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# BREAST STILL BEST: AN ARGUMENT IN FAVOR OF ONE HIV POSITIVE MOTHER'S RIGHT TO BREASTFEED

MONIQUE ANIKWUE

An HIV positive woman has an approximately seventy-five percent chance of having a healthy child.<sup>1</sup> While the number of HIV positive women who choose to have children cannot be determined with certainty, many of the women face a series of unique legal obstacles during the course of birthing and raising their children.<sup>2</sup> This may be unsurprising given the seemingly catastrophic nature of HIV/AIDS and the ubiquitous social stigma that is concomitant with the illness.<sup>3</sup> Various federal and state government agencies often threaten HIV positive mothers with the loss of custody, other parental rights, and criminal charges.<sup>4</sup> These criminal charges may range from the intent to harm a child, to child endangerment.<sup>5</sup> Criminal and civil charges often arise when HIV positive mothers choose to make parental decisions that are at odds with traditional notions regarding HIV and its transmission.<sup>6</sup>

Presently, a mother's decision to breastfeed her newborn child is not controversial. The emotional, physical, and economical benefits of breastfeeding are well documented and recognized;<sup>7</sup> similarly, breastfeeding enjoys widespread legal support, and a majority of states have laws that encourage breastfeeding.<sup>8</sup> In *Dike*

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1. Samantha Catherine Halem, Note, *At What Cost?: An Argument Against Mandatory AZT Treatment of HIV-Positive Pregnant Women*, 32 HARV. C.R.-C.L. L. REV. 491, 510 (1997).

2. See Marnie Ko, *On the Run: HIV-Positive Mothers Resist Pressure to Put Their Children on Drug Therapies*, REP. NEWSMAGAZINE, Nov. 8, 1999, available at <http://www.marnieko.com/aidsrun.htm> (reporting of one HIV positive mother who waged a legal battle to prevent doctors from administering AZT to her child and of another HIV-positive mother who went into hiding in Canada after social workers demanded that she relinquish custody of her children).

3. See generally Celia Farber, *HIV and Breastfeeding: The Fear. The Misconceptions. The Facts.*, MOTHERING, Sept./Oct. 1998, available at <http://www.mothering.com/12-0-0/html/12-4-0/12-4-hivmisconception.shtml>.

4. See generally Brian Doherty, *Doctor's Orders, Parent's Battle Medical Authorities for Control of Their Children*, REASON ONLINE, Feb. 2001, at <http://reason.com/0102/fe.bd.doctors.shtml> (last visited Apr. 8, 2003).

5. *Id.*

6. *Id.*

7. See generally Corey Silberstein Shdaimah, *Why Breastfeeding is (Also) a Legal Issue*, 10 HASTINGS WOMEN'S L.J. 409 (1999). See also, discussion *infra* Section IV.A.

8. See Elizabeth N. Baldwin & Kenneth A. Friedman, *Breastfeeding Legislation in the United States*, NEW BEGINNINGS, Nov./Dec. 1994, available at <http://www.lalecheleague.org/Law/NBNovDec94p164.html>.

*v. Orange County*,<sup>9</sup> the Fifth Circuit affirmed the District Court's holding that breastfeeding is a constitutional right<sup>10</sup> worthy of the same constitutional protections as other uniquely sacred and intimate relations.<sup>11</sup> However, in the case of Kathleen Tyson, an HIV positive mother from Oregon, the decision to breastfeed became more than simply controversial, it became illegal.<sup>12</sup>

The uncertainty of the cost versus the benefits of AZT<sup>13</sup> treatment of young children served as the gravaman of *In re Nikolas E.*<sup>14</sup> In *In re Nikolas E.*, the Maine Supreme Court affirmed an HIV positive mother's right to refuse to treat her HIV positive son with AZT.<sup>15</sup> The Court determined that the mother's decision was "rational and reasoned"<sup>16</sup> given that the "likely effects of the treatments on the child"<sup>17</sup> were unknown.

This Note seeks to draw a correlation between the case of *Nikolas E.* and that of Kathleen Tyson. It ultimately suggests that the Oregon Court could have adequately applied the same rational and reasoned standard that the Maine Supreme Court applied in *In re Nikolas E.*

Part I of this note will provide an overview of the HIV/AIDS illness. Part II will explore the case and surrounding controversy of Kathleen Tyson. Part III will explore and analyze *In re Nikolas E.* Part IV will discuss the suitability of the *Nikolas E.* standard to the case of Kathleen Tyson, and why the decision of Kathleen Tyson to breastfeed her newborn son could be deemed reasonable and rational by a court of law.

