio Chan
Kelly Condit
Bernidice Diaz
Kaoru Endo
Diana Fischmann
Amy Goldman
Sheina Jean-Marie
Milani Patel
Tanya Santos
Lilly Schofield
Jennifer Takigawa

Business Department Valentino Caruso Elizabeth Buchen

Editorial Advisory Board
Bradley Crotty
Ross Feldberg, Ph.D.
Charlene Galarneau, Ph.D.
Katharine McGinigle
Lacey Prouty

TuftScope Mayer Campus Center Tufts University Medford, MA 02155

ISSN 1534-7397

TuftScope is published by Turley Publications Palmer, MA

About the Journal

With recent advances in biotechnology and advanced medical techniques comes a multitude of ethical and philosophical questions, and a need for policy review. Conceived in the Fall of 2000 by undergraduate students, TuftScope brings together various students, academics, policymakers, and industry representatives to talk about pertinent healthcare and biosocial debates in today's world.

TuftScope, the Interdisciplinary Journal of Health, Ethics, & Policy, accepts original articles on government health policy, public health, bioethics matters, medical education, research in the mentioned fields, and other various issues dealing with the science and art of medicine or our country's healthcare system. The principle objective of TuftScope is to bring together seemingly different viewpoints, citizenship and the health sciences, to transform thoughts and ideas into active citizenship and working policies.

TuftScope is a recognized, funded student organization of Tufts University.

Disclaimer: Statements and opinions expressed in articles herein are those of the author(s) and not necessarily those of the editor(s), publisher, or Tufts University.

Electronic Access http://www.tuftscope.com

> General Inquiries info@tuftscope.com

Advertising Information www.tuflscope.com business@tuflscope.com

The Interdisciplinary Journal of Health, Ethics, and Policy

Volume 1

December 1, 2001

Number 2

Original Articles

- 4 A New Lens: Arguments for a Conceptual Shift in the Debate Surrounding the Use of Cloning Technology for Stem Cell Research Jayme Dowdall
- 10 HIV and Harm Reduction:
 A Case Study of Cambridge Cares About AIDS, Inc.
 Rachel Jervis

Correspondence

- 15 Anthrax: A National Threat or a National Headache?

 Grace Mitchell
- 16 Women Physicians Find Balance in Practicing and Parenting Kate McGinigle
- 18 From the Editors

 Brad Crotty, Kate McGinigle
- 19 News compiled by TuftScope staff

On the Web

Get Full Text Articles
Participate in Discussion Forums
Visit TuftScope Conference Websites
Read Guidelines for Authors
Request Reprints

Online at www.tuftscope.com

The Interdisciplinary Journal of Health, Ethics, and Policy

Volume 1 December 1, 2001 Number 2

A NEW LENS: ARGUMENTS FOR A CONCEPTUAL SHIFT IN THE DEBATE SURROUNDING THE USE OF CLONING TECHNOLOGY FOR STEM CELL RESEARCH

Jayme Dowdall

The stem cell debate in the United States came to a head in the context of the abortion debate and media hype reporting the certainty of attempts to clone humans.1.2 Frequent announcements of the utility of adult stem cells or even the presence of these cells in fat leftover after liposuction makes the case for using embryonic stem cells more challenging by fostering misunderstanding in the public sphere about the plausible sources of stem cells. In the recent congressional hearing on human cloning, subcommittee member Peter Deutsch enumerated the potential benefits of stem cell research including the prevention treatment and cure of Parkinson's, Alzheimer's, diabetes, leukemias, other cancers, heart disease, and liver failure.4 It is, however, widely accepted in the scientific community that while embryos are the best source of stem cells, their procurement is also the most ethically problematic. Without the access to embryonic cells it is feared the therapeutic potential of stem cells will be greatly diminished and patients with these diseases will continue to suffer.

Cloning technologies are then necessary to produce the quantity and specific types of embryos to lead to therapeutic benefit. However, the word cloning itself evokes the oft-mentioned 'yuck factor.' In an attempt to separate this guttural rejection from the technology, philosopher and bioethicist Gregory Pence suggests we use the morally neutral phrase, somatic cell nuclear transfer or SCNT.⁵ SCNT means the same thing as cloning but without the eliciting the same charged emotive response. SCNT "refers to the process by which the genotype of an adult, differentiated cell can be used to create an new human embryo by transferring its nucleus to an enucleated human egg." This essentially makes it possible for one to take any somatic, or body cell, and turn into an embryo.

Further complicating the use of SCNT in stem cell research is the necessary, deliberate, creation and disaggregation of a human embryo. 6 As bioethicist Gregory Pence comments, we will not be able to know the full potential of embryonic stem cell research "unless we try-but we can't try until we separate murder from embryo research."7 Although the scientific validity of the techniques employed in SCNT research has been demonstrated, SCNT research is prohibited from receiving federal funding. The absence of federal grant funding for research involving SCNT embryos results in a delay of potentially life-saving therapies for millions of sick individuals. The absence of federal funding for SCNT research impairs the ability of academic laboratories from collaborating with privately funded research. An ethical defense for SCNT technology and its application, and a balanced oversight mechanism of this technique is necessary. I argue the creation of embryos derived from SCNT, and research on these embryos, is morally permissible. Therefore the policy debate should be refocused to a discussion of adequate oversight in this arena.

It is important to identify current constraints on SCNT and how they came to be to focus the arguments for SCNT to affect a change in public policy. In Health Policymaking in the United States, Longest defines public policies as "authoritative decisions made in the legislative, executive or judicial branches of government intended to direct or influence the actions, behaviors, or decisions of others." The SCNT debate is framed in statutory language of specific pieces of legislation and the rules and regulations for the operation of a government program specifically, the National Institutes of Health.

Currently, prohibition of SCNT applies only to those who apply to the NIH for federal money for their research as a condition of the grant reward. The August 2000 guidelines prohibit the use of federal funds for SCNT and the use of embryos derived from this technique. These constraints are to ensure the research is conducted in an "ethical manner." As this prohibition is founded on moral grounds, we must look at who made

the decision and on what basis.

The NIH convened a working group of scientists, patients, patient advocates, ethicists, clinicians, and lawvers to suggest guidelines for SCNT research. They received input from the public, professional groups, Congress and the National Bioethics Advisory Commission or NBAC.9 NBAC's recommendation for the guidelines surrounding SCNT has been heavily criticized.10 While NBAC acknowledged that the crux of their deliberation on the issue was over the use of federal funds for this research.11 which is crucial to dissect the weight their recommendation should hold. NBAC's recommendation should not be mistaken for an ethical verdict on SCNT. The recommendation should only be viewed as a suggestion on the use of federal funds in a given time frame. Meilaender further supports this claim by asserting the chief limit for the NBAC debate on this technique "not so much involves the status of the embryo but the status of public support."12

Congress was also listed as a source for input for guideline formation. The March 28, 2001 Congressional Subcommittee Hearing on issues raised by human cloning research made clear the lack of synchrony present between government agencies. The NIH, the very agency that commissioned the research guidelines, was invited to the hearing but deferred due to a "lack of expertise in this area." If the NIH does not have capacity in this area, should they be involved in the formation of guidelines founded in ethical principles? Cleary, as committee chairman Michael Bilirakis remarks, "other bodies may hold meetings and write reports and issue voluntary guidelines, but only the Congress can make the laws for our nation."4 This statement highlights the tension and power play between the various agencies of policy formation and begs an analysis of the most appropriate form of oversight for SCNT.

The purpose of a congressional ban is precisely to prohibit an unacceptable means to otherwise desirable ends.12 However, such a ban would likely effect public and private research for an indefinite period of time. This ban would be based similarly on recommendations from NBAC, expert testimony, and the public comment. Therefore the input at least from NBAC could be misinterpreted as ethically definitive. A congressional ban would likely be in place for some time and would act as a definitive ethical verdict on the technology making it infinitely more challenging for this ban to be revisited at a later date. Meilaender disagrees, stating the NBAC recommendation for the prohibition of SCNT "is a limit to be chipped away at gradually, as the little words 'at this time' indicate."12 It appears however, the five year ban would be overlooked should this recommendation

become an actual congressional ban. 10 We must look beyond these recommendations to provide a solid ethical defense for the permissibility of SCNT.

Controversy in this debate is centered on the status of the embryo; therefore we must define what an embryo is. A widely used definition of the embryo is as the McGraw-Hill Dictionary of Scientific and Technical Terms states, "the product of conception up to the third month of human pregnancy."13 However, according to United States congressional statue, the embryo is defined as "any organism that is derived by fertilization, parthenogenesis, cloning, or any other means from one or more human gametes."14 The first definition, rooted in conception, does not define the product of SCNT as an embryo because conception is not involved in this process. There are many different mental pictures associated with the word 'embryo' as the term is imbedded in a continuum of stages. This is problematic as we expect science to provide us with clear exacting definitions.

