EXTENT TO WHICH FEMALE OFFSPRING EXPOSED TO DIETHYLSTILBESTROL (DES) IN UTERO RECEIVE DES TASK FORCE RECOMMENDED HEALTH CARE

By

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ABSTRACT

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Diethylstilbestrol (DES), a drug previously given to prevent miscarriages, has since proven to have a strong teratogenic potential and to have left many who were exposed in utero with physiological abnormalities. A descriptive study was conducted to identify the extent to which DES daughters received the health care recommended by the Federal Government's DES Task Force. Data were collected by means of a self-administered questionnaire from 670 DES daughters aged 16 to 40 who belonged to DES Action and subscribed to their quarterly newsletter, DES Action Voice. A questionnaire was developed for the purpose of this study and based upon the guidelines set by the 1985 DES Task Force in reference to recommended health care for DES daughters. Data were analyzed using descriptive statistics. There is a significant deficit in the extent to which DES daughters received the health care recommended by the FederalGovernment's DES Task Force. Further research needs to be undertaken to explain underlying causes for this deficit.

This thesis is dedicated

to my mother and

my sister, Mary,

who are DES exposed.

ACKNOWLEDGEMENTS

A sincere thank you is extended to my thesis committee members, Barbara Given, Chairperson, Sandra Hayes, Patty Peek, and Joanne Pohl. I would also like to recognize the work and patience of Manfred Stommel.

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To everyone who, in any way, contributed toward helping me attain my educational goals I extend a very special THANKS!

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TABLE OF CONTENTS

Page

Page

LIST OF TABLES

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

THE PROBLEM

Introduction

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Background

Diethylstilbestrol, the scientific name for DES, is a legal prescription compound that was given by physicians with the best of intentions to millions of American women for more than thirty years in the debatable belief that it would prevent miscarriages (Meyers, 1983). DES was not only prescribed for pregnant women in the United States but other countries as well, including Australia, France, Israel, Mexico, Spain, Belgium, West Germany, Italy, the Netherlands, England, the Philippines, and many, if not all, the South American countries (Orenberg, 1981).

DES, a synthetic nonsteroidal estrogen, was first synthesized in 1938. DES was approved by the Food and Drug Administration (FDA) in 1941 for use in various estrogen-related disorders during and after menopause. Six years later, in 1947, during the height of the baby boom, it was approved for use during pregnancy to prevent miscarriages. "Doctors thought that DES, taken during pregnancy, would prevent miscarriages, especially if the woman had had a previous

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miscarriage, or had slight bleeding or diabetes" (DES Action National, 1983, p. 2). These women received this drug under many different brand names as pills, injections, or vaginal suppositories. In 1971, DES-type drugs were banned in the United States by the FDA for use during pregnancy after a medical report was published linking DES and vaginal cancer in daughters exposed in utero. The FDA withdrew its approval for DES use during pregnancy, and pregnancy use was then listed under the "Contraindications" section of descriptive drug information (Meyers, 1983, p. 87).

The actions and uses of DES as defined by Govoni and Hayes (1985) states:

> Actions and Uses: Reportedly the most potent nonsteroidal synthetic estrogen compound. Has strong teratogenic potential; may cause vaginal or cervical cancer in offspring if mother is treated with diethylstilbestrol during pregnancy. Interferes with implantation of fertilized ovum in uterus by unclear mechanism; does not terminate pregnancy. Suppresses lactation. Excessive or prolonged use may inhibit anterior pituitary secretions. . . . If the patient who has been taking diethylstilbestrol becomes pregnant, she should be informed of the teratogenic potential of this drug. (pp. 425-426)

"Any mother whose children were born during the thirty years in which this drug was widely prescribed, and who received medication during the first five months of her pregnancy, may have been given DES. She and her children may be 'DES exposed'" (DES Action National, 1983, p. 2).

The DES story is an ever-evolving story whose chemical impact on the women who took it, the children they bore, and even on their grandchildren, grows with time (Meyers, 1983). Inasmuch as the oldest women exposed to DES-type drugs before birth are just turning 40 years of age, there is a possibility other problems may be encountered as these women grow older. The problem is not fading, but becoming more prominent. "... new problems, including a second peak incidence of invasive clear-cell cancer in DES daughters, might occur as the DES-exposed population grows older ..." (Orenberg, 1981, p. 127). Therefore, effective means to monitor this population needs to be maintained. Nurses need to be able to deal with this epidemic.