## I. HIV: DISEASE, TRANSMISSION, AND TREATMENT

Following infection, the HIV virus invades various cells and tissues in the body.<sup>18</sup> In particular, the HIV virus especially affects certain white blood cells, the helper T-lymphocytes or CD4+ cells.<sup>19</sup> The virus is able to attach itself to the receptor site on CD4+ cells

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9. *Dike v. Orange County Sch. Bd.*, 650 F.2d 783 (5th Cir. 1981).

10. *Id.* at 787.

11. *Id.*

12. Jeff Wright, *Tyson Says She Wants What's Best for Her Son*, REGISTER-GUARD, Mar. 18, 1999, available at <http://www.aliveandwell.org/index.php?page=ktyson>.

13. Retrovir® is GlaxoSmithKline's brand of zidovudine.

14. *In re Nikolas E.*, 720 A.2d 562 (Me. 1998).

15. *Id.* at 568.

16. *Id.* at 567-68.

17. *Id.*

18. *Bragdon v. Abbott*, 524 U.S. 624, 633-34 (1998).

19. *Id.*

and fuse its membrane to the CD4+'s membranes. As a retrovirus,<sup>20</sup> HIV can use the CD4+ cell to make additional copies of itself.<sup>21</sup> These additional copies subsequently infect other cells, and eventually the virus kills the host CD4+ cell.<sup>22</sup> When the body's CD4+ levels drop to less than 14 percent of the body's complete composition of lymphocytes, a person is diagnosed as having AIDS.<sup>23</sup>

Since the advent of the AIDS epidemic in the 1980s, scientists have struggled to outline with certainty the methods by which HIV/AIDS may be transmitted.<sup>24</sup> Scientific studies have consistently indicated that the virus may be spread vis-à-vis inoculation directly into the bloodstream, by exposure of broken skin or an open wound, or by mucous membranes exposed to HIV-infected fluids.<sup>25</sup>

Transmission may also occur by perinatal transmission from an HIV-infected mother to her infant.<sup>26</sup> While methods of transmission among adults are largely understood, the nature of transmission between HIV infected mothers and their newborns continues to puzzle many scientists and researchers.<sup>27</sup> Studies concerning the transmission of HIV from mothers to their newborn infants yield conflicting results.<sup>28</sup> Some studies have indicated that breastfeeding very likely leads to HIV transmission,<sup>29</sup> while others indicate that breastfeeding may actually help the newborn infant guard against contracting the virus.<sup>30</sup>

Many of the nuances of the transmission of HIV/AIDS remain a mystery to scientists and researchers even after over two decades of research. Similarly, the efficacy and ramifications of the methods of treating the virus in the absence of a cure are not fully known.<sup>31</sup>

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20. *Id.*

21. *Id.*

22. *Id.*

23. *Id.*

24. P.T. Cohen, Univ. of Cal. San Francisco, *Clinical Overview of HIV Disease: HIV InSite Knowledge Base Chapter*, June 1998, at <http://hivinsite.ucsf.edu/InSite.jsp?doc=kb-03-01-01> (last visited Apr. 8, 2003).

25. *Id.*

26. *Id.*

27. See Farber, *supra* note 3.

28. *Id.*

29. *Id.*

30. *Id.*

31. David Scondras, *Sick of Taking Your Medicines? Hang in There, Help Is on the Way*, REASONS FOR HOPE: HIV TREATMENT SERIES, at [http://www.thebody.com/sfac/help\\_way.html](http://www.thebody.com/sfac/help_way.html) (last visited Apr. 8, 2003).

The United States Food and Drug Administration has approved some fourteen drugs for the treatment of HIV/AIDS.<sup>32</sup> AZT was the first drug approved for the treatment of HIV.<sup>33</sup> AZT belongs to a class of drugs called nucleoside analogs.<sup>34</sup> The human body breaks down these drugs into chemicals that halt HIV infection of uninfected cells.<sup>35</sup> These drugs do not however rid previously infected cells of the virus.<sup>36</sup>

Significant side effects are often concomitant with AZT treatment.<sup>37</sup> Among the known short term side effects are nausea, bone marrow suppression, and periodic seizures.<sup>38</sup> Known long-term side effects include cancer and significant damage to the reproductive system.<sup>39</sup> The efficacy of treating infants and other young children with AZT is not fully known. "The long-term health benefits of . . . drug therapy for infants have not been scientifically established . . . . There is a substantial risk of negative side effects of . . . drug treatment."<sup>40</sup>

