THE ROLE OF GENETICS IN INDIANA NURSING EDUCATION

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Honors 499

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THE ROLE OF GENETICS IN INDIANA NURSING EDUCATION

The science of genetics has made tremendous advances in recent years. We have new knowledge about hereditary diseases and debilities. Some of our new knowledge has raised serious moral/ethical questions which are being debated rather widely. The first voluntary moratorium on research in the history of science has only recently been lifted. Geneticists themselves have been awed by the potential implications of their own findings.

Has the subject of genetics been sufficiently integrated into educational programs at all recommended levels? Are our citizens scientifically literate with respect to the principles of human genetics? The Biological Sciences Curriculum Study, Center for Education in Human and Medical Genetics, has undertaken to establish guidelines in this field. Supported by the National Foundation—March of Dimes, and the Congressional Commission for the Control of Huntington's Disease, the BSCS found evidence of need for such guidelines in general public education and in health professional education in particular. Accordingly, BSCS has encouraged input from the health education community to develop effective educational programs meeting that community's specific needs.

A 1977 article in the American Journal of Human Genetics, citing a study of the attitudes of 1,092 American physicians toward genetic screening, conducted by I. M. Rosenstock, noted:

More than 90% of the physicians polled by Rosenstock wanted continuing education in genetics. In addition, the family physicians reported that the journals they read contain little information on the subject. Thus, if they are to obtain such knowledge, it must come from postgraduate courses.
In 1978, BSCS staff member Joseph D. McInerney noted that "few health care personnel are aware of the importance of genetics to their professional roles." This results, in McInerney's judgement, from the fact that human and medical genetics receive only limited attention in medical schools and in schools of allied health... and those few medical schools that do emphasize genetics are traditionally those whose graduates become biomedical researchers.

Also in 1978, Dr. Barton Childs, of the Department of Pediatrics, Johns Hopkins University School of Medicine, conducted a survey of genetics education in 107 four-year medical schools listed by the Association of American Medical Colleges. He concluded that "... provision for teaching genetics to students in American medical schools is at best irregular and at worst nonexistent."5

A review of available literature has not disclosed a study of genetics education in schools of nursing or in nursing education programs conducted by hospitals. The present report deals with a survey conducted in April and May of 1980 among nursing educators in Indiana, 250 of whom voluntarily replied to a questionnaire. The survey sought to determine the current status of genetics education in Indiana nursing programs, the perceived need (if any) for continuing education, and the attitudes of nursing educators toward particular bioethical questions raised by recent studies in this field. The findings of the study tend to parallel those reported by Rosenstock and Childs among physicians and medical schools, but those responding to the Indiana survey of nursing educators indicated a definite awareness of the importance of genetics to their professional roles, and an expressed desire to meet those needs through continuing education.
Materials and Methods

A 35-item, four page questionnaire (see Appendix) was prepared, and a total of 616 copies were mailed to chairpersons, deans, or directors of Indiana state-approved departments, colleges, and schools of nursing. The names used were obtained from a November 10, 1979, list prepared by the Indiana State Board of Nurses' Registration and Nursing Education. A cover letter requested that each administrator give a copy of the questionnaire to each nursing educator under her supervision, and that the replies be returned as a group from each institution. At least some questionnaires were returned by personnel from 28 of the 31 listed programs.

Duplication of faculty listed for two and four-year programs may be responsible for 19 questionnaires being returned blank, and for the total response, 250 individuals, being less than half of the total mailing. Names of individual faculty members were not available beyond those of the administrators to whom the questionnaires were sent. The 31 nursing programs included in the study were identified as comprising ten four-year baccalaureate programs, fourteen two-year associate degree programs, and seven hospital programs. Five institutions listed in the two-year category were cited as also offering upper division baccalaureate programs.

The questionnaire included seven questions (Nos. 1, 30-35) concerning the specific educational background, teaching experience, and area of nursing instruction of each individual responding. Eight questions (Nos. 2-6 and 11-13) sought specific information about the faculty
members' perceptions of the current nursing program and the amount of
genetic education presently available or required for nursing students.
One question (No. 11) sought specific information about which topics
in a list provided were included in the current curriculum. The faculty
members were additionally asked to check those topics "for which you
feel additional information would be helpful in your teaching." Four
questions (Nos. 7-10) asked educators to what extent they might per-
ceive a need for genetic education for nurses, and if continuing
education programs in human genetics would be favored, how might they
prefer such programs be constructed. Sixteen questions sought to deter-
mine the opinions of those responding with regard to specific statements
involving moral/ethical issues raised by possible applications of new
genetic knowledge.