"Although the actual number of women who received DES in the United States between 1940 and 1971 is not known, it is variously estimated at between 500,000 and three million" (Orenberg, 1981, p. 36). "Estimates, based on marketing 1959-1965, indicate that from two to three million American women received DES during pregnancy resulting in exposure of between two and three million sons or daughters" (Holmes, Hoskins, & Gross, 1981, p. 30). "At least 3 percent of the nation's current population was exposed during pregnancy to a new and apparently miraculous drug that by today's standards hadn't been sufficiently tested" (Meyers, 1983, p. 13). When DES was approved for use in humans by the FDA in 1941, few criteria existed for judging new drugs. In 1962, a new Congressional drug regulation law required manufacturers to prove effectiveness as well as safety. This meant a belated re-evaluation for DES (Orenberg, 1981).

A University of Chicago study, published in 1953, revealed that DES was useless in preventing miscarriages; however, the FDA did not question the drug for nearly three decades after its initial approval. Early in 1971, Herbst and his colleagues gave proof to Dr. Charles Edwards, then commissioner of the FDA, that DES given during pregnancy could cause cancer in the female offspring. The FDA was slow to act even after this evidence was presented (Orenberg, 1981).

A 1971 article linking DES and vaginal cancer created a great panic in millions of American mothers and daughters exposed to DES. "That panic subsided to the level of anxiety as researchers determined that the rate of vaginal/cervical cancer in DES daughters is no greater than 1.4 in 1,000, and that the disease has been diagnosed so far in roughly 400 women" (Meyers, 1983, p. 20). This anxiety will continue to exist and needs to be dealt with by health care providers. There is the concern that as DES daughters reach menopause they may be at an increased risk for clear cell adenocarcinoma. A DES daughter, whether she is a teenager or a married woman, must live with that possibility for the rest of her life. DES has been described by Orenberg (1981) as, ". . . a drug that could cross the placenta to reach the fetus and then cause serious disease two to three decades after exposure" (p. 36). ". . . DES had gone from being a miracle drug to the world's first transplacental carcinogen" (Meyers, 1983, p. 19).

Statement of Problem

The discovery of possible alterations in health not only cause great concern to the offspring who were exposed to DES in utero but to members in the health care delivery system as well. The alterations

in physiological functioning as well as psychological areas of concern representative of the DES-exposed population must be addressed. Thus, the question being addressed is: To what extent do DES daughters receive the health care recommended by the Federal Government's DES Task Force?

Subquestions

1. For those DES daughters who were told of their exposure during puberty, are periodic screening examinations being done beginning at age 14 or at the onset of menses (whichever is earlier)?
2. Are DES daughters receiving the appropriate screening procedure at each examination which minimally includes a thorough pelvic examination using palpation, cytology test, and tissue inspection including the use of one-half strength aqueous Lugol's solution for cervical and vaginal staining?
3. Are DES daughters being examined at least once a year?
4. Are more frequent examinations being done for women with extensive atypical epithelial changes?
5. Is colposcopy being utilized in:
   a. all cases where abnormal cytology (Pap smear) is observed?
   b. cases of extensive or widespread epithelial changes (such as, squamous metaplasia)?
   c. the initial examination (for baseline data)?
6. Are biopsies being performed only:
   a. when indicated by abnormal Pap tests?
   b. when there is other evidence of significant epithelial abnormalities?

7. Are breast examinations of DES daughters being performed according to the current National Cancer Institute (NCI) guidelines regarding the frequency of screening examinmations?

Purpose

This research study will focus on the female offspring exposed to DES in utero and disclose current health practices utilized by this population specific in monitoring the potential effects of DES exposure in utero. The main objective of this research is to acquire an accurate description of the characteristics of female offspring exposed to DES in utero, and to describe the pattern and type of health care received. It is hoped that this will stimulate further interest and research in the DES-exposed female population. The information gained in this study is extremely important in laying the foundation for further research which may provide the means which would allow members in the health care delivery system to more effectively direct and individualize care for this population. The ultimate goal of further research generated by this study is to apply scientifically documented knowledge to improve the effectiveness of health care delivered, so that the care provided to DES clientele will have the greatest impact.