Compounding this conceptual difficulty is the misnaming of the techniques that are commonly used in assisted reproductive technologies. The Canadian Royal Commission on New Reproductive Technologies acknowledged this in their 1993 report:

The term 'embryo' refers to the developing entity after implantation in the uterus until about eight weeks of fertilization...the terms embryo donation, embryo transfer, and embryo research are therefore inaccurate, since all of these occur with zygotes, not embryos. Nevertheless, because the terms are still commonly used in public debate, we continue to refer to embryo research, embryo donation, and embryo transfer.¹⁵

NBAC furthered the confusion here in the United States by continuing to "use the broad terms embryo research, embryo donation and embryo transfer to refer to zygotes, because this is how the public commonly uses them."11 NBAC refused to utilize a valuable forum to flesh this out in terms of what the embryo means to people. For the majority of this paper, I too will take the easy way out and refer to all entities meeting the congressional definition as an embryo. The public debate centers not on what an embryo actually is as opposed to what it means to people.16 Michael West, from Advanced Cell Technology acknowledges this sentiment by saying, "If you ask the average person, they will tell you it's a tiny little person with buggy eyes." In light of these misconceptions about the definition of an embryo, we should focus on what we value about the embryo, regardless of what we consider it to be.

To say that an entity has moral status is to say some-

thing about how one should act towards that thing or person.11 Thus, elucidation of the moral status of the embryo should provide an idea of the respect one should provide it. Some argue the embryo should be respected because it is biologically distinct. Conception marks the point at which a new life is generated that is neither that of the father or of the mother.18 The Catholic Church justifies this assertion of value by citing recent scientific advances recognizing from the point of fertilization that "the biological entity of a new human being is already constituted. 19 It may also be argued that the embryo is valued insofar as the gamete donors value the embryo. This custom combination of gametes creates a genuine moral connection between the gamete donors and their embryo.20 This value is linked to their embryo's potential to develop into a healthy baby with specific genetic material.

While these arguments provide justification for respecting the embryo, we must flesh out the appropriate magnitude of respect that we should assign to the embryo. In terms of potentiality, the moment the zygote has formed it has the potential for developing into a person. They also have the potential to spontaneously abort, which the majority of embryos do. So it is the exception, not the rule that embryos make it to term. Some argue the possession of this potential demands the unconditional respect that is morally due to a human being.¹⁹ The Church sees every human life at every stage as equally worthy of protection.18 In summary, embryos, as potential persons, must be accorded the rights and standing of persons.21 It is the potentiality of personhood that provides the moral imperative to accord the embryo with rights that actual persons enjoy.

The idea of assigning an embryo the full moral standing of an adult is not without its critics. Meyer claims the embryo should not be given less moral standing than adult humans and other sentient animals because the embryos are alive as living cells and because they are regarded by others as morally valuable.20 Criticism is also directed to the criterion of biological uniqueness, which is not clearly defined in the early embryo. The embryo may separate into twins making it difficult to establish developmental individuality necessary for personhood at this time. 6,20 According to this critique, respect could be more properly assigned at approximately fourteen days when the genetic uniqueness of the embryo is determined.22 This leaves the embryo's potential for development into a human being as the most salient criterion for assigning it significant moral weight.6

Analysis in terms of potentiality is also problem laden. To say that X is potentially Y, it follows that X is

not Y.²¹ The aforementioned arguments suggest that although X is not Y, X should be treated as Y. However, the converse argument can be made as well. The appeal to probabilities is the most commonsensical of arguments; morals are often measured by the account one has taken of probabilities.²³ Therefore if the determinations of moral status in terms of potential, are not to appear arbitrary, they should relate to some real difference in probabilities.²³ A "developmental view" sees an embryo as increasing in moral weight over the course of a pregnancy as it is increasingly possible they embryo will produce a child.⁶

A discussion of probability can also begin with the constituents of the embryo. The odds the respective gametes must overcome to form an embryo are enormous. The sperm possess a 1 in 200,000,000 chance of meeting an egg and only 390 of the thousands of eggs a women has at birth are ovulated. These odds provide a point at which to make a distinction between an enormous shift in potentiality between the likelihood of the gametes and the likelihood of the embryo to produce a child.23 However, philosopher Peter Singer argues that even this distinction is blurry. Singer states, "it is very difficult to understand why people should value the potential of the embryo and not the egg-and-sperm."24 The tension between these views lies in the determination of what comprises significant probability. However, Noonan's argument for distinction is a convincing one.

The location of the embryo is an additional factor that must be considered. Conception occurring in the womb has the maximal potential for producing a child as no external action is needed for the fertilized egg to implant. Embryos conceived outside the body must be transferred into the womb. Requiring a third party, these extracorporeal embryos have reduced potential, as they are dependent on the willingness for a woman to carry the child. While this may As Meyer asserts, "an embryo properly starts on that trajectory only when the gamete sources intentionally have it placed in the womb." Therefore, extracorporeal embryos have a reduced potential, and therefore reduced moral status until they are placed in the womb.

The SCNT technique in and of itself is only morally problematic in the same manner as in vitro fertilization. In SCNT, the embryo must be 'tricked' into fertilization via an electric shock. One might argue that this violates the natural order of embryos as objects of conception, though the products of SCNT clearly have the potential for forming a human being. This objection, along with the objection to conception occurring outside the body, can be countered in the same manner as

objections to IVF. Therefore, the technique itself does not create any new moral dilemmas.²⁵

The sliding scale of potential and therefore moral status established by the analysis of traditional and extracorporeal conceptions facilitates the determination of the moral status of the embryo. In SCNT, the enucleated egg and somatic nucleus have even less potential of becoming a child than the egg and the sperm. Compounding this lack of potential is that SCNT embryos are a long way from producing a healthy child as evidenced by animal experimentation in this area. Therefore, the SCNT embryo can be said to have less moral status in the petri dish than an extracorporeal embryo created by IVF. The genetic identity distinction is even more problematic. In SCNT an entity of the mother or of the father is produced, not a novel combination of the two. Observationally, we do not treat identical twins as having far less value than other children. Technology may advance where SCNT and IVF embryos have the same potential of producing a healthy baby at implantation. It is problematic that the moral status of the SCNT embryo is dependant on technological advances. This suggests that the criterion of biological uniqueness is not one that is applicable across the board for affording moral status to embryos.

The advent of an embryo without conception challenges the notion of the union of the gametes and sexual aspects of procreation as being of theological or ethical significance. An egg activated by nuclear transfer is not a human "embryo" in the traditional sense of that term, because it is not the result of fertilization.6 The congressional definition of the embryo focuses on the origins of the embryo with no mention of the end result. Both definitions skirt around the quality that differentiates embryos from other biological material, namely the ability to produce a child. I argue it is imperative to refer to the embryo as an entity implanted in the womb with the potential for producing a child. The meaning of embryo to most people lies in the real potentiality for a birth. The moral status of the entities prior to implantation is simply too different to call them both by the same name.

The idea of what is being destroyed in order for research to proceed is the real concern. The result of SCNT has some minimal value, similar to IVF zygotes prior to implantation. Peter Singer's rationale of the zygote having no more potential than the egg and the sperm is particularly relevant. Implantation is a significant barrier in forming a child. The concern that Singer's declaration will lead to the devaluation of children is unfounded. Surely it is possible for the value of these zygotes to be different before implantation with the no-

tion this different status will cease once the embryo is residing in the womb. How then, should one treat the embryo in the dish?

Although, as Meyer argues, the moral status of an entity must be clarified before the moral permissibility of its intentional destruction can be ascertained, ²⁰ this is not as fruitful an exercise as one would hope. Even if we hold something in high regard, this has no bearing on whether or not it can be ethically destroyed. As Meyer states, "a genuine moral respect for embryos can be joined - without incongruity but not without careful attention to how that respect is displayed- with their use and destruction in legitimate research. ²⁰ However, we must focus the arguments to allow embryo research in the United States to the following condition in the NIH budget:

Grant, cooperative agreement and contract funds may not be used for (1) the creation of a human embryo or embryos for research purposes; or (2) research in which a human embryo or embryos are destroyed, discarded, or knowingly subjected to risk of injury or death greater than that allowed for research on fetuses in utero...The term human embryo or embryos includes any organism, not protected as a human subject...that is derived by fertilization, parthenogenesis, cloning, or any other means from one or more human gametes or human diploid cells.¹⁴

Once again, the term embryo lumps together many entities with differing moral status. While the objection in general to zygote research is the destruction of nascent human life, whether at the embryonic or fetal stages, it is very much still a value discussion in terms of potential.⁶ St. Thomas Aquinas argued that taking the life of an early fetus did not involved the evil of murder even though the early fetus or embryo was potentially a person.²¹ Clearly, potential to form a human being does not command the same rights and respect as an adult moral agent.