Data and Discussion

The 250 respondents had completed an average of 8.3 years of teaching,
and an average of 14.2 years in nursing practice. Ten (4%) held doctorates,
one (0.4%) the Ed.S., 188 (75.2%) held master's degrees, and 51 (20.4%)
held bachelor's degrees. The most recently earned degree was received
an average 7.3 years ago (from a reference point of 1980).

Of those earning the master's degree, 31.2% received specialty
training in the medical-surgical area; i.e., 14.1% indicated medical/
surgical; 13.1%, surgical; 2.0%, general clinical, and 2.0%, medical.
The next largest area of specialization was pediatric nursing, indicated
by 18.2%. Maternal/newborn nursing was the specialty of 12.6%; psychi-
atric nursing, 10.6%; education, 10.1%; community health nursing, 5.1%;
counseling and guidance, 3.5%; administration, 3.0%; and other specialties,
4.0%.
The teaching areas of all respondents were solicited with the following results: 37.2% indicated medical/surgical nursing; i.e., 17.6% specified general clinical; 11.6%, surgical; 6.0%, medical/surgical; and 2.0%, medical nursing. A primary teaching assignment in maternal/newborn nursing was indicated by 16.8%; pediatric nursing by 12.2%; psychiatric nursing, 9.4%; community health nursing, 5.6%; critical care nursing, 3.6%; fundamentals of nursing, 2.8%; nursing leadership/management, 2.8% and other areas, 11.6%. (This total exceeds 100% due to seven respondents indicating more than one primary teaching area.)

All respondents were asked to indicate the number of college level genetics courses taken during their education. Fully two-thirds of the respondents (67.6%) answered "none"; 26% indicated one, 5.6% said two, and 0.8% reported taking three genetics courses.

The undergraduate nursing curriculum currently may be said to follow a similar pattern, as only 17.2% of the respondents indicated that a specific course or instructional unit on genetics was part of their respective curricula. (A negative answer was given by 81.2% of the respondents, and 1.6% did not answer.) However, of those who said no specific course or unit on genetics was available, 79.3% indicated that principles of genetics were diffused throughout various aspects of their nursing curriculum. Yet 15.8% reported neither a specific course nor a general diffusion of genetic principles being offered (4.9% did not answer this question).

The instructors were asked how much instructional time, "throughout the academic preparation of your students, is devoted to the subject of genetics?" Three to four hours of instruction were indicated by 30.8% of
the respondents, and one to two hours by 19.2%. Eight percent indicated no instructional time whatsoever devoted to genetics, and only 1.2% indicated more than 20 hours. There were no answers given to this question by 19.6% of those who returned questionnaires. Of those responding to this question, 96.5% indicated no more than ten hours of instructional time being devoted to genetics education in their entire nursing curriculum!

One-third of the respondents taught at schools offering four-year programs in nursing, and almost another third (31.6%) at schools offering both two and four year instructional programs. Roughly half of all respondents indicated that no clinical experiences with genetic defects/diseases are required in their programs. Yet 96.8% of the respondents felt that a nurse should have a role in health education with respect to genetic diseases and 90.8% felt a nurse ought to have sufficient knowledge of human genetics to provide preliminary counseling and referral!

Not surprisingly in view of the responses already cited, 97.6% of those replying indicated they would favor continuing education programs for nurses and nursing instructors in the field of human genetics. Only 1.2% opposed the idea, and another 1.2% failed to answer this question. Of those favoring such a program, 81.5% indicated preference for one-day seminars; 11.3% indicated a preference for week-end seminars; 10.2% voted for three-day seminars; and 1.6% preferred week-long seminars. (This total also exceeds 100% due to many giving more than one answer; two respondents favored all of the suggested formats.)