Inquiry into the problem proposed lends itself to nursing researchers a potential to yield new knowledge for nursing practice and specific clinical focus. This relatively new and ever-increasing issue is fertile ground that has the potential to be cultivated to generate a scientific basis for nursing practice. Information about the health care received by DES daughters would facilitate nursing

assessment, plan, and interventions. From this study, hypotheses can be formulated and further research avenues identified. The aim of this study is to survey the DES female population regarding health care received specific to their exposure to DES.

By obtaining an accurate description of health care received by the female exposed to DES in utero, potential deficits in the recommended health care prescribed by the DES Task Force may be disclosed. Thus, further research could be undertaken to explain underlying causes for this deficit so that attention can be focused in these areas. Knowing which factors prevent persons from obtaining an optimal level of preventative health care could assist nurses in thwarting the development of these influences, or in finding solutions to counteract the effects of already developed factors. From this research, development of strategies that provide effective nursing care to this high-risk group could be formulated. Thus, the outcome of this study lays the foundation that is needed to proceed to a higher level of inquiry.

Conceptual Definitions

DES Daughter

From the preceding definitions and descriptions of DES, the definition of DES daughter is derived. The concept DES daughters is defined in this study as the female offspring conceived between 1947-1971 who were exposed for any length of time to DES in utero. In a vast number of cases, proof of exposure to DES is not obtainable to the DES daughters due to faulty or destroyed medical records, and/or inability of their mothers to recall or elicit this information.

DES Task Force

The DES Task Force is a group of scientific, medical, governmental, and consumer consultants convened at the behest of Joseph Califano, then Secretary of the Department of Health, Education and Welfare (DHEW), and implemented by Dr. Julius Richmond, Surgeon-General of the United States in 1978, to review all aspects of the DES problem, making recommendations for health care of the exposed, and research directions for medical investigators.

Recommended Health Care

Recommended health care is the screening procedure and examination guidelines advocated by the DES Task Force for daughters exposed to DES in utero (see Appendix A). The gynecologic examination of a DES-exposed female is similar to, but more detailed than, a routine pelvic examination. The components of the gynecologic examination for women exposed to DES in utero include: vaginal and cervical palpation (digital), bimanual (recto-vaginal) examination, vaginal and cervical inspection (speculum), cytology (separate slide of vaginal fornices and cervix), colposcopy (optional), iodine staining of cervix and vagina, biopsy of atypical findings, and breast examination (see Appendix B).

Assumptions

1. DES-related changes may not show up on the usual pelvic examination or Pap smears performed by most health care providers; some special procedures must be used.
2. The female offspring exposed to DES in utero requires special health care.

3. The health care guidelines recommended by the Federal Government's DES Task Force are available to all health care providers.
4. Health care providers, as well as DES-exposed clients, have options in choosing which available health care resources will be used.
5. The physiological abnormalities resulting from intrauterine exposure to DES may result in the inability to bear children.
6. The total effect of DES on the reproductive tract of women exposed in utero, as they advance through the childbearing and into the perimenopausal years, is unknown.
7. The long-term sequelae of health-related risk factors of those females exposed to DES in utero and their offspring are as yet not completely known.
8. The impact of exposure to DES in utero is a significant health problem.
9. There are many women who do not know that they were exposed to DES in utero.
10. An individual's health practice has a significant impact on one's overall and long-term health.

Limitations

1. The sample for this study is made up of voluntary participants from DES Action. This sample may represent a group biased toward seeking care. Thus, there is a possibility that the sample for this study may differ in the extent to which it can be said to represent the population.

2. The sample does not include those DES-exposed females who are unaware of their exposure to DES in utero.
3. Content of the self-report survey is essentially limited by the extent to which respondents are willing to report on the topic.
4. The researcher will not be present at the time the questionnaire is completed to answer questions that may arise.
5. Respondents differ in their reading levels, in knowledge of medical terminology, and in their ability to communicate in writing.
6. Mailed questionnaires are known to have a generally low response rate.
7. The survey data collected in this study will not permit the researcher to infer cause-and-effect relationships.

Overview of Proposed Research

In Chapter 1, the background and statement of the research problem was introduced along with a statement of the purpose and importance of the study. Conceptual definitions, assumptions, and limitations of the study were also presented.

In Chapter 2, the conceptual framework upon which this study is guided, major concepts in the study, and relationship of the concepts used within the framework will be discussed.