A zygote has no nervous system so it cannot possibly suffer in any way from the experimentation. The early embryo's lack of organs also makes it unreasonable to believe that it is in any way capable of having thoughts, feelings, or experiences.⁶ While we still find it ethically permissible to experiment on animals and people with brains and nervous systems, the zygotes seem a less problematic substrate for experimentation precisely because of the embryo's incapacity for suffering. We must be mindful of specious tendencies in embryo research. Peter Singer argues, "experimenting on a human embryo is not to be compared in significance with experimenting on a living, sentient mouse."²⁴ This distinction is due to the difference of these entities in their abilities to suffer.

NBAC suggests that the use of IVF embryos in clinical excess raises fewer ethical questions because it does not alter their final disposition. The use of these embryos appeared to be a compromise for those who oppose the separation of conception and the sexual act. Although the people holding this view find the creation of too many embryos in infertility medicine or the practice of abortion ethically unacceptable, they believe that no useful purpose is served by refusing to use the cells or tissues made available in this manner. They also reason that it is unlikely that the use of these cells or tissues in research will encourage either the creation of spare embryos in infertility medicine or abortion, since there are independent reasons these practices occur.

The primarily concern with research zygotes, of which SCNT zygotes are a part, is the slippery slope "instrumentalization" the leading to "commodification" of human life in general.6 The concern that these zygotes are created to be destroyed provides for zygotes to be used as a means to an end. One ascertains this is the morally relevant difference between generating an embryo for the sole purpose of creating a child and producing and embryo with no such goal.11 How significant is this difference? The slippery slope presupposes that the zygote is human enough to warrant prohibiting its use as a source of cells or tissues.6 However, this objection is rejected by the minimal moral status assigned to the extracorporeal embryo in terms of potentiality.

The instrumentalization concerns dissolve when these two sources are compared side by side. Both the research IVF and SCNT zygotes are defined by their parameters. If the embryos are not implanted into a womb, there will be no child. This is the same fate for IVF zygotes created with the 'intent' to produce a child. The qualification of intent is a superficial one. Practically, how would one regulate intent? Those who are doing human reproductive cloning research can easily tell oversight bodies they do not intend to create a child with their research. Therefore, intent does not create a useful moral or practical distinction in this arena if the proper respect is granted to the embryos. The actual action of transfer and implantation does create a real distinction in potential and moral status and it is at this point that the technology should be subject to oversight.

An additional concern is that SCNT research will further human reproductive cloning.⁶ This is a misinformed fear. For those researchers who want to use SCNT zygotes for stem cell research, there is no objective to produce a healthy baby. The research will be focused on the early embryo instead of overcoming problems with carrying a healthy cloned child to term.

The technique in the early stages is not the problem, reprogramming of the genes is the obstacle that needs to be overcome to produce a healthy cloned child.⁴ Although SCNT is identically used for both stem cell research and human reproductive cloning, the technique itself should not be banned. Regulation at implantation effectively addresses the ethical concern of leading to human cloning with this technique without quelling stem cell research.

Additionally, there is a concern that embryo research will lead to widespread abuses in human subjects research. Great Britain has permitted the use of embryos in research since 1990 with the Human Fertilization and Embryology Act (HFEA). The HFEA also permitted research involving the deliberate creation of embryos, and no human subjects abuses have been recorded. With this heightened scrutiny, it is easy to believe that where zygote research is allowed it will be monitored closely and subjected to layers of oversight. This would minimize the chance for bad science and bad ethics to become widespread in this area of research.6 Therefore, there is no reason to think that permission to create and use embryonic stem cells in research or the development of SCNT will lead to the predicted harms.6

Even if one grants personhood to the fertilized egg, its destruction in stem cell research is justified. This is so even in the absence of an extreme utilitarian calculus where the alchemy of stem cell research outweighs all moral obligations. This research on SCNT embryos is justified so long as this source of cells is the only reasonable alternative, the minimum number of zygotes will be used and it will be for a compelling reason. SCNT should not be prohibited from federal funding because it is (a) not objectionable in and of itself, (b) the slippery slope arguments are not convincing (c) it has a reduced potential (and therefore reduced value) as an embryo. All these factors lead to the conclusion that when its nature and purposes are understood, SCNT can command broad ethical support.6

The promise of a resolution to the controversy of using federal funds for SCNT zygote research is due to a paradigm shift in approaching the issue. As Meilaender argues, "the public debate need not be restricted to a seemingly endless argument about the embryo's status." The new strategy should be framing the debate in terms of solvable problems. It is true that there are valid concerns about this technology and people are willing to accept delays in the progress of stem cell research rather than permit the use of cell line sources that they regard as morally objectionable. This is a concern about the manner in which we live as a society. The concern that "we will have done evil in

the present for a future good that does not come to pass" remains.¹² This is the proper frame shift for the debate on SCNT. We must address the issues on affording the research substrate appropriate respect, for it matters how one acts in addition to the action itself. This is a conceptually challenging shift, but one I have argued will be much more fruitful than discussions in terms of potentiality and moral status.

We must understand what is compelling for the public.7 If we are to make policy recommendations we must elucidate the specific problems with SCNT research not in terms of language but in terms of meaning. We must be very deliberate in examining exactly what is it that we should strive to protect. It is this deliberate focus that will frame this debate in terms of solvable problems. However, sometimes making progress is elucidating where the solution is not to be found. I argue the solution is not found in terms of the status of the embryo for this examination does not provide a guide for how one should act towards the embryo. In light of the abortion debate, Don Marquis states, "the problem with the ethics of abortion is the problem of determining the fetal property that settles the moral controversy."26 The SCNT debate is also solvable by identifying a similar property.

Author Biography

Jayme Dowdall, '02, is a Biochemistry and Molecular Biology major at Boston University. She is a coordinator for the International Student Bioethics Initiative and is active in the Bioethics Society at Boston University.

References

- Falco, Miriam. Cloning Experts to Tell House Committee Pros. Cons. 2001. CNN.com/Health. Available: http:// www.cnn.com/2001/HEALTH/03/27/cloning.reality/ index.html. March 27th 2001.
- ² Raymo, Chet. "Cloning and the Human Self." <u>Boston Globe</u> 3/20/2001 2001: 2.
- ³ Saltos, Richard. "Fat Is Found a Source for Stem Cells." <u>Boston Globe</u> 4/10/200 2001, sec. A01.
- 4 "Issues Raised by Human Cloning Research." <u>Subcommittee on Oversight and Investigations Hearing</u>, 2001 of The House Committee On Energy and Commerce.
- ⁵ Pence, Gregory E. "Will Cloning Harm People?" Flesh of My Flesh: The Ethics of Cloning Humans: A Reader. Ed. 1998. 115-27.
- ⁶ Lanza, Robert P., et al. "The Ethical Validity of Using Nuclear Transfer in Human Transplantation." <u>The Journal of the</u> <u>American Medical Association</u> 284.24 (2000): 3175-79.
- ⁷ Pence, Gregory E. Who's Afraid of Human Cloning? Lanham [Md.]: Rowman & Littlefield, 1998.
- ⁸ Longest, Beaufort B. Health Policymaking in the United

- States. Ann Arbor: AUPHA Press, 1994.
- 9 "National Institutes of Health Guidelines for Research Us ing Human Pluripotent Stem Cells." 2000. Vol. 65 FR 69951.
- Wolf, Susan M. "Ban Cloning? Why Nbac Is Wrong." Hastings Center Report, 27.5 (1997): 12-15.
- ¹¹ NBAC. Ethical Issues in Human Stem Cell Research: Volume I, Report and Recommendations of the National Bio ethics Advisory Commission. Rockville, Maryland: National Bioethics Advisory Commission, 1999.
- ¹² Meilaender, Gilbert. "The Point of a Ban: Or, How to Think About Stem Cell Research." <u>Hastings Center Report</u> 31.1 (2001): 9-16.
- ¹³ Parker, Sybil P., ed. <u>Mcgraw-Hill Dictionary of Scientific and Technical Temrs</u>. Fifth ed. New York: McGraw-Hill, Inc. 1994.
- 14 "The Omnibus Consolidated Fiscal Year 1998 Appropriations Act." 1997.
- The Canadian Royal Commission on New reproductive Technologies. <u>Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies</u>. Ottawa: Minister of Government Services, 1993.
- ¹⁶ Hughey, Mark, and Tracey Fuller. "Personal Communica tion." 2001.
- ¹⁷ Fischer, Joannie. "The First Clone." <u>U.S. News and World</u> Report December 3 2001: 50-63.
- ¹⁸ Tonti-Filippini, Nicholas. "The Catholic Church and Reproductive Technology." <u>Bioethics: An Anthology</u>. Eds. Helga Kuhse and Peter Singer. Oxford: Blackwell Publishers Ltd, 1999. 93-95.
- ¹⁹ Congregation for the Doctrine of the Faith. "Instruction on Respect for Human Life and Its Origin and on the Dignity of Procreation." <u>Ethical Issues in the New Reproductive Technologies</u>. Ed. Richard T. Hull. Second ed. Belmont: Wadsworth Publishing Company, 2001. 21-39.
- Meyer, Charles R. "Cloning: Of Wonders Wild and New: The Passionate Debate Rages on as Scientists and Ethicists Ponder the Potential Benefits and Dangers of Cloning." Minnesota Medicine. 82.3 (1999): 14-20.
- ²¹ Engelhardt, H. Tristram. <u>The Foundations of Bioethics</u>. 2nd ed. New York: Oxford University Press, 1996.
- ²² Rowland, Robyn. "Human Embryo Research: A Global So cial Experiment." <u>Bioethics: An Anthology</u>. Eds. Helga Kuhse and Peter Singer. Oxford: Blackwell Publishers Ltd, 1999, 95-99.
- ²³ Noonan, John T. "An Almost Absolute Value in History." <u>The Morality of Abortion: Legal and Historical Perspectives</u>. Ed. John T. Noonan. Cambridge: Harvard University Press, 1970. 51-59.
- ²⁴ Singer, Peter. "New Assisted Reproductive Technology." <u>Bioethics: An Anthology</u>. Eds. Helga Kuhse and Peter Singer. Oxford: Blackwell Publishers Ltd, 1999. 99-102.
- ²⁵ Lanza, Robert P., Jose B. Cibelli, and Michael D. West. "Human Therapeutic Cloning." <u>Nature Medicine</u>. 5.9 (1999): 975-77.
- ²⁶ Marquis, Don. "Why Abortion Is Immoral." <u>Bioethics:</u> <u>An Anthology</u>. Eds. Helga Kuhse and Peter Singer. Oxford: Blackwell Publishers Ltd, 1999. 46-57.