Further revelation of self-perceived genetics education needs on the part of Indiana nursing educators is provided by data summarized in
Table 1. A list of topics was provided and each respondent was asked to check from the list those topics normally included in nursing instruction as now conducted, and in a second column to check those subjects for which additional information would be helpful in each respondent's teaching. This table thus provides two indicators: of subject matter areas now included in nursing instruction, and of topics for which additional information is needed by the educators.

While this study did not probe the reasons for prioritizing genetic information in the manner shown, one may infer that those subjects currently ranked lowest in present use might be so ranked because of their controversial nature or, to some extent as shown, by a felt need for more information on the part of the teacher.

It is also significant to point out that, although respondents were invited to check as many subjects as were applicable to them, only two subject areas--human genetic diseases and sex linked defects--now appear to be receiving mention by more than half of the nursing educators who answered this survey. All other suggested topics were cited by fewer than 50% as subject areas currently included in their nursing instruction.

Despite this, the educators responding seemed to feel that graduates of their programs would be expected to have received instruction on several human genetic diseases/defects, either through classroom or clinical experience, or both. In a list of 32 such diseases/defects (Table 2), 14 received affirmative checks by one-half (125) or more of the respondents.

There is an apparent discrepancy in the data cited in these two tables in that only 146 respondents (Table 1) indicated that education or instruction on "human genetic diseases" was offered as a part of their
Table 1. Responses from 250 nursing educators asked to indicate (Column 1) those topics which they would normally include in their nursing instruction and (Column 2) those topics for which they felt additional information would be helpful in their teaching.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Now Included</th>
<th>Need More Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Human genetic diseases</td>
<td>146</td>
<td>55</td>
</tr>
<tr>
<td>Sex linked defects</td>
<td>137</td>
<td>39</td>
</tr>
<tr>
<td>Prenatal diagnosis of genetic disease</td>
<td>121</td>
<td>50</td>
</tr>
<tr>
<td>Mendelian inheritance</td>
<td>107</td>
<td>24</td>
</tr>
<tr>
<td>Mitosis and meiosis</td>
<td>103</td>
<td>12</td>
</tr>
<tr>
<td>Genes and mental retardation</td>
<td>102</td>
<td>49</td>
</tr>
<tr>
<td>Genetic counseling</td>
<td>99</td>
<td>87</td>
</tr>
<tr>
<td>Genetic screening</td>
<td>93</td>
<td>76</td>
</tr>
<tr>
<td>Genes and the environment (nature vs. nurture)</td>
<td>83</td>
<td>69</td>
</tr>
<tr>
<td>Principles of probability</td>
<td>70</td>
<td>46</td>
</tr>
<tr>
<td>Ethics of human genetics</td>
<td>68</td>
<td>93</td>
</tr>
<tr>
<td>Nucleic acids in protein synthesis</td>
<td>55</td>
<td>26</td>
</tr>
<tr>
<td>Genes, race, and IQ</td>
<td>46</td>
<td>56</td>
</tr>
<tr>
<td>Polygenic inheritance</td>
<td>34</td>
<td>35</td>
</tr>
<tr>
<td>Recombinant DNA</td>
<td>24</td>
<td>41</td>
</tr>
<tr>
<td>Genetic engineering</td>
<td>13</td>
<td>52</td>
</tr>
</tbody>
</table>
Table 2. Responses from 250 nursing educators asked to indicate from a list of human genetic diseases/defects those for which they would expect their graduates to have received classroom instruction and/or clinical experience.