In Chapter 3, a review of literature will be presented inclusive of the results of early studies related to the use of DES; the inception and study results of the DES Adenosis (DESAD) Project; formation of the DES Task Force; subsequent establishment of the DES Task Force recommended health care, with reference to recommendations made by researchers other than members of the DES Task Force in

relation to necessary screening and management of DES daughters; and health behaviors of women in relation to breast self-examination (BSE) and Papanicolaou (Pap) smear.

In Chapter 4, the research design and methods used to guide this study will be presented. The data collection procedure, population, selection of the sample, operational definitions, scoring, reliability and validity, analysis of data, and protection of human rights will be described.

In Chapter 5, data presentation and analysis of research results will be presented. Tables will be used to illustrate the results of the data.

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CHAPTER II

CONCEPTUAL FRAMEWORK

Overview

The DES daughters are in essence the gatekeepers to maintaining their health. It is they who make the decision of whether or not to seek health care and comply to the stringent schedule of the prophylactic examinations. For those who are asymptomatic, it is easy for them to become lax in postponing their ever-so important requirement for screening. To others, the fear of the unknown keeps them away. DES daughters with their multitude of problems must take responsibility for seeking care. They could become victims of health care neglect by falling through the "cracks" of the health care system. "Health is the responsibility of a total society and all of its members. The meeting of health needs requires many health roles and shared or fluctuating responsibilities" (Fitzpatrick & Whall, 1983, p. 139). Daughters exposed to DES in utero must become their own self-care agent.

Viewing the DES daughter as her own self-care agent is a critical component from which a framework or model can be implemented or derived to direct her health care. Dorothy Orem has constructed a conceptual framework building upon the concept of self-care. The DES daughters' health care can be guided by utilizing Orem's self-care model.

An overview of Orem's self-care theory will be presented. This overview will include a description of the conceptual framework from which her theory is derived, a definition of person, environment,

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An overview of Orem's self-care theory will be presented. This overview will include a description of the conceptual framework from which her theory is derived, a definition of person, environment,

health, and nursing theory of goal attainment. Lastly, the implication of the study variables will be presented.

Orem's Self-Care Theory

Orem's self-care theory incorporates humankind as a self-care agent. "Self-care may be simply defined as activities a person initiates and performs on his own behalf in order to maintain life, health, and well-being" (Anna, Christensen, Hohon, Ord, & Wells, 1978, p. 8). Orem (1985) states, "In the term self-care, the word self is used in the sense of one's whole being. Self-care carries the dual connotation of 'for oneself' and 'given by oneself'. The provider of self-care is referred to as self-care agent" (p. 84). DES daughters is used synonymously with female offspring, client, and self-care agent. It is this purposive agent that is capable of goal-directed activity and possessing decision-making capabilities. The behaviors that the self-care agent engages in, like the DES daughters, are in the form of deliberate action. The core of Orem's philosophy is the belief that we have an innate ability to care for ourselves.

> According to this model, mature individuals have the capacity to act on their own behalf to meet their usual requirements for self-care. The individual's abilities or potentials must therefore be tapped or supplemented to take the action necessary to 1.) cope with the effects of illness, 2.) make adjustments in lifestyle, and 3.) modify either behavior, the situation, or both when changes occur in the individual's health state. (Marten, 1978, pp. 9-10)

The purposes to be attained through the kinds of actions termed self-care are named self-care requisites. Three types of self-care

requisites are identified: universal, developmental, and health-deviation. They rest on the following assumptions:

> 1. Human beings, by nature, have common needs for the intake of materials (air, water, foods) and for bringing about and maintaining living conditions that support life processes, the formation and maintenance of structural integrity, and the maintenance and promotion of functional integrity.
>
> 2. Human development, from the initial period of intrauterine life to the fullness of adult maturation, requires the formation and the maintenance of conditions that promote known developmental processes at each period of life cycle.
>
> 3. Genetic and constitutional defect and deviations from normal structural and functional integrity and well-being bring about requirements for (a) their prevention and (b) regulatory action to control their extension and to control and mitigate their effects. (Orem, 1985, p. 86)

Orem (1985) described the person as a "unity that can be viewed as functioning biologically, symbolically, and socially" (p. 175). She focused on the person's ability to perform self-care, which is defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 84).

Orem interrelated human beings and environment. Orem (1985) stated, "Requisites for self-care have their origins in human beings and their environments" (p. 36). A clear definition of environment was not developed by Orem. Developmental environment however was described in detail. Such an environment "promotes personal

development in relation to becoming able to meet present or future demands for action" (Orem, 1985, p. 138). A developmental environment consists of "environmental conditions that motivate the person being helped to establish appropriate goals and adjust behavior to achieve results specified by the goals. . . . It is the total environment, not any single part of it, that makes it developmental" (Orem, 1985, pp. 140-141).