## II. ILLEGAL BREASTFEEDING, THE CASE OF KATHLEEN TYSON

After being in a monogamous relationship with her husband for nearly a decade, Kathleen Tyson was understandably stunned when a routine HIV test taken in the context of a battery of pre-natal tests returned positive.<sup>41</sup> The Eugene, Oregon native's doctor subsequently told her that even though her viral load<sup>42</sup> was extremely low, she should begin taking a combination of AIDS drugs, euphemistically called "Cocktails,"<sup>43</sup> because she was pregnant. After a six-week period on the drugs, the severity of the side effects drove Tyson to stop taking the medicines.<sup>44</sup> Several

32. *Id.*

33. *Id.*

34. *Id.*

35. *Id.*

36. *Id.*

37. See Halem, *supra* note 1, at 494.

38. *Id.*

39. *Id.*

40. George Kent, Mothers Opposing Mandatory Medicine (MOMM), *MOMM on Trial: The Missing Testimony on Human Rights, Breastfeeding, and Forced Drug Treatment*, Apr. 23, 1999, at <http://www.informedmomm.com/stories/mom-on-trial.htm> (last visited Apr. 8, 2003).

41. Susan Gerhard, *Safe and Sound Underground HIV-Positive Women Birthing Outside the System*, MOTHERING, Sept./Oct. 2001, available at <http://www.mothering.com/12-0-0/html/12-3-0/hiv-underground.shtml>.

42. *Id.*

43. *Id.*

44. *Id.*

months later, Tyson gave birth to a son, Felix, who appeared to be completely healthy.<sup>45</sup>

Subsequent to Felix's negative HIV tests taken at birth, the doctors at the hospital immediately suggested to Tyson and her husband that they start Felix on the AZT protocol and that Tyson refrain from breastfeeding altogether.<sup>46</sup> Within hours of the Tysons' refusal of both suggestions, local physicians reported her to Oregon Child Protective Services.<sup>47</sup> A summons was issued for Kathleen Tyson to appear in court; Tyson was charged with "intent to harm" Felix.<sup>48</sup> When the Tysons subsequently appeared in court, they were ordered to begin administering AZT treatments to Felix and Kathleen Tyson was ordered to stop breastfeeding immediately.<sup>49</sup> The court's "emergency order" removed legal custody of Felix from the Tysons, but allowed the infant to remain in the physical custody of his family.<sup>50</sup>

From April 16 to April 20, 1999, Judge Maurice Merten conducted a fact-finding hearing in Lane County Juvenile Court.<sup>51</sup> After limiting the admissibility of most of the Tyson's case in chief on relevance grounds,<sup>52</sup> the state retained legal custody of Felix. Judge Merten upheld the prohibition on breastfeeding but did not require AZT administration, although at the time of trial Felix had already completed the six weeks of AZT treatment required in the initial court order.<sup>53</sup> Today, Felix Tyson is a healthy four-year old. Felix, like Kathleen Tyson's husband and nine-year old daughter, continues to test negative for HIV.<sup>54</sup>

### III. A MOTHER'S RIGHT AFFIRMED, THE CASE OF NIKOLAS E.

In January 1997, Valerie Emerson's four-year old daughter died of pneumonia while taking AZT.<sup>55</sup> The following year, when a physician recommended that Emerson's younger son, Nikolas, begin

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45. *Id.*

46. Wright, *supra* note 12.

47. *Id.*

48. *Id.*

49. *Id.*

50. *Id.*

51. *Id.*

52. See Kent, *supra* note 40.

53. See Gerhard, *supra* note 41.

54. *Id.*

55. *Nikolas E.*, 720 A.2d at 562.

an aggressive AZT treatment protocol, Valerie Emerson was understandably reluctant.

With her daughter's painful death in mind, and after reviewing the inconclusive research that was available concerning the risks and benefits of AZT treatment in young children, Emerson declined the physician's advice to immediately start her son on AZT treatments.<sup>56</sup> Emerson did, however, express that if her son's condition were to significantly worsen, she would not discount the possibility of starting Nikolas on the treatments.<sup>57</sup>

Following Emerson's decision to postpone AZT treatments, the physician reported her to the State child protective agency, with the recommendation that she be relieved of her parental rights.<sup>58</sup> After the report was issued, the State of Maine arranged a meeting with Valerie Emerson and a consultation with several pediatric AIDS specialists.<sup>59</sup> Following Emerson's continued skepticism in the efficacy of the treatments and her continued refusal to voluntarily administer the treatments to her son, the State filed a petition for a child protection order seeking custody of Nikolas for the purpose of beginning his AZT treatments.<sup>60</sup> The district court denied the petition and the Supreme Court of Maine granted an expedited appeal.<sup>61</sup>

The court conducted a tripartite review of the district court's holding. The court's review included a balancing of the interests of the state, the child, and Valerie Emerson.<sup>62</sup> The court further placed the burden on the State to prove by a preponderance of the evidence that Valerie Emerson's decision to withhold AZT treatments from her son amounted to an "imminent threat of serious harm."<sup>63</sup>

In determining whether Emerson's decision had indeed placed Nikolas at an immediate and heightened risk of harm, the court first reviewed the opinions of the physicians consulted in the case.<sup>64</sup> The court determined that while the physicians agreed that a

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56. *Id.* at 563.