<table>
<thead>
<tr>
<th>Disease/Defect</th>
<th>Believe Instruction Received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Classroom</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>230</td>
</tr>
<tr>
<td>Rh factor</td>
<td>226</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>226</td>
</tr>
<tr>
<td>Sickle cell anemia</td>
<td>220</td>
</tr>
<tr>
<td>Spina bifida/anencephaly</td>
<td>219</td>
</tr>
<tr>
<td>Cleft lip/palate</td>
<td>217</td>
</tr>
<tr>
<td>PKU</td>
<td>207</td>
</tr>
<tr>
<td>Hemophilia A and B</td>
<td>202</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>189</td>
</tr>
<tr>
<td>Tay-Sachs Disease</td>
<td>183</td>
</tr>
<tr>
<td>Huntington's Disease</td>
<td>176</td>
</tr>
<tr>
<td>Colorblindness</td>
<td>139</td>
</tr>
<tr>
<td>Polysyntacty</td>
<td>137</td>
</tr>
<tr>
<td>Klinefelter's Syndrome</td>
<td>125</td>
</tr>
<tr>
<td>Osteogenesis imperfecta</td>
<td>124</td>
</tr>
<tr>
<td>Turner's Syndrome</td>
<td>119</td>
</tr>
<tr>
<td>Galactosemia</td>
<td>106</td>
</tr>
<tr>
<td>Cooley's anemia</td>
<td>96</td>
</tr>
<tr>
<td>Albinism</td>
<td>89</td>
</tr>
<tr>
<td>Brachydactyly</td>
<td>72</td>
</tr>
<tr>
<td>Porphyria</td>
<td>71</td>
</tr>
<tr>
<td>Cri du chat Syndrome</td>
<td>71</td>
</tr>
<tr>
<td>Achondroplasia</td>
<td>57</td>
</tr>
<tr>
<td>Hurler's Syndrome</td>
<td>56</td>
</tr>
<tr>
<td>Hunter's Syndrome</td>
<td>51</td>
</tr>
<tr>
<td>Edward's Syndrome</td>
<td>35</td>
</tr>
<tr>
<td>Alcaptonuria</td>
<td>34</td>
</tr>
<tr>
<td>Xeroderma pigmentosum</td>
<td>31</td>
</tr>
<tr>
<td>Patau's Syndrome</td>
<td>27</td>
</tr>
<tr>
<td>Fabry's disease</td>
<td>25</td>
</tr>
<tr>
<td>Jacob's Karyotype</td>
<td>22</td>
</tr>
<tr>
<td>Lesch-Nyhan Syndrome</td>
<td>19</td>
</tr>
</tbody>
</table>
current curricula. In Table 2, however, it is indicated that eleven genetic/chromosomal diseases are believed to be subjects of instruction in nursing programs represented by 176 or more educators. Two explanations for this are possible: (1) failure to stress the genetic nature of the eleven diseases which may be treated without reference to genetic origin, or (2) a difference in interpretation of the two questions involved and from which data in these two tables were constructed. The nursing educators cited in Table 1 indicated specifically topics which they included in their nursing instruction. For Table 2, respondents were asked to check genetic diseases and defects "for which you would expect your nursing graduates to have received instruction" (leaving open the possibility that respondents might assume this instruction to be taking place within their program but under the supervision of another faculty member).

Sixteen different value laden statements were included in the questionnaire, with nursing educators asked to indicate personal opinions on each issue. Table 3 gives the statement and the number of Indiana nursing educators who either agreed or strongly agreed with each statement. The number who indicated no opinion on the subject is also given. The balance of the respondents to each statement either disagreed or strongly disagreed with each statement.

The statement receiving the highest "no opinion" score deals with recombinant DNA, a subject area which the respondents had already indicated ranking low on the list of genetic subjects included in current teaching material. It would appear that a lack of information on the issue may be a cause of both responses.
Table 3. Responses of Indiana nursing educators to sixteen value-laden statements.