The Interdisciplinary Journal of Health, Ethics, and Policy

Volume 1

December 1, 2001

Number 2

HIV, HARM REDUCTION, AND YOUTH: A CASE STUDY OF CAMBRIDGE CARES ABOUT AIDS, INC.

Rachel Jervis

History of HIV Prevention and Education

Since the discovery of HIV and AIDS in 1981, members of the medical and public health professions have been struggling to find a way to decrease incidence, reduce transmission, and find a cure for AIDS. What began as a "gay disease" in the United States and other western countries now decimates populations throughout the world. Over the past twenty years, AIDS has ravaged families, communities, and countries.

Officials around the world are in agreement that HIV/AIDS is a crisis, but approaches to minimize the epidemic are varied. Biomedical approaches generally focus on prescription of highly active antiretroviral therapies, called HAART and "drug cocktails," that reduce the viral load in AIDS patients; this in turn reduces transmission.1 Additionally, doctors and researchers have been fervently searching for a vaccination against AIDS. If this "magic bullet," or technical solution2, is developed, AIDS will not immediately disappear.3 Early on, vaccinations would be risky, expensive, and not widely manufactured. Officials would have to decide who gets access to the vaccination and how to administer it without destroying the effects of previous AIDS education campaigns.4 If the public believes that a vaccination will protect them, safe sex habits will decrease, causing other sexually transmitted diseases to skyrocket. Until a vaccination or cure is found, prevention techniques fall heavily on the fields of public and community health.

As a whole, common prevention methods have been effective. Unlike a vaccine or cure, prevention is a continuous process. Relaxation of education and prevention could backfire, causing increased prevalence of the disease. Many of the HIV/AIDS prevention techniques have focused on minimizing transmission in certain populations. Specifically, education campaigns have targeted men who have sex with men (MSM), intravenous drug users (IDU), adolescents, minorities, women, and pregnant women who are HIV positive. Targeting youth has been a major concern of healthcare workers. One-half of new HIV cases are in youth below the age of

25.5 HIV educators must be well prepared and suitable for the target audience. For example, one study found that for adolescents, education from peers is more effective than from trained professionals. Likewise, culturally competent staff and programs are necessary to reach minorities and special needs populations. Another approach to AIDS prevention is preventing STDs in general. HIV and other STDs are both contracted through sexual behavior. Furthermore, a person suffering from another STD is more vulnerable to HIV.

HIV's routes of transmission (bodily fluids such as semen and blood) have been understood since the early 1980s, yet new infections continue. There are two main reasons for this. First, the misconceptions, mistakes, and conservative views that shrouded the discovery and early publicity of AIDS have not been erased completely. Stigmas around HIV/AIDS are still strong. Homophobia and stereotypes about drug-users have led people to avoid testing, deny their risk, delay treatment, and suffer needlessly.5 Conservative governing bodies have allocated funding for teaching abstinence in schools, but not safe sex. These government groups are uncomfortable with candid AIDS education programs that address taboo issues such as homosexual sex, intravenous drug use, and condom use. Consequently, many adolescents and adults are not getting crucial information about how to protect themselves from HIV.

Secondly, it is very difficult to change a population's sex and drug practices.³ Demanding that individuals get a vaccination and getting 100% compliance is difficult. Demanding that they partake in only safe sex, not use needles recreationally, and ask personal questions of their sexual partners is impossible. Consequently, many community health professionals have been examining other prevention techniques aimed at lowering HIV rates, but with less emphasis on eliminating behaviors that can lead to HIV transmission. This technique is harm reduction.

Harm Reduction

Harm Reduction policies place emphasis on minimizing the negative consequences of a behavior, not eliminating the behavior itself.⁸ In the case of IDU, drug use is considered an inevitable behavior and community health workers focus on decreasing the harm and risk associated with drug use.

Riley et al. describe harm reduction in terms of five features. These features are:

- 1. Pragmatism: It is not practical or feasible to eliminate all risky behavior, such as drug use and potentially risky sexual practices. Instead emphasis must be placed on alleviating the risks associated with these behaviors.
- Humanistic Values: An individual is free to make his or her own decisions in regard to drug use or sexual behavior. These choices are respected and not questioned.
- 3. Focus on Harm: Harm can be physical, social, economic, or community-wide. Harm is of primary importance, the extent and nature of the individual's behavior is of secondary concern.
- 4. Balancing Costs and Benefits: The costs and benefits of harm reduction on the individual and the community surrounding him or her are considered. These analyses are complex.
- 5. Priority of Immediate Goals: Harm reduction aims to solve immediate and realistic goals before tackling larger more idealistic goals.9

Harm reduction techniques have been employed to counteract the difficulties of asking communities to change their behavior. Community Health workers are providing a wide array of options for people. The hope is that each individual can find a way to protect him or herself. Examples of harm reduction include: subsidized clinics in low income neighborhoods, needle exchange programs for drug users, and clinics with homosexual doctors for gay patients who are uncomfortable talking about their sexual practices. By making these services more accessible, community health workers hope that individuals will take advantage of these services.³

How to face the problem

Organizations throughout the world are struggling to prevent the spread of AIDS in their communities and target groups. One such group in the Boston area is Cambridge Cares About AIDS, Inc (CCAA). This article is a case-study that will explore the methods CCAA has employed to fight the battle of HIV transmission in youth, what they have found most successful, and how their AIDS prevention techniques have changed over

the years.

CCAA: Mission

The City of Cambridge's AIDS Task Force formed CCAA in 1988. They describe themselves and their mission as follows:

Cambridge Cares About AIDS, Inc. (CCAA) is a multi service organization with a primary focus on the needs of individuals and families making up the "second wave" of the AIDS epidemic-commonly intravenous drug users, women and homeless persons.... Since its inception, the mission of CCAA has been to develop a comprehensive approach to the AIDS epidemic that is sensitive to the cultural and racial diversity of people living with HIV and those at risk of infection. To fulfill this mission, CCAA focuses on two primary goals: (1) to provide education and services to limit the spread of HIV disease in the community and (2) to extend quality, community-based services to those who are already infected. To achieve these goals, the agency has developed comprehensive programs in housing, client support services, prevention education and harm reduction.9

CCAA has many outreach programs outside of their primary facility. They run shelters, meal programs, and needle exchange centers throughout the Cambridge-Boston area. They also run Youth On Fire, a drop-in center for homeless youth.