57. *Id.* at 564.

58. *Id.* at 563.

59. *Id.*

60. *Id.* at 564.

61. *Id.*

62. Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 11 (2000).

63. *Nikolas E.*, 720 A.2d at 566.

64. *Id.* at 567-68.

benefit was likely, the court stressed that this benefit, given the conflicting and incomplete research presently existing, simply could not be quantified:

The Department [] has proven that according to the current conventional medical wisdom in the relatively new and rapidly evolving art of treating children with certain elevated levels of HIV in the blood, that Nikolas would benefit from such treatment. However, it has not sufficiently prove [sic] what that benefit will likely be and that no significant injury or harm may ultimately befall the child if that therapy is commenced . . . . With the relative uncertainty of efficacy of the proposed treatment, it *can only reasonably be left up to the parent to make an informed choice in this regard.*<sup>65</sup>

As a result of the current body of research and the State's failure to present with any certainty the benefits of placing Nikolas on the drug treatments, the court determined that the district court's holding that Emerson had acted in a rational and reasoned manner was not one of clear error.<sup>66</sup> Today, Nikolas Emerson is healthy and has recovered from a learning disability previously attributed to his HIV. He remains unmedicated.<sup>67</sup>

#### IV. AN APPLICATION OF THE NIKOLAS E. STANDARD TO THE CASE OF KATHLEEN TYSON

##### A. *The Importance of Breastfeeding*

In 1977, Barbara Damon was prohibited from returning to a public swimming pool because she refused to nurse her infant son in the rest room.<sup>68</sup> Several years later, while Marlene Pennekamp was nursing her infant in her car, a police officer asked her to cease nursing immediately and warned her that she was in danger of an indecent exposure citation.<sup>69</sup> Throughout the late-1970's and early-1980's, these scenarios became increasingly common as women continued to endure myriad forms of harassment as a result of their breastfeeding in public.<sup>70</sup>

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65. *Id.* at 566 (emphasis added).

66. *Id.* at 567.

67. See Gerhard, *supra* note 41.

68. See Baldwin & Friedman, *supra* note 8.

69. *Id.*

70. *Id.*

As these scenarios became more commonplace, however, so did the indignation of women throughout the nation. While New York amended its indecent exposure statute because of the Barbara Damon incident,<sup>71</sup> many states failed to follow suit. Finally, in 1993, Rep. Miguel DeGrandy proposed a new Florida Law that did more than simply amend indecent exposure laws.<sup>72</sup> The statute read in pertinent part: "A mother may breastfeed her baby in any location, public or private, where the mother is otherwise authorized to be, irrespective of whether the nipple of the mother's breast is uncovered during or incidental to the breastfeeding."<sup>73</sup> The Florida bill was soundly passed into law; other states quickly followed Florida's lead and enacted legislation with the purpose of protecting a woman's right to breastfeed in public.<sup>74</sup> Today, a majority of states have breastfeeding laws;<sup>75</sup> these laws range in purpose from allowing women to breastfeed in any public place<sup>76</sup> to excusing breastfeeding mothers from jury duty.<sup>77</sup>

In addition to formal legislation, the range of confirmed benefits of breastfeeding has led to an increased acceptance of breastfeeding in American culture. Breastfeeding has become more a symbol of affection and nurturing than a sexual or shameful act.<sup>78</sup>

In addition, breastfeeding has significant benefits for babies:

human milk feeding decreases the incidence and/or severity of diarrhea, lower respiratory infection, . . . bacterial meningitis, botulism, and urinary tract infections . . . . There are a number of studies that show a possible protective effect of human milk feeding against sudden infant death syndrome, insulin-dependent diabetes . . . Crohn's disease, ulcerative colitis, lymphoma, allergic diseases, and other chronic digestive diseases. Breastfeeding has also been related to possible enhancement of cognitive development.<sup>79</sup>

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71. *Id.*

72. *Id.*

73. *Id.*

74. *Id.*

75. For a compilation of states with breastfeeding legislation, see La Leche League website at <http://www.lalecheleague.org/LawBills.html>.