<table>
<thead>
<tr>
<th>Values Statement</th>
<th>Percent Strongly Agree/Agree</th>
<th>Percent No Opinion</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A fetus should be aborted if by medical tests in the second trimester of pregnancy it is shown to be severely genetically defective (i.e., the child would die prior to its fourth birthday).</td>
<td>51.2</td>
<td>10.4</td>
</tr>
<tr>
<td>2. The developing human from conception to birth should have the same rights under the law as does a human infant from the moment of birth.</td>
<td>42.0</td>
<td>10.0</td>
</tr>
<tr>
<td>3. Scientific research designed to develop the knowledge and skills necessary for producing humans with special abilities or physical, mental, and behavioral traits should be encouraged and supported.</td>
<td>21.2</td>
<td>12.0</td>
</tr>
<tr>
<td>4. Society will one day mandate the use of scientific knowledge to produce individuals with certain inherited traits that will enable these individuals to provide exceptionally superior service to society.</td>
<td>14.0</td>
<td>10.0</td>
</tr>
<tr>
<td>5. A married couple should have the right to go to a &quot;sperm bank&quot; and choose sperm that would be likely to give their legal offspring certain desired characteristics.</td>
<td>30.8</td>
<td>10.8</td>
</tr>
<tr>
<td>6. Extraordinary medical procedures should be used to keep alive newborns with seriously debilitating inherited defects or diseases.</td>
<td>4.4</td>
<td>4.4</td>
</tr>
<tr>
<td>7. If a couple has a 25 percent (one-out-of-four) chance of producing a severely defective child, they should not have any children.</td>
<td>24.8</td>
<td>11.6</td>
</tr>
<tr>
<td>8. A married couple should have the right to use modern scientific technology to detect the sex of their unborn child in the second trimester of pregnancy and abort it if the child is not of the sex the couple prefers.</td>
<td>6.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Values Statement</td>
<td>Percent</td>
<td>Percent</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>9. Individuals born with severe inherited physical and/or mental defects that could have been detected prior to birth should have the right to sue their parents for allowing them to be born.</td>
<td>2.0</td>
<td>5.2</td>
</tr>
<tr>
<td>10. Physicians have the responsibility of informing their patients (prospective parents) of how recent medical discoveries related to human genetics could affect the well being of their yet-to-be-born children.</td>
<td>93.2</td>
<td>5.2</td>
</tr>
<tr>
<td>11. Federal tax dollars should be used to support research in medical genetics.</td>
<td>80.8</td>
<td>6.0</td>
</tr>
<tr>
<td>12. Individuals who have an inherited form of mental retardation or &quot;feeble-mindedness&quot; should be sterilized.</td>
<td>37.2</td>
<td>17.6</td>
</tr>
<tr>
<td>13. Biology teachers have the responsibility of informing their students of genetic information that could affect future decisions of these students regarding marriage and having a family.</td>
<td>82.8</td>
<td>7.2</td>
</tr>
<tr>
<td>14. A fetus should be aborted if by medical tests in the second trimester of pregnancy it is shown to have Down's Syndrome, which results in physical defects, marked mental retardation, and shortening of life expectancy.</td>
<td>29.2</td>
<td>17.6</td>
</tr>
<tr>
<td>15. State and/or federal legislation prescribing who is genetically fit to reproduce should be enacted and enforced.</td>
<td>3.2</td>
<td>3.2</td>
</tr>
<tr>
<td>16. Research on recombinant DNA in bacteria should be regulated by federal legislation.</td>
<td>38.0</td>
<td>35.6</td>
</tr>
</tbody>
</table>
The statements used in this questionnaire had been previously used in the same manner with secondary school biology/life science teachers from four states including Indiana, and with 117 freshmen Honors College students at Ball State University, and others. It may be interesting to note some comparisons. The three statements most agreed with by all three surveyed groups are those involving the responsibilities of physicians (No. 10), biology teachers (No. 13), and the Federal government (No. 11) with regard to finding and disseminating genetics information. The students gave biology teachers slightly more responsibility than physicians but otherwise all three groups agreed in ranking these statements, in the order presented, as those with which they most agreed. In fact, both the students and the nursing educators found only one other statement among the sixteen to which more than 50% of those answering gave support. In each case the support for the fourth-ranked statement was barely more than 50%, and the groups did not agree in selecting the same statement for this fourth ranking.

The biology teachers found more to agree with in this list of statements and registered less opposition than the college freshmen or the nursing educators on the statements dealing with abortion. Not surprisingly, perhaps, considering a higher degree of familiarity with the subject matter, the regulation of research on recombinant DNA was favored by a majority of biology teachers, and by one-third of the Honors College freshmen, while all three groups indicated more "no opinion" votes on this issue than any other. Only 18.6% of the biology/life science teachers were unsure about this, however, as compared with 35.6% of the nursing educators and 46.2% of the freshmen polled.
According to the three studies, the use of Federal tax dollars to support research in medical genetics would have the approval of 89.6% of the secondary school life science teachers responding, 80.8% of the nursing educators responding, and 70.1% of the Ball State University students questioned. That no one has sought to mobilize this support may be responsible for the fact that, in 1976, a meeting was held in California where it was reported that "there is currently no publicly visible constituency to support requests for genetic programs, whether in research, training, or service." The meeting, sponsored by the National Foundation--March of Dimes, had in attendance representatives of the executive branch of both state and Federal governments, representatives from the offices of three U.S. Senators, Medicare, MediCal, and volunteer health organizations, in addition to private practitioners.