Cambridge and HIV/AIDS

Reported in January 2001, there are 1,633 HIV cases in the Boston-Cambridge area.10 It was not until 1999, however, that HIV patients who do not show symptoms of full-blown AIDS were reported. HIV patients tested at anonymous testing sites are not included in this count. Those infected are predominantly male, and disproportionately likely to be African American or Hispanic. The vast majority of HIV positive individuals fall between the ages of 30-49. The Boston area has a very low HIV rate among youth, despite growing national trends of HIV among youth. Note that the Boston Health Commission defines youth as aged twenty and below. 10 The Center for Disease control considers youth to be below the age of 25.5 CCAA serves youth aged fourteen to twenty-four. Overall HIV prevalence in the Boston area has decreased since 1991. Among youth (those below age 20), the level of prevalence is steady. In 1999, the most recent available data, the HIV/AIDS mortality rate for the area was 12.3 deaths per 100,000.10

CCAA: Staff

Cambridge Cares has thirty-four paid positions. Seven of these are peer leader positions. Peer leaders are HIV positive individuals who informally counsel and run support groups for CCAA clients. Many of them are clients themselves. The diverse staff members are of varied races and ethnicities, speak many languages, and have varied levels of education. Employees are homosexual, heterosexual, bisexual, and transgendered. Some are HIV positive and others are not.¹¹

The diversity of the CCAA staff is a valuable asset used to reach a broad group of clients. Of the 500-600 individuals (and their families and partners) that CCAA sees per year, 90% have a history of chemical dependency, 40% are women, 50% were infected through intravenous drug use, 65% are racial and linguistic minorities, 85% are homeless or at risk of becoming homeless, and 95% live at or below the poverty line. CCAA does not specify the percentage of youth served, but the success of the Youth on Fire program indicates the high proportion of clients under the age of twenty-four. It is crucial that the Cambridge Cares staff be available to these clients. Though professionals of any race, sexuality, or gender can be compassionate and knowledgeable about AIDS counseling, clients often feel more comfortable talking to a person with a similar background as themselves. There is one key exception to this tendency: immigrants often feel more comfortable talking to a counselor who is not a member of their community. These immigrants fear confidentiality breaches and stigmas within their small communities.11

CCAA: Environment and Harm Reduction Principles

Cambridge Cares About AIDS is located in Central Square, Cambridge, MA. They share building space with the YWCA on Temple Street. Their entrance is not labeled, nor is the CCAA logo visible in the waiting room, with the exception of brochures and pamphlets. Presumably, this discretion protects the confidentiality of CCAA clients, and people in need of their services generally hear about them by word of mouth.

Though Cambridge Cares has many specific programs, they use their welcoming environment for impromptu, unofficial gatherings and counseling. Each client has a caseworker with whom he or she meets with weekly or a few times a month. In addition to scheduled appointments, clients are encouraged to come to "drop-in" hours. Clients come, have meals, snacks, socialize, and interact with peer leaders (HIV positive employees of CCAA). This relaxed environment is conducive to comfortable discussion about uncomfortable topics such as sexual practices, living with a terminal

disease, and HIV stigmas. CCAA stresses the importance of an environment in which clients are comfortable sharing experiences, concerns, and ideas. Peer leaders are a crucial part of drop-in hours. They draw upon their own experiences of being HIV positive to talk with clients and create a "normal" environment that clients may not find elsewhere.

Creating this relaxed forum for conversation is one of the principles of Harm Reduction. CCAA's harm reduction services were originally part of "Prevention and Education." Recently, however, they have made harm reduction its own unit. Cambridge Cares identifies three main target populations: (a) homeless and runaway youth; (b) intravenous drug users; and (c) men who have sex with men are the focus of an HIV prevention campaign in Cambridge and Somerville.

Youth on Fire

Youth on Fire is located in the Harvard Epworth Church on Massachusetts Avenue in Harvard Square. It serves fourteen to twenty-four year olds who are homeless, runaways, or have unstable home lives. Youth on Fire is open on Monday, Wednesday, and Friday between noon and 6pm. The brochure lists their resources and services such as health care services, counseling and support, food and nutrition program, showers, laundry, clothing, free voicemail boxes, computers, educational opportunities, job search, peer-led education and support groups, art supplies, and linkages to other services. Youth on Fire is a comfortable environment where youth come to eat, sleep, watch TV, and play pool. It is a home of sorts where these individuals can relax.

Youth on Fire also offers workshops. Previous topics have included HIV prevention and drug awareness. This combination of a comfortable social environment and education about crucial issues is referred to as a comprehensive approach to prevention. 11 By connecting with a potentially marginalized segment of the population and educating and encouraging them, Youth on Fire and CCAA are preventing a variety of problems such as HIV and violence. As the program coordinator stated, "You cannot give a kid a condom if you don't feed him first." 12

Needle Exchange

Cambridge Cares has one of only four legal needle exchange programs in Massachusetts. The needle exchange program has four sites in Cambridge and serves over 200 individuals each month. In addition to needle exchange, they offer confidential testing and counseling for HIV, Hepatitis B and C vaccinations, and links clients to health and human service resources.

Pros and Cons of Needle Exchange

Needle exchange programs are often met with resistance within communities. Citizens fear that needle exchanges will attract drug users to their neighborhoods, encourage drug use, and send the wrong messages about drug use to their children. However, there is no evidence that drug users are willing to travel substantial distances for needle exchanges.¹³ Of the limited studies done in the United States, none have found an increase in drug usage and all have suggested decreases in HIV transmission.¹⁴

Residents of Cambridge opposed the needle exchange program early on for similar reasons to those cited above. In response, CCAA administrators have spoken in the community to educate citizens about the specifics and benefits of needle exchange programs. Once informed, Cambridge residents have been supportive of CCAA's needle exchange program. Continuing community education programs are essential to maintain the present levels of community support.

Needle Exchange: An Active Approach

Many communities oppose needle exchanges because they perceive them to be a passive approach that enables the IDU population. CCAA disagrees with these perceptions. Needle exchange and harm reduction programs are an active engagement. Harm Reduction approaches the people at risk and works with them to improve their situations. This is the opposite of the abstinence of treatment model that does not offer treatment until those in need seek it.11 It is necessary to go into the community and initiate the stages of change needed to protect people rather than wait for the people to seek help themselves. For example, the active engagement model goes and offers clean needles to IDU to help modify their behavior and make it safer. Abstinence of treatment models wait until the drug user seeks help to stop using the drug to intervene. In effect, harm reduction is a proactive approach to the problem.8,11

Prevention in the MSM population

Cambridge Cares dedicates much of its time, staff, and funding towards HIV prevention for men who have sex with men. This program has recently been revamped. Community Health workers were alarmed to see an increase in HIV incidence in homosexual men. Early in the AIDS epidemic the gay community was the first to stress the importance of safe sex and prided themselves on their decreased levels of incidence after this push. Consequently, when rates began to increase in the past couple of years, health workers reexamined the focus of their attentions, looked for possible causes for the increase in HIV transmission in MSM and redirected

their programs to focus on these changes.

Both time and the recent drug cocktails have changed how HIV is seen in the MSM community. The younger generations have a distance from the horrors of HIV. They do not have the "visual reminder" of young men becoming ill, covered in lesions, crippled, and dying miserable deaths. This younger generation has a level of complacency. The younger generation was "left out of the experience." By missing out on horrific scenes of death and disease, these young men were not included in the tight-knit community of homosexuals that responded to the epidemic together and garnered the respect of the country.

These men have also seen the wonders of protease inhibitors in lengthening the lives of AIDS patients. Though these drugs have improved physical conditions for people living with AIDS, they have had their complications and unintended consequences. For example, there is the "Lazarus syndrome." Many individuals living with HIV had prepared themselves for short lives and made decisions based on the short-term results. When these individuals gained access to medication and their life expectancy increased, they had to shift the focus of their lives to accommodate for more long-term concerns.11 Some members of the younger generation view AIDS as a manageable disease because of the drug treatments. HIV positive individuals who do not carry the old telltale signs of infection reinforce those perceptions. Yet these individuals carry an immense burden. AIDS patients still live with anxiety, suffer from side effects of medication, and often suffer from depression.11 They hardly consider this a manageable disease.

Cambridge Cares has enacted new programs to work with the younger generation and prevent HIV transmission. When asked about the use of scare tactics, such as reminders of the horrors of AIDS and illness, CCAA employees are quick to say that CCAA dislikes the use of scare tactics. Though scare tactics are based in reality, they create a barrier against seeking help rather than inviting people to seek help, which is a principle of harm reduction. Also, there will always be a group of people that think it can "never happen to them;" these people will be unaffected by scare tactics.

A trend in HIV prevention among young MSM is "Mpowerment." Once community health workers realized that previous methods of intervention and prevention for young gay men were ineffective, they changed the focus. Instead of education campaigns, Mpowerment uses three principles: (1) relate HIV risk reduction to the satisfaction of other aspects of life; (2)

utilize the power of peer influence; and (3) seek to "mobilize and empower" the gay community. ¹⁶ Both formal and informal peer outreach is used in the Mpowerment model. Most notably, Mgroups are groups of 8-10 young MSMs who meet for a few hours to discuss safe sex, their communities, distribute condoms, practice condom use on various objects, and train to conduct informal outreach. ^{16,17}

CCAA focuses a portion of its time on Club Outreach. Members of the CCAA staff go to clubs and
other public sex environments to advertise safe sexual
practices. They provide user-friendly and basic information about safe sex and distribute condoms. Depending on their relationship with the club, the CCAA staff
sets up a table, circulates through the club, or stations
themselves at the bar. There is one CCAA employee
who goes onto the dance floor, dances with various men,
and dances them back to the table for information. At a
recent meeting to discuss other club outreach techniques, it was suggested that staff members be human
condom distributors, dispensing condoms from their
clothing. CCAA uses any technique that gets people's
attention.¹¹

As a result of the push for safe sex and conforming to non-risky behavior, there has been a backlash. A segment of the MSM population is attracted to unprotected sex as a form of freedom. CCAA realizes this and tries to work within the confines of this belief. They offer risk reduction sessions that teach about methods of safer sex that do not incorporate condoms.