76. *See, e.g.*, VA. CODE ANN. § 18.2-387 (2002).

77. *See, e.g.*, 1999 Or. Laws 1085 (1999).

78. *See* Shdaimah, *supra* note 7, at 412

79. *Id.* at 410 (quoting Am. Acad. of Pediatrics Pol'y Statement, *Breastfeeding and the Use of Human Milk*, PEDIATRICS, Dec. 1997, at 1035, available at <http://www.aap.org/policy/re9729.html>).

Similarly, breastfeeding research indicates that lactating women enjoy reduced risks of ovarian and premenopausal breast cancer.<sup>80</sup> Thus, a woman's decision to breastfeed becomes substantively more than a lifestyle choice. It becomes a decision imbued with significant benefits for mother and child that extend far beyond the actual lactating period.

*B. The Link Between HIV Transmission and Breastfeeding: An Overview of the Current Body of Scientific Research*

For physicians in the United States and throughout the industrialized world,<sup>81</sup> a stricture against breastfeeding is standard advice to an HIV positive mother. Indeed, research indicates that mother-to-child transmission is the most substantial source of HIV infection in children under the age of 10 years.<sup>82</sup> Mother-to-child transmission is believed possible in any one of three stages: during the term of the pregnancy, labor and delivery, and breastfeeding.<sup>83</sup> Much remains to be discovered about mother-to-child transmission, however, especially vis-à-vis breastfeeding.

In the early 1990s, the Joint United Nations Program on HIV/AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), and the World Health Organization (WHO) issued guidelines for HIV positive mothers; these guidelines advised women with HIV to continue to breastfeed.<sup>84</sup> By 1998, all three organizations, however, underwent a shift in their approach to breastfeeding by HIV positive mothers.<sup>85</sup> In April 1998, the WHO, UNAIDS, and UNICEF held a symposium in Geneva to discuss guidelines concerning HIV and infant feeding.<sup>86</sup> The stated intent of the symposium was to "initiate the development of guidelines to

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80. *Id.* (quoting Am. Acad. of Pediatrics Pol'y Statement, *Breastfeeding and the Use of Human Milk*, PEDIATRICS, Dec. 1997, at 1036, available at <http://www.aap.org/policy/re9729.html>).

81. In underdeveloped countries, this is often not the case because of the absence of suitable alternative feeding methods.

82. UNICEF-UNAIDS-WHO, A REVIEW OF HIV TRANSMISSION THROUGH BREASTFEEDING (1998), available at <http://www.unaids.org/publications/documents/mtct/hivmod3.pdf> [hereinafter HIV TRANSMISSION].

83. *Id.*

84. See Gerhard, *supra* note 41.

85. *Id.*

86. WHO-UNAIDS-UNICEF, TECHNICAL CONSULTATION ON HIV AND INFANT FEEDING IMPLEMENTATION OF GUIDELINES (1998), available at <http://www.unaids.org/publications/documents/mtct/meetrev.pdf> [hereinafter TECHNICAL CONSULTATION].

help national authorities implement . . . polic[ies].<sup>87</sup> At the conclusion of the symposium, the consortium recommended that alternate feeding methods in lieu of breastfeeding were the most appropriate choice for HIV positive mothers.<sup>88</sup>

Much about HIV transmission via breast-milk remains a mystery. Since 1998, scientists and medical researchers have struggled to quantify the risk of transmission that breastfeeding poses.<sup>89</sup> Research attempts to unravel the mechanism of HIV transmission via breast milk.<sup>90</sup>

HIV has been identified in breast milk and colostrum<sup>91</sup> as a cell-associated and cell-free virus.<sup>92</sup> Currently, it is unknown which components are responsible for transmission.<sup>93</sup> Suggested probabilities of transmission range from five to twenty-five percent.<sup>94</sup> Various factors are thought to have an effect on these probabilities.<sup>95</sup> For example, some studies indicate that the duration of the breastfeeding may have an effect on the likelihood of transmission.<sup>96</sup> Another study indicated that recent infection of the mother may have a positive effect on the likelihood of mother-to-child transmission during the course of breastfeeding.<sup>97</sup> The particular factors and combination, if any, that increase the likelihood of transmission are still unclear. Scientists and researchers have been unable to determine either the portal of entry for the virus in infants<sup>98</sup> or the most likely time during lactation in which infection occurs.<sup>99</sup>

Just as the positive ramifications of breastfeeding are well documented in non-HIV positive women, it is widely assumed that those same positive effects are present in HIV positive women.<sup>100</sup> A recent study indicated that breast milk of HIV positive mothers

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87. *Id.*

88. *Id.*

89. *Id.*

90. *Id.*

91. A thick, yellow milk secreted by the breasts several days following delivery, it later becomes breast milk and is replete with nutrients and antibodies.