It would appear that these data also broadly support a realization of need for further genetics education among Indiana nursing educators, and a correlation of this self-analysis may be made with the data obtained by Rosenstock and others from a survey of physicians. The 97.6% response favoring continuing education programs, cited in this study, compares favorably with Rosenstock's finding that "more than 90%" of American physicians polled also wanted continuing education in genetics.

The Rosenstock reference previously cited noted that little information on genetics was provided in the journals read by family physicians. A similar situation was found in reviewing recent issues of major nursing and nursing education journals in preparation for this report. Most
index references to "Genetics" led to brief book reviews about other publications in this subject area, and no directly relevant articles on genetics or genetics education were found in those sources.

One article noted dealt with how nurses spend their time and what activities nurses perform. This article, based on a study of nurses who were in positions in which direct patient care predominated, was generally supportive of the data from the study on which the present report is based. The need for genetics understanding may be inferred from the notation that 61.1% of the practicing nurses polled reported as a regular activity the instruction and counseling of patients and families in the areas of health promotion and maintenance, including the involvement of patients in planning for their own health care.

To the credit of the nursing educators responding to the present study an awareness of the importance of genetics to their professional roles was evident and the interest expressed in continuing education must be noted in any analysis of the limited genetics instruction currently reported in the curricula of Indiana nursing programs.

Summary

Those who have been exposed to information on human genetics may attach more importance to the role of this subject in general education than do those who are less aware of genetics and the implications of recent findings as they may affect future society. Indiana nursing educators have not been unaware of the relevance of this subject to their work, but they have not had direct access to much helpful information. Genetics instruction as a part of nursing education programs in
Indiana has therefore been limited. The educators themselves are aware of this limitation, and favor programs of continuing education in genetics.

A recommendation which stems logically from a review of the data obtained in this study is that some form of continuing education program in human genetics should be formulated and implemented as a means to assist nursing educators in increasing the information provided in this area to their students. That the education received by these students and future nurses would be improved by so doing seems self-evident. The result would be that practicing nurses might have better ability to counsel and understand the genetic nature of diseases as these may affect patients entrusted to their care.
Literature Cited


Appendix
Dear

The science of genetics has made tremendous advances in recent years. Some of the advances in the area of human genetics have serious moral/ethical implications as they relate to the practice of nursing. The Human Genetics and Bioethics Education Laboratory at Ball State University is interested in acquiring data about the educational and informational needs that nurses perceive they have in the areas of human genetics and related bioethical problems.

We are trying to establish if there is a need for continuing education programs, workshops and mini-courses, treating these subject areas with specific relevance to the nursing profession.

Your cooperation in this endeavor is earnestly solicited and will be greatly appreciated. We would like your approval and assistance in distributing the enclosed questionnaires to members of your nursing faculty. This survey will enable us to assess the current status of human genetics education in programs designed to train nurses in various fields, and will also serve to provide data on the perceived need for additional education, if any, in the judgment of a representative sample of nursing educators in Indiana.

This information may also be helpful to you, by providing a statewide view of how other nursing programs handle the subjects of human genetics and related bioethical issues. We will be happy to share these data with you and others who return the questionnaire. The data collection to which we are asking you to contribute is being underwritten by Ball State University and its Department of Biology.

Please return the completed questionnaires by April 18, 1980. Enclosed is a self-addressed, stamped envelope for this purpose. Thank you for taking your valuable time to distribute, collect, and return these survey forms.

Sincerely,

[Signature]

Jon R. Hendrix
Director, HGABEL
March 28, 1980

Dear Nursing Educator:

The science of genetics has made tremendous advances in recent years. The Human Genetics and Bioethics Education Laboratory at Ball State University is interested in acquiring data about the educational needs of nurses with respect to human genetics and related bioethical issues. We are also interested in surveying the current state of genetics education in the curricula of nursing programs in Indiana.