Conclusions

The tactics used by Cambridge Cares About AIDS, Inc to reduce the transmission of HIV in youth and the broader population are varied and creative. They focus on adaptability and cooperation. CCAA's goal is to provide alternative behaviors that clients can work into their lives. This method of harm reduction is appropriate for their clientele and the Cambridge community. One must be cautious in applying their successes to other communities and populations. Harm reduction is a personalized technique. In order to succeed, programs must be tailored to a specific target group and in a specific community. Other communities can learn from CCAA's triumphs, but must adapt programs to their own needs.

Author Biography

Rachel Jervis is from Gainsville, FL. She is a sophomore at Tufts University, majoring in Biology and participating in the Community Health Program. She would like to thank Monique Tula and Dan Curley of CCAA, David Clark of YOF, and Rebecca Gasior for their time and assistance.

References

- ¹ Center for Disease Control. "Combating Complacency in HIV Prevention." Atlanta, GA: Centers for Disease Control, 1998.
- ² Hardin, Garett. "Tragedy of the Commons." 1968.
- ³ Bradley-Springer, Lucy. "HIV Prevention: What Works?" American Journal of Nursing. Volume 101, June 2001: 45-50.
- ⁴ Crawford, Catherine M., PH.D, and Anne Osborne Kilpatrick, PH.D. "Innovative Strategies in AIDS Education: The Key to Continued Success." <u>The Journal of Health Administra</u> tion Education. Winter 1992: 77-86.
- ⁵ Centers for Disease Control. "HIV Prevention Strategic Plan through 2005." Atlanta, GA: Center for Disease Control, 2001.
- ⁶ Siegel, David M. MD, MPH; Aten, Marilyn J. PhD, RN; Roghmann, Klaus J. PhD; Enaharo, Maisha MPH. "Early Effects of a School-Based Human Immunodeficiency Virus Infection and Sexual Risk Prevention Intervention." <u>Ar</u> <u>chives of Pediatrics & Adolescent Medicine</u>. Volume 152(10), October 1998: pp 961-970.
- ⁷Folkers, Gregory K. MS, MPH; Fauci, Anthony S. MD. "The AIDS Research Model: Implications for Other Infectious Diseases of Global Health." <u>American Medical Associa</u> <u>tion</u>. Volume 286(4), 25 July 2001: pp 458-461.
- ⁸ Riley, Diane, Ed Sawka, Peter Conely, David Hewitt, Wayne Mitic, Christine Poulin, Robin Room, Eric Single, and John Topp. "Harm Reduction: Concepts and Practice. A Policy Discussion Paper." <u>Substance Abuse & Misuse</u>. 1999, v.34, 9-24.
- ⁹Cambridge Cares About AIDS, Inc. Brochure
- ¹⁰ Boston Public Health Commission. "Health of Boston 2001." Boston, MA: Boston Public Health Commission, 2001.
- ¹¹ Interview with Monique Tula and Dan Curley of Cambridge Cares About AIDS, Inc. November 2, 2001. Interviewed by Anna Brennan, Karen Hennelly, Rachel Jervis, and Jennifer Michelson.
- ¹²Phone interview with David Clark, Program Coordinator of Youth on Fire. Nov 6, 2001. Interviewed by Rachel Jervis.
- ¹³ "Expanding Needle Exchange." Boston, MA: Boston Globe, June 17, 2000.
- ¹⁴ Gibson, David R., Neil M. Flynn, and Daniel Perales. "Ef fectiveness of syringe exchange programs in reducing HIV risk behavior and HIV seroconversion among injecting drug users." <u>AIDS</u>. V.15:1329-1341. Lippincott Williams & Wilkins, 2001.
- ¹⁵ Abraham, Yvonne. "Unsafe sex on rise: With AIDS drugs many gay men see less danger." <u>Boston Globe</u>. June 18, 2000.
- ¹⁶ Kegeles, Susan M., Robert B. Hays, and Thomas J. Coates. "The Mpowerment Project: A Community-Level HIV Prevention Intervention for Young Gay Men." <u>American Journal of Public Health</u>. V.86:8, 1996.
- ¹⁷ Center for Disease Control. "The Mpowerment Project: A Community-Level HIV Prevention Intervention for Young Gay Men." Atlanta, GA: Centers for Disease Control, 2000.
- ¹⁸ Follow-up Phone interview with David Clark, director of Youth on Fire. Nov 19, 2001. Interviewed by Rachel Jervis.

Correspondence

Anthrax: A National Threat or a National Headache?

Grace Mitchell

In the wake of the humanizing events of September 2001, we are constantly wary of what may be yet to come, and the most recent threat of biowarfare in the form of anthrax continues to heighten anxiety. However, there are also those who argue that anthrax, even in its most lethal form, is not a particularly effective means of disturbing entire populations due to its biological and chemical makeup. If experts can take into account the limitations of anthrax as a biological weapon, then rather than masochistically fearing for our lives, we should be aware of them as well.

Until this past September, cases of any of the three forms were extremely uncommon in the United States, and few people were concerned with anthrax as a national threat. However, as there have been three deaths and nine other confirmed cases in New York, New Jersey, Washington, D.C., and Florida these past couple months, particular attention is now being paid to the nature and danger of anthrax. It is possible many people fear the threat of anthrax because they do not know much of the science behind it. In order to make a rational decision regarding public health, one must understand the biology of anthrax. Three forms of bacillus anthracis exist, the most dangerous being inhalation anthrax. Once the spores of the bacteria are inhaled, the first phase of the illness is usually a one to six day incubation period, characterized by nonspecific symptoms such as cough and mild fever. The second stage is rapidly progressive and the 100% death rate usually occurs within twenty-four to thirty-six hours.1 The cutaneous form can be caught when the spores are introduced to a cut or abrasion on the body, resulting in the formation of a large, edema-filled eschar, which eventually dries and falls off with little ultimate scarring. Gastrointestinal anthrax is due to ingestion of undercooked meat containing anthrax, and leads to abdominal pain, severe diarrhea and ulcers on the various gastrointestinal organs. Cutaneous and gastrointestinal anthrax do not pose as much of a problem in humans, as they are easier to treat antibiotically. Left untreated, however, these result in 20 and 50 percent mortality rates, respectively.

The U.S. Department of Defense warns that anthrax is easy to weaponize, as it is extremely stable and can be stored almost indefinitely as a dry powder. It can theoretically be loaded, in a freeze-dried condition, in munitions or disseminated as an aerosol with crude sprayers.² However, although it is important to keep the public informed of these potential threats, the cryptic factoids posted online outlining imminent dangers offer little scientific support and probably only succeed in increasing tension. Moreover, with regards to national worry, it certainly does not help matters when the media incorrectly calls anthrax a virus rather than a bacterium.

On the other hand, just as easy to access is the Center for Disease Control and Prevention webpage, which assures readers that all the identified strains are similar and consistent with a naturally occurring strain that shows no evidence of genetic alteration or bioengineering.3 Similarly, scientific researchers attempt to assuage fears by pointing out the logistic difficulties of weaponizing anthrax. For example, the notion of a crop dusting equivalent ignores the fact that chemicals and bacteria are different. Chemicals can vaporize while bacterial cells would clump in a liquid mist and drop to the ground. Aerosolizing the spores too would be difficult both because the process is tedious and expensive, a feat that would require millions of dollars and proper machinery.4 While airborne spores aren't completely avoidable, they probably would not affect entire populations to accomplish a terrorist group's goal: any potential victims will have to inhale thousands of spores for the toxins that cause the disease to be secreted, quite a large number when most of the spores either drop to the ground or are blown away by the wind and are eventually killed by sunlight.5 After all, of the millions of people in the United States targeted by terrorists, how many have actually perished?

The recent cases of anthrax have indeed been unfortunate and unexpected, stemming from contaminated envelopes in the U.S. mail. However, as confirmation of this attempted pathway of infection was elucidated, experts acted quickly to test postal workers and treat patients. This swiftness, coupled with the unlikely effectiveness of destruction via some method other than mail hopefully will calm citizens, at least for the time being. Anthrax is certainly not the only biological pathogen under question; smallpox has also been circulating around rumor circles, for example. Yet despite all the fears, whether regarding possible biowarfare or flat out demolition, the American people should not forget that this country has the support of the rest of the globe, which includes research facilities, finance and brainpower. As in all possible panic situations, the best remedy is to remain calm. When all that is left to fall back upon is the human immune system, the best protection from bioterrorism, according to Dr. Timothy Paustian, is to "stop worrying, stop smoking, don't drink too much, eat well, exercise and stop worrying."

Author Biography

Grace Mitchell is from Bethesda, MD. She is a junior at Tufts University, majoring in biology.