92. TECHNICAL CONSULTATION, *supra* note 86.

93. *Id.*

94. *Id.*

95. *Id.*

96. *Id.*

97. *Id.*

98. *Id.*

99. *Id.*

100. *Id.*

protects against viral infections<sup>101</sup> and lactoferrins<sup>102</sup> inhibit the transmission of HIV *in vitro*.<sup>103</sup> Similarly, several proteins associated with breast milk demonstrate an adverse effect on the virus' ability to bind to CD4+ cell's receptors.<sup>104</sup>

Mixed feeding, a combination of breast and formula feeding, has an alarming effect on infants and their rate of HIV transmission.<sup>105</sup> The combination of formula feeding and breastfeeding can result in allergic reactions, infectious illness, and intestinal damage in infants.<sup>106</sup> In turn, intestinal damage may facilitate transmission of HIV through the infant's intestinal tract. Studies indicate that among HIV positive women "mixed feeding may be more risky for HIV transmission than exclusive breastfeeding."<sup>107</sup>

An October 2000 WHO technical consultation on mother-to-child transmission adopted the following conclusions. The study promulgated some of the most current data available on mother-to-child transmission of HIV that is as follows:

- The benefits of breastfeeding are the greatest in the first six months of life (optimal nutrition, reduced morbidity and mortality . . . .).
- Exclusive breastfeeding during the first 4-6 months of life carried greater benefits than mixed feeding with respect to morbidity and mortality from infectious diseases other than HIV.
- Although breastfeeding no longer provides all nutritional requirements after six months, breastfeeding continues to offer protection against serious infections and to provide significant nutrition to the infant.
- Breastfeeding is associated with a significant additional risk of HIV transmission from mother to child . . . . This risk depends on clinical factors and may vary according to pattern and duration of breastfeeding . . . the absolute risk of transmission through breastfeeding is 10-20 percent.<sup>108</sup>

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101. *Id.*

102. Proteins that bind iron which are found in breast milk.

103. TECHNICAL CONSULTATION, *supra* note 86.

104. *Id.*

105. See HIV TRANSMISSION, *supra* note 82.

106. *Id.*

107. *Id.*

108. WHO, NEW DATA ON THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV TRANSMISSION AND THEIR POLICY IMPLICATIONS: CONCLUSIONS AND RECOMMENDATIONS

### C. Discussion

As confirmed in *Dike v. Orange County*, breastfeeding is a constitutionally protected right.<sup>109</sup> In *Dike*, the Fifth Circuit held that "Breastfeeding is the most elemental form of parental care. It is a communion between mother and child that, like marriage is intimate to the degree of being sacred."<sup>110</sup> Further, the court held that "[i]n light of the spectrum of interests that the Supreme Court has held specially protected we conclude that the Constitution protects from excessive state interference a woman's decision regarding breastfeeding her child."<sup>111</sup>

The right to breastfeed, like any other constitutional right, is not absolute and must be balanced against countervailing interests. Determining the contours of all the pertinent interests in the Tyson case is difficult, especially when scientific evidence and research often yield contradictory and inconclusive results. Similarly, it is difficult to assess what exactly amounts to "excessive state interference." Certainly because myriad factors seem to be more conducive to HIV transmission, these cases must be evaluated on a case-by-case basis; the particular facts and circumstances of the HIV positive mother must be evaluated.

A 1998 WHO study concluded that certain factors are associated with the degree of risk of mother-to-child transmission of HIV.<sup>112</sup> Some of the primary factors associated with the risk of transmission are also reflective of the disease's progression in the mother.<sup>113</sup> These factors include low CD4+ cell counts, high viral loads, and other viral characteristics.<sup>114</sup> Kathleen Tyson had none of these discernible symptoms of the virus, and her physician described her viral load as extremely "tiny."<sup>115</sup>

The Maine Supreme Court, in *In re Nikolas E.*, looked at the current body of medical research to support its holding.<sup>116</sup> The Court realized that whether Nikolas Emerson could receive some

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(2000), available at [http://www.unaids.org/publications/documents/mtct/MTCT\\_Consultation\\_Report.doc](http://www.unaids.org/publications/documents/mtct/MTCT_Consultation_Report.doc).

109. *Dike*, 650 F.2d at 783.

110. *Id.* at 787 (quoting *Griswold v. Connecticut*, 381 U.S. 479, 486 (1965)).