Your cooperation in completing the attached questionnaire is earnestly solicited and will be greatly appreciated. Your responses will become part of pooled data (note that there is no way to identify individual respondents to the questionnaire). Your response is vital to the attainment of an accurate representation of opinion in this field and will help to determine the possible need for future nursing workshops, mini-courses, or seminars in human genetics and the moral/ethical implications of recent advances in this science.

Please return the completed questionnaire to the Director of your nursing program as soon as possible. Thank you very much for taking your valuable time to complete this questionnaire. The data summarized from this study will be made available to you upon request.

Sincerely,

Jon R. Hendrix
Director, HGABEL
HUMAN GENETICS QUESTIONNAIRE

Check the appropriate responses or follow the specific instructions for each question.

1. In what areas of nursing instruction do you teach? (Indicate your primary assignment with a "1" and any secondary assignments with a "2".)
   - Pediatric nursing
   - Psychiatric nursing
   - Surgical nursing
   - Maternal/newborn nursing
   - Community health nursing
   - General clinical nursing
   - Other, specify __________

2. Does your undergraduate nursing curriculum contain a specific course or instructional unit on genetics?
   - Yes __
   - No ___

3. If you replied "no" to question number 2, are genetic principles diffused throughout various aspects of your nursing curriculum?
   - Yes __
   - No ___

4. How much instructional time throughout the academic preparation of your students is devoted to the subject of genetics?
   - None __
   - 1-2 hrs. __
   - 3-4 hrs. __
   - 5-6 hrs. __
   - 7-8 hrs. __
   - 9-10 hrs. __
   - 11-15 hrs. __
   - 16-20 hrs. __
   - More than 20 hrs. ___

5. What type of nursing program is offered at your institution?
   - 2 year __
   - 3 year ___
   - 4 year ___

6. Does the program require clinical experiences with genetic defects/diseases?
   - Yes __
   - No ___
   - Explain: ___________________________________________________________________

7. Do you feel that a nurse should have a role in health education with respect to genetic diseases?
   - Yes __
   - No ___
   - Explain: ___________________________________________________________________

8. Ought a nurse have sufficient knowledge of human genetics to provide preliminary counseling and referral?
   - Yes __
   - No ___

(continued on reverse side)
9. Do you favor continuing education programs for nurses and nursing instructors in the field of human genetics?

___ yes  ___ no

10. If you would be in favor of such a program, would you prefer:

___ one day seminars
___ three day seminars
___ weekend seminars
___ week-long seminars

11. In column I below, please check those topics which you normally include in your nursing instruction. In column II check those topics for which you feel additional information would be helpful in your teaching.

<table>
<thead>
<tr>
<th>Col. I</th>
<th>Col. II</th>
</tr>
</thead>
<tbody>
<tr>
<td>mitosis and meiosis</td>
<td>Mendelian inheritance</td>
</tr>
<tr>
<td>nucleic acids in protein synthesis</td>
<td>principles of probability</td>
</tr>
<tr>
<td>polygenic inheritance</td>
<td>human genetic diseases</td>
</tr>
<tr>
<td>genetic screening</td>
<td>genetic counseling</td>
</tr>
<tr>
<td>sex linked defects</td>
<td>genetic engineering</td>
</tr>
<tr>
<td>recombinant DNA</td>
<td>ethics of human genetics</td>
</tr>
<tr>
<td>prenatal diagnosis of genetic disease</td>
<td>genoic and the environment (nature vs. nurture)</td>
</tr>
<tr>
<td>genes and mental retardation</td>
<td>genes, race, and IQ</td>
</tr>
<tr>
<td>other topics, specify</td>
<td></td>
</tr>
</tbody>
</table>

12. Please check any of the following human genetic diseases/defects for which you would expect your nursing graduates to have received instruction. Indicate whether the experience is classroom and/or clinical in nature.