References

- Swartz, Morton N. "Recognition and Management of An thrax – An Update." <u>NEJM</u>. Nov 29, 2001.
- ² DefenseLink, U.S. Department of Defense, http:// www.defenselink.mil/other_info/agent.html
- ³ Center for Disease Control and Prevention, http:// www.bt.cdc.gov/DocumentsApp/faqanthrax.asp#top.
- 4 Novak, Gary. "Anthrax: As Disinformation." http://nov55.com/elbr.html.
- ⁵ Tucker, Jonathan B. "Anthrax: Separating Fear From Fact" (author Jessica Reaves). <u>Time</u>. Oct 12, 2001: online. http://www.time.com/time/nation/article/0,8599,178989,00.html.
- 6 Paustian, Timothy. http://www.bact.wisc.edu/microtextbook/ disease/anthrax.html.

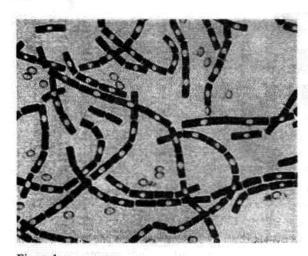


Figure 1
Gram stain of bacillus anthracis with characteristic rod-shape. From Kenneth Todar.

Women Find Balance in Practicing and Parenting

Kate McGinigle

Peanut butter and jelly or ham and cheese? Benign or cancerous tumor? My daughter's soccer game or two more patients? Is it possible to fill the roles of physician and parent at the same time? Yes, but it is hard, especially for women. Female physicians are expected to keep their traditional roles as homemakers; therefore, one of their biggest challenges is to balance practicing and parenting.

Studies have shown that women feel the crunch of managed care more so than their male counterparts. Due to the women's more nurturing bedside manner and the importance they place on discussing health concerns with their patients, they are not able to see as many patients each day. As an example:

Ob/Gyn Mary Jane Minkin enjoys discussing health concerns with patients in her New Haven, Conn. practice. So does her partner, Thomas Hanson. But Minkin figures she spends an average of 50 percent more time with each patient than Hanson does. He bills for more visits, but she attracts more patients to the practice.²

Despite the importance of attracting patients, with cost containment and HMO's paying less, women doctors feel pressured to see more patients to keep their finances stable. Thus, many have expanded their hours to avoid shortchanging their patients or compromising the quality of their service. This seems like a smart professional choice, but it has many repercussions on families. Many female doctors, working 70-hour weeks, feel that they do not have time for a family. Others place the importance of a family over their careers and find that they have to stop practicing.

With so many women facing the same obstacles and sharing the same concerns, several have found ways to have the best of both worlds. Women are bonding together because they have found that it is more effective to make changes as a group than work individually. Consider the following example from the three female doctors in practice together:

The three women share concerns about balancing time between their patients and their families; each has children at home and sees patients part time. "If I were practicing full time, I might go crazy," says Fran Cogen, who nevertheless works four days a week—three at the clinic and one as a diabetes specialist at Children's National Medical Center in Washington, DC.²

Another example is four female internists who founded the Bluegrass Medical Group in Lexington, KY last year, placing importance on preventive care and patient education.³ Since they share a common philosophy of spending time with each patient without sacrificing their families, the women have found that working together has helped them fulfill all areas of their lives.

In general, female practices are advantageous for those involved. In addition to an innate support system, these practices offer the doctors more flexibility. Since they are all going through the same experiences professionally and nonprofessionally, they understand it when one of their colleagues has to come in late due to a crisis at home and they are willing to pitch in to help cover. And for the most part, they are also able to schedule their hours around ballgames and parent-teacher conferences. Some women have even been able to arrange taking more time off in the summer when their children are not in school. By accepting help from each other, women who are driven by their careers and needed by their families have started to realize the benefits of the balance they are able to provide for each other. These women are ambitious, yet realistic.

Author Biography

Kate McGinigle is from Chapel Hill, NC. She is a junior at Tufts University, double majoring in biology and biomedical engineering and minoring in Italian.

References

- ¹AFL-CIO. "Working Women Working Together." Available: http://www.aflcio.org/women [Date visited: 1/4/01]
- ² Nancy Henderson. January 26, 1998. "Managed care is toughest on women doctors." Available: http://www.findarticles.com/cf_0/m3229/n2_v75/20389707/p1/article.ihtml [Date visited: 1/4/01]
- ³ Franklin, Vicki. "Spreading Their Wings: Saluting Women Alumni of UK College of Medicine," <u>Kentucky Medicine</u>, Fall 2000

INFORMATION FOR AUTHORS

Scope of Journal

The mission of TuftScope is to promote a well-rounded discussion of health and health issues in today's society with an emphasis on active citizenship. TuftScope accepts submissions (including opinion/editorial and research) on public & community health, government policy, health economics, bioethics, education, and the influence of technology in order to have a full discussion regarding how the major topics in these fields are part of communities, governments, and public policy.

How to Submit

Address an e-mail message to submissions@tuftscope.com. Attach your work, in the proper file format, and in the body of the e-mail enter the title, author(s), affiliation, and author(s)'s contact information. Omit all identifying information from your attached submission except for the email body.

Guidelines for Authors

Submissions must be submitted in a word processing program. File must be Microsoft Word with *.doc extension, or text with *.txt or *.rtf file extensions.

Do not format end notes and foot notes with word processing formatting. Please use standard MLA notation for citations, and include the reference list on an attached page.

Submissions are recommended to be 2000 - 2900 words in length, although no set limit exists. TuftScope, however, reserves the right to edit submissions for length. In the event that a submission must be edited, it will be sent to the author for approval before publication.

Include a title page with title, author(s) name, affiliation, site of research (if applicable), sponsor of research (if applicable), lead author's mail and e-mail address.

Special consideration for research authors: Include an abstract, 250 words or less.

From the Editors

In their recent paper to the Congress of the Ukraine, Cooper, Mann, and Dowdall, coordinators of the International Students Bioethics Initiative, hit the mark with respect to community building via bioethics education. Due to the complex nature of new policy and its far reaching political and cultural ramifications, it is becoming increasingly important for community leaders to understand the fundamental issues at hand. We agree with the authors that the most important message of their paper is that students can build community because they are citizens capable of significant contribution and positive change.

The undergraduate years are a good starting point because during that time students are exposed to many new thoughts, ideas, and cultures through an interdisciplinary liberal arts program. The broad array of coursework during a student's undergraduate career is important in leading to key problem solving skills and perspectives needed for active citizenship. Just as premed students should take humanities courses, those who want to pursue a career in public service should take science and philosophy courses. Having a diversified course load helps students understand the complexities of bioethical problems. The increasingly interdisciplinary perspective of bioethics marks a new 'era'. More so than ever before, bioethics "involves conceptual and moral questions of cultural and religious significance, including understandings of personhood, communitarian and individualist perspectives, and ideological justifications for different setting of personal and social priorities, which are often different, and at times conflicting."

However, the process does not stop when you receive your diploma. Continuing education is necessary in order to stay current. For example at Tufts University School of Medicine, first year students must take a course that reinforces their role in the community by teaching them about human development and how to discuss and manage ethical issues that may arise. Some, perhaps most, of these students will have a profound role in their communities as they apply their knowledge to influence policy.

The importance of active citizenship cannot be stressed enough. By reviewing the points made in Cooper, Mann, and Dowell's paper, we would like to demonstrate how bioethics education truly is a building block of the community. The authors describe five key objectives of bioethics education:

- 1)stimulating the moral imagination,
- 2) recognizing ethical issues,
- 3) developing analytical skills,
- eliciting a sense of moral obligation(s) and per sonal responsibility, and
- learning to tolerate and resist disagreement and ambiguity.

It is important to note that these skills are universal, and not solely limited to any particular plan of study. Instead, these skills are part of the continuum of a liberal arts experience. They can also be continuously refined through volunteerism and community experiences, and private or independent sector practice.

A current application of these concepts and skills that is still under debate in Congress are concerning the use of cloning techniques for stem cell derivation regardless of funding sources. Somatic Cell Nuclear Transfer, the process by which the nucleus of a somatic cell is inserted into a zygotic stage cell in order to create stem cell lines, is currently mentioned in many bills, and is also a subject of debate in this issue of *TuftScope*. Making decisions and passing laws on such topics are very difficult tasks because there may never be a clear-cut, correct answer. But, the above skills help break down the many complexities and intricacies of the root arguments.

Stem cells have wide potential for therapy, but have a high moral price tag. The American public is typically very passionate about a particular view regarding stem cell research, but often do not acknowledge other sides. While citizens must have the courage to challenge the status quo and they must realize that these multi-faceted issues have many solutions and need compromise. As representatives of the people, Congress must now hear many arguments, read many reports, and decide where they stand. Other community leaders must also confront these issues. Church leaders must decide if they will discuss these issues with their congregation, just as educators decide if they should incorporate this material into their curriculums.