111. *Id.*

112. See HIV TRANSMISSION, *supra* note 82.

113. *Id.*

114. *Id.*

115. See Gerhard, *supra* note 41.

116. *In re Nikolas E.*, 720 A.2d at 566.

benefit from the drug protocol was not an issue.<sup>117</sup> The Court correctly determined that the central issue was whether *any benefit was outweighed by any risk of harm*.<sup>118</sup>

The holding of *In re Nikolas E.* recognized an inability to soundly quantify the risks associated with AZT treatment. The current body of medical and scientific research regarding mother-to-child transmission reflects a similar inability to substantively quantify the risk of transmission vis-à-vis breastfeeding. While it may be said with some certainty that a risk does exist, it is questionable whether the risk was great enough to justify a court order denying Kathleen Tyson a constitutional right. The WHO and UNAIDS, acquiesce that not enough is known about the risk of transmission to suggest a blanket prohibition on breastfeeding by HIV positive mothers. Rather, the WHO's official statement is that "HIV positive mothers should be enabled to make fully informed decisions about the best way to feed their infants in their particular circumstances."<sup>119</sup> Further, the breadth of widely accepted benefits from breastfeeding is impossible to ignore.

The official WHO position on breastfeeding by HIV positive mothers evinces a deference to the doctrine of informed consent. As a formal doctrine, informed consent is rooted in various *inter alia* legal and ethical principles.<sup>120</sup> The doctrine is often considered to have gained its legal vindication vis-à-vis the United States Supreme Court.<sup>121</sup> One of the three prongs of informed consent is the right to make informed medical decisions.<sup>122</sup> In one of the earliest cases delineating the importance of this right, *Mary E. Schloendorff v. The Society of the New York Hospital*, Justice Cardozo stated, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."<sup>123</sup>

Even when pregnant, it was within Kathleen Tyson's rights to make the informed decision to refuse the AZT protocol that her doctor had suggested, regardless of the effect of this on the

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117. *Id.*

118. *Id.*

119. See WHO, *supra* note 108.

120. Elizabeth B. Cooper, *Testing for Genetic Traits: The Need for a New Legal Doctrine of Informed Consent*, 58 MD. L. REV. 346, 369 (1999).

121. See *Jacobson v. Mass.*, 197 U.S. 11 (1904) (recognizing that a competent person has a right to refuse unwanted medical treatment). See also *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 270 (1990) ("The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment.")

122. See Cooper, *supra* note 120, at 370.

123. *Mary E. Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914), *overruled on different grounds*, *Bing v. Thunig*, 143 N.E.2d 3 (N.Y. 1957).

developing fetus.<sup>124</sup> The right of a parent to make informed decisions regarding her child, rather than herself, however, is somewhat diluted.<sup>125</sup>

Infants are legally incompetent, and parents serve as those who make the informed medical decisions.<sup>126</sup> When parents seek to make informed decisions that contravene recommended medical procedures and/or jeopardize the lives of their children, the scope of a parent's informed consent right becomes even murkier. The state has the ability to override the decisions of parents in certain circumstances.<sup>127</sup> Subsequent to *Prince*, the circumstances in which courts have acted *parens patriae* (in the place of parents) to override parental decisions regarding the health of their children varies.<sup>128</sup> The common denominator of these cases, however, is seemingly a cost-benefit analysis: "The greater the harm to the child to be averted, and the more lasting protection the treatment can provide, the more likely the override becomes."<sup>129</sup>

Under the doctrine of medical consent and the attendant theory of override, should Kathleen Tyson have been allowed to breastfeed her son? Under Professor Sangree's formula, the risks and benefits of Tyson's breast milk would again require evaluation. In looking at the totality of her circumstances, most pertinently, Tyson's low viral count and HIV-negative breast milk, and the spectrum of benefits associated with breastfeeding the benefits of Tyson's breastfeeding would have arguably outweighed the quantifiable risks of doing so. Similarly, it may be argued that in the context of infectious diseases, the doctrine of override is more applicable to highly contagious/communicable diseases like smallpox and tuberculosis, rather than HIV.<sup>130</sup>

As applied to the standard promulgated by the Supreme Court of Maine, the issue of whether Kathleen Tyson should have been

124. Suzanne Sangree, *Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies*, 41 BUFF. L. REV. 309, 377 (1993).

125. *Id.* at 374.

126. *Id.* at 371.

127. See *Prince v. Mass.*, 321 U.S. 158, 166 (1944) ("the family itself is not beyond regulation").

128. Pennsylvania provides an example of the variance in state court interpretations of *Prince*. See *In the Matter of Tara Cabrera*, 552 A.2d 1114 (Pa. 1989) (holding that an override of parent's refusal of blood transfusion to minor child is appropriate even when the transfusion could greatly minimize the risk of a stroke). *But see In re Green Appeal*, 292 A.2d 387 (Pa. 1972) (holding that an override of parent's refusal of medical procedure to alleviate minor child's spinal collapse is inappropriate).