<table>
<thead>
<tr>
<th>Class room</th>
<th>Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td>PKU</td>
<td>spina bifida/anencephaly</td>
</tr>
<tr>
<td>Tay-Sachs Disease</td>
<td>cleft lip/palate</td>
</tr>
<tr>
<td>Rh factor</td>
<td>polydactyly</td>
</tr>
<tr>
<td>sickle cell anemia</td>
<td>brachydactyly</td>
</tr>
<tr>
<td>Huntington's Disease</td>
<td>alcaptonuria</td>
</tr>
<tr>
<td>hemophilia A and B</td>
<td>galactosemia</td>
</tr>
<tr>
<td>colorblindness</td>
<td>Cooley's anemia</td>
</tr>
<tr>
<td>muscular dystrophy</td>
<td>achondroplasia</td>
</tr>
<tr>
<td>diabetes mellitus</td>
<td>albinism</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>osteogenesis imperfecta</td>
</tr>
<tr>
<td>Edward's Syndrome</td>
<td>porphyria</td>
</tr>
<tr>
<td>Patau's Syndrome</td>
<td>xeroderma pigmentosum</td>
</tr>
<tr>
<td>Cri du chat Syndrome</td>
<td>Fabry's disease</td>
</tr>
<tr>
<td>Turner's Syndrome</td>
<td>Hurler's Syndrome</td>
</tr>
<tr>
<td>Klinefelter's Syndrome</td>
<td>Hunter's Syndrome</td>
</tr>
<tr>
<td>Jacobs' Karyotype</td>
<td>other, specify</td>
</tr>
<tr>
<td>Lesch-Nyhan Syndrome</td>
<td></td>
</tr>
</tbody>
</table>

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13. Will your graduates be familiar with the location of human genetic counseling centers and diagnostic services in the state of Indiana?

___ yes     ___ no

Explain: ________________________________________________

__________________________________________________________________________

14-29. Many of the issues related to human genetics and the application of new scientific knowledge to human beings are highly controversial and raise serious moral/ethical questions. React to each of the following statements by circling the response that best reflects your opinion or position on the issue.

14. A fetus should be aborted if by medical tests in the second trimester of pregnancy it is shown to be severely genetically defective (i.e., the child would die prior to its fourth birthday).

15. The developing human from conception to birth should have the same rights under the law as does a human infant from the moment of birth.

16. Scientific research designed to develop the knowledge and skills necessary for producing humans with special abilities or physical, mental, and behavioral traits should be encouraged and supported.

17. Society will one day mandate the use of scientific knowledge to produce individuals with certain inherited traits that will enable these individuals to provide exceptionally superior service to society.

18. A married couple should have the right to go to a "sperm bank" and choose sperm that would be likely to give their legal offspring certain desired characteristics.

19. Extraordinary medical procedures should be used to keep alive newborns with seriously debilitating inherited defects or diseases.

20. If a couple has a 25 percent (one-out-of-four) chance of producing a severely defective child, they should not have any children.

(continued on reverse side)
21. A married couple should have the right to use modern scientific technology to detect the sex of their unborn child in the second trimester of pregnancy and abort it if the child is not of the sex the couple prefers.

22. Individuals born with severe inherited physical and/or mental defects that could have been detected prior to birth should have the right to sue their parents for allowing them to be born.

23. Physicians have the responsibility of informing their patients (prospective parents) of how recent medical discoveries related to human genetics could affect the well-being of their yet-to-be-born children.

24. Federal tax dollars should be used to support research in medical genetics.

25. Individuals who have an inherited form of mental retardation or "feeble-mindedness" should be sterilized.

26. Biology teachers have the responsibility of informing their students of genetic information that could affect future decisions of these students regarding marriage and having a family.

27. A fetus should be aborted if by medical tests in the second trimester of pregnancy it is shown to have Down's Syndrome, which results in physical defects, marked mental retardation, and shortening of life expectancy.

28. State and/or federal legislation prescribing who is genetically fit to reproduce should be enacted and enforced.

29. Research on recombinant DNA in bacteria should be regulated by federal legislation.

Individual replies to this questionnaire are confidential, but the following personal information is requested to assist in our interpretation of these data:

30. What is the highest degree you have earned? ______________________________________

31. When was the degree received? (year) ____________________________________________

32. What type of specialty was involved at the master's degree level?
   ______ pediatric nursing
   ______ psychiatric nursing
   ______ surgical nursing
   ______ maternal/newborn nursing
   ______ community health nursing
   ______ other, specify ______________________________

33. How many years of nursing practice have you completed? ____________________________

34. How many years of teaching have you completed? ________________________________

35. How many college level genetics courses have you taken? ___________________________