We support the full discussion of these issues. As there is more informal discussion, the general public will be become more comfortable with these ideas. It is challenging to morally keep up with the demands of scientific advances. Developing the above skills is only the first step. Meanwhile, one must be aware of one's stances as well as one's biases and limitations. "Thorough understanding of the effects of their actions and inaction on themselves and the people in their society and their decision to act in a way to uphold the dignity of self and community according to these effects."

Having now considered the importance of a bioethical education, we shall share some practical examples that are currently being used. These examples, researched by Cooper, Mann, and Dowdall, show how interdisciplinary and comprehensive analysis sets the stage for cooperative community problem solving in bioethics. Bradley Smith Ph.D., organic chemistry professor at the University of Notre Dame, assigns Double Helix, the literary documentary of James Watson and Francis Crick's discovery of the double helix structure of DNA. Smith emphasizes the methods used during data collection and challenges his students to evaluate their ethical nature. The University of Connecticut Health Center, through the Legal and Ethical Aspects of Medicine (LEA) program, the uses open classrooms discussions often moderated by a lawyer and including professionals and students from a variety of disciplines. In addition, medical residency ethics curricula have used case presentations, journal club meetings and videos to stimulate ethics discussion. Literature, performance of theater and poetry, and writing exercises also prove to be useful discussion-starters. Several suggested books include: The Use of Force, by William Carlos Williams, An Infected Heart by John Stone, and What the Dr. Said by Raymond Carver.

A large portion of the authors' educational scheme incorporates the specific target of pre-professional students. These students do indeed need the broad skills associated with bioethics; however, by targeting only them, those going into public service are overlooked. It is imperative that scientists and policy makers work together because only then can they incorporate the best aspects of each position. TuftScope takes this one step further. We challenge every member of the community to take an active role in learning and implementing the above techniques. Some may think that they have no part in science or bioethics, while the truth is that even the average constituent should be aware of decisions being made which affects their health and culture. The voter, as an active citizen, has the obligation to learn about issues, to read and discuss other viewpoints, and to express their beliefs through their representatives and, most importantly, through participating in elections.

Brad Crotty

Kate McGinigle

In the News

College News

Alcohol Study

Tufts University is one of the 24 Boston area colleges to sign the November 1998 Cooperative Agreement developed by the Boston Coalition's Task Force on Underage & Problem Drinking. The agreement was made on the basis that "if all campuses could be moved just a bit further along the continuum of improved student awareness and behavior, the entire city would benefit." The findings of the Tufts University Alcohol Study released in May 2001 revealed that a student's drinking frequency as well as his or her consumption are directly correlated to the student's perception of the frequency and consumption of his or her peers. The study recommends that the University institute a social norms campaign to correct misconceptions about alcohol-related norms among students.

Student misconceptions about their peers' drinking is a nationwide problem. Studies have shown that providing information to students about "accurate" drinking norms is associated with decreased drinking on campus. The Montana Social Norms Project has emerged as a leader in the development of social norms campaigns for use on college and university campuses, and more recently, for statewide dissemination.

Meningitis

Meningitis is an acute, contagious illness caused by bacteria, viruses and fungi that infect the tissues that cover the brain and spinal cord. Bacterial meningitis is very serious and can result in brain damage, hearing loss, disability or death. During outbreaks, the percentage of people carrying the bacterium may approach 95%, yet the percentage of people who develop the disease is only 1%. Since contracting the disease is so rare, many do not take it seriously and insurance companies are unwilling to pay for the vaccinations. However, the number of meningitis cases has doubled among 18-24-year-olds in the past decade. Annually, there are about 100 to 125 cases, which result in five to fifteen deaths. College students are at the high end level of contracting meningitis because a majority of them live in dorms. Smoking and irregular sleep patterns are also known to increase risk. The best thing to do, according to the Center for Disease Control, is to get a vaccine, fighting against four of the strains (A,C,Y, and W-135) that cause meningitis. Also, maximize your body's own immune system response. A lifestyle including a balanced diet, adequate sleep, exercise, and the avoidance of excessive stress is important.

National

Stem Cell Debate

The announcement that scientists at Advanced Cell Technology (ACT), a small, privately financed company in Worcester, Massachusetts produced the first cloned human embryos was followed by debates over the moral permissibility of their use as sources of stem cells. They can theoretically grow into to all kinds of human cells and can be used as replacement tissue to treat diseases.

ACT experimented with two methods of cloning, both of which can produce embryos without a man's sperm to fertilize a woman's egg. One of these two known as therapeutic cloning takes the genetic material of an unfertilized egg out and replaces it with that of adult skin cells. The resulting clone is an exact genetic copy of the donor of the adult cell, and therefore, receivers of stem cells would not have to take anti-rejection drugs. The second method known as parthenogenesis involves chemically stimulating an egg to divide and would only have the genes of the egg cell.

Stem cell research traditionally raised ethical concerns because a human embryo must be destroyed in order to derive its stem cells. Cloned embryos produced by parthenogenesis, however, lack genes from a male and cannot grow to become human beings. Since a human life is not theoretically destroyed with this second method, Dr. Michael D. West, the chief executive of ACT, hoped there would be no ethical objections regarding the derivation of stem cells. The chances of a therapeutically cloned human embryo to develop into a human being are also slim because the risk of getting a deformed or dead embryo is greatdepending on the age of the adult cells used.

The Biotechnology Industry Organization supports "therapeutic applications of cloning of cells and tissues - techniques that would not result in cloned children, but could produce treatments and cures for some of humanity's most vexing diseases and disabilities, especially and most immediately diabetes and Parkinson's."

President George W. Bush decided over the summer that federal funds could only be used for stem cells produced before August 9, 2001. Thus, there are not enough stem cells for future research, and ACT is an example of a private company searching for new sources. When Bush limited funding for stem cell research, most of it shifted to the private sector.

Ashcroft Order to Stop Assisted Suicides

Attorney General John Ashcroft gave federal agents the authority to revoke the license to prescribe drugs of any doctor who prescribes lethal drugs for terminally ill patients. Ashcroft's order affects citizens of Oregon, the only state in the U.S. where mentally competent patients diagnosed to have less than six months to live may decide to end their lives using lethal drugs. Some critics believe that the authority to decide whether or not a doctor's prescription of drugs is ethically permissible should not be in the hands of federal law enforcement agents. Ashcroft suggests that drug agents can discern the "important medical, ethical and legal distinctions between intentionally causing a patient's death and providing sufficient dosages of pain medication necessary to eliminate or alleviate pain."

Aftermath of September 11th

Dr. Peter Piot, the executive director of the joint United Nations program on HIV and AIDS, stated that the September 11th attacks have not only diverted funds away from the Global Fund to Fight Infectious Diseases HIV/AIDS, Tuberculosis and Malaria, but are also displacing the sense of urgency addressing the rising incidence of HIV in the central Asian republics of Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan.

A study appearing this fall in the New England Journal of Medicine concluded that a significant population of the United States was suffering from stress immediately after the terrorist attacks. 35% of children have at least one of five stress syndromes. Suggested reasons for the high stress levels were personalization, expansive media coverage, and the threat of further attacks.

UN Anti-Tobacco Campaign

Despite strong support from other nations, United States' rejection of several points failed to pass measures aimed at curbing worldwide tobacco use during the World Health Organization's (WHO) meeting held in November 2001. U.S. delegates argued against banning marketing terms such as "light" or "low-tar." The week prior to the WHO meeting, the National Cancer Institute announced that such terms are misleading to consumers. U.S. delegates defend their positions on the basis of protecting freedom of speech rather than of acting in the interest of wealthy tobacco companies. Countries such as Africa would like to see tighter controls and harsh penalties for tobacco companies that stray from guidelines due to the great health care costs and loss of labor incurred as a result of tobacco-related diseases and deaths.

Looking to make a difference?

Get involved in one of the many programs coordinated by the Tufts Chapter of the American Medical Student Association

Join a Committee or Project Team!

Bone Marrow Drive

Health Policy

Community Outreach

Healthy Tufts Week 2002

Advocacy

Pre-Med Workshops

Visit us on the web at http://ase.tufts.edu/premed To learn more and contact committee coordinators

Are you making an IMPACT on campus or beyond?

Share your experiences in IMPACT!, a new student journal of active citizenship on Tufts campuses.

The articles written for impact are intended to foster active citizenship on campus by spotlighting student and/or organizational achievement and dedication to the goals of UCCPS – to create citizens in all Tufts students. A short discussion of the problem and a detailed look at the chosen solution and the implementation are important to share.

Look for the first issue of IMPACT next semester! Submissions are invited from all.

UCCPS

Send Questions and Submissions to IMPACT@tufts.edu
IMPACT! Is a student coordinated publication of
the Tufts University College of Citizenship & Public Service

Narch 9, 2005

Are you currently doing CSCATCING

Present it at the 4th Annual Tufts Undergraduate Research & Scholarship Symposium!

Present original works in a campus wide event! Students in all fields welcome!

> Register Online at ase.tufts.edu/symposium

TuftScope
Mayer Campus Center
Tufts University
Medford - Massachusetts - 02155