129. Sangree, *supra* note 124, at 377.

130. See Halem, *supra* note 1, at 510.

allowed to breastfeed her child becomes two-fold. One, would Kathleen Tyson's decision to breastfeed her son put him at a risk of "immediate and serious harm?"<sup>131</sup> Two, whether Tyson's decision, in light of the current understanding of HIV transmission via breastfeeding, could be considered "rational and reasoned."<sup>132</sup>

Putting HIV/AIDS "on trial"<sup>133</sup> is illogical, the disease is catastrophic and the statistics are sobering. Since the advent of the age of AIDS, approximately five million children have been infected through mother-to-child transmission.<sup>134</sup> Last year, over half a million children were infected.<sup>135</sup> It is not illogical, however, to argue that the state should have blocked Kathleen Tyson's decision to breastfeed her child only if it was certain to lead to a negative outcome.<sup>136</sup> In the case of Kathleen Tyson, her particular circumstances indicated breast milk that tested negative for HIV and a nearly undetectable viral load. Nonetheless, the presiding judge refused to hear any evidence that was contrary to his belief that the scientific principles regarding HIV transmission through breastfeeding were "settled."<sup>137</sup>

It cannot be ignored that scientific and medical research fails to make the probability of HIV transmission through breastfeeding clearly known. Further, the health benefits of different feeding methods by HIV positive mothers are unknown.<sup>138</sup> As the current body of research on HIV transmission via breastfeeding continues to be plagued with uncertainties and speculation, so too does the research concerning the benefits and harm of the antiretroviral/AZT therapy on infants and young children.

The state's view of what the best methods of raising children may be cannot serve as the legal basis for the decision to prevent a mother from making substantive decisions regarding raising her child.<sup>139</sup> The legal basis must be rooted in substantive scientific research that can support a violation of a mother's constitutional right to breastfeed her child. When substantive scientific evidence is neither available nor conclusive, and especially in those unique cases where the mother's maternal risk factors for HIV are *de*

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131. *In re Nikolas E.*, 720 A.2d at 566.

132. *Id.* at 567.

133. Kent, *supra* note 40.

134. See WHO, *supra* note 108.

135. *Id.*

136. Kent, *supra* note 40.

137. Doherty, *supra* note 4.

138. See HIV TRANSMISSION *supra* note 82.

139. Kent, *supra* note 40.

*minimis* as they were for Kathleen Tyson, a balance must be struck between a mother's autonomy and the state's interest in its infant citizens.<sup>140</sup>

## V. CONCLUSION

Whether Kathleen Tyson should have been allowed to breastfeed her newborn son is a difficult issue fraught with legal and ethical implications. HIV/AIDS is a catastrophic illness but much remains unknown about the transmission of the disease through breastfeeding. Breastfeeding is a constitutional right and therefore any challenge to it must be subjected to the rigorous demands of strict scrutiny analysis. When the state, through substantive legal decisions, overrides an individual's constitutional right, the decisions must be rooted in substantive evidence.

In addition to overriding Tyson's constitutional right to breastfeed, the Oregon court also overrode Tyson's decision in the context of informed consent in making its decision. Informed consent is a powerful theory; it is a part of the common law and had been codified by a majority of states in their statutes.<sup>141</sup>

The Oregon Court's decision to ignore the myriad constitutional issues implicated in the Tyson case belies some of the nuances that are often associated with the legal claims of HIV positive parents. HIV positive parents who seek to duly adjudicate claims like Tyson's may suffer from the same prejudices that society has cultivated towards HIV positive individuals since the emergence of the virus. It is indisputable that those suffering from HIV or AIDS are often stigmatized and prejudiced. Similarly, society is fearful of the idea of an HIV positive woman who is pregnant. The fear and mystery of HIV and AIDS may combine with prejudice and other negative attitudes to form a potent disadvantage to those like Kathleen Tyson in their respective legal battles.

As the Supreme Court articulated in *Prince v. Massachusetts*, the rights of parents when it comes to their children are not without limits.<sup>142</sup> Certainly, the holding of *Prince* applies to Kathleen Tyson. However fear, prejudice, and inconclusive evidence cannot summarily dismiss the constitutional rights that Kathleen Tyson and those like her possess.

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140. *Id.*

141. Sangree *supra* note 124, at 364.

142. *Prince*, 321 U.S. at 166.