Orem (1985) defined health as the "state of wholeness or integrity of human beings." Persons are said to be healthy "when they are structurally and functionally whole or sound" (p. 173). That is to say that they do not have any signs of disease or morbidity and possess full vigor and strength. "Her definition of health includes the capacity to live as a human being within one's physical, biologic, and social environments and achieve some measure of his/her potential" (Fitzpatrick & Whall, 1983, p. 139). Physical, psychological, interpersonal, and social aspects of health are, according to Orem, inseparable.

> Health, then, must include that which makes a person human (form of mental life), operating in conjunction with physiological and psychophysiological mechanisms and a material structure (biologic life) and in relation to coexistence with other human beings (interpersonal and social life). (Orem, 1985, p. 174)

Orem (1985) considered nursing to be a helping service, "a creative effort of one human being to help another human being" (p. 132). The special concern of nursing is "the individual's need for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from

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Orem's Self-Care Theory

Orem's self-care theory incorporates humankind as a self-care agent. "Self-care may be simply defined as activities a person initiates and performs on his own behalf in order to maintain life, health, and well-being" (Anna, Christensen, Hohon, Ord, & Wells, 1978, p. 8). Orem (1985) states, "In the term self-care, the word self is used in the sense of one's whole being. Self-care carries the dual connotation of 'for oneself' and 'given by oneself'. The provider of self-care is referred to as self-care agent" (p. 84). DES daughters is used synonymously with female offspring, client, and self-care agent. It is this purposive agent that is capable of goal-directed activity and possessing decision-making capabilities. The behaviors that the self-care agent engages in, like the DES daughters, are in the form of deliberate action. The core of Orem's philosophy is the belief that we have an innate ability to care for ourselves.

> According to this model, mature individuals have the capacity to act on their own behalf to meet their usual requirements for self-care. The individual's abilities or potentials must therefore be tapped or supplemented to take the action necessary to 1.) cope with the effects of illness, 2.) make adjustments in lifestyle, and 3.) modify either behavior, the situation, or both when changes occur in the individual's health state. (Marten, 1978, pp. 9-10)

The purposes to be attained through the kinds of actions termed self-care are named self-care requisites. Three types of self-care

requisites are identified: universal, developmental, and health-deviation. They rest on the following assumptions:

1. Human beings, by nature, have common needs for the intake of materials (air, water, foods) and for bringing about and maintaining living conditions that support life processes, the formation and maintenance of structural integrity, and the maintenance and promotion of functional integrity.

2. Human development, from the initial period of intrauterine life to the fullness of adult maturation, requires the formation and the maintenance of conditions that promote known developmental processes at each period of life cycle.

3. Genetic and constitutional defect and deviations from normal structural and functional integrity and well-being bring about requirements for (a) their prevention and (b) regulatory action to control their extension and to control and mitigate their effects. (Orem, 1985, p. 86)

Orem (1985) described the person as a "unity that can be viewed as functioning biologically, symbolically, and socially" (p. 175). She focused on the person's ability to perform self-care, which is defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (p. 84).

Orem interrelated human beings and environment. Orem (1985) stated, "Requisites for self-care have their origins in human beings and their environments" (p. 36). A clear definition of environment was not developed by Orem. Developmental environment however was described in detail. Such an environment "promotes personal

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development in relation to becoming able to meet present or future demands for action" (Orem, 1985, p. 138). A developmental environment consists of "environmental conditions that motivate the person being helped to establish appropriate goals and adjust behavior to achieve results specified by the goals. . . . It is the total environment, not any single part of it, that makes it developmental" (Orem, 1985, pp. 140-141).

Orem (1985) defined health as the "state of wholeness or integrity of human beings." Persons are said to be healthy "when they are structurally and functionally whole or sound" (p. 173). That is to say that they do not have any signs of disease or morbidity and possess full vigor and strength. "Her definition of health includes the capacity to live as a human being within one's physical, biologic, and social environments and achieve some measure of his/her potential" (Fitzpatrick & Whall, 1983, p. 139). Physical, psychological, interpersonal, and social aspects of health are, according to Orem, inseparable.

> Health, then, must include that which makes a person human (form of mental life), operating in conjunction with physiological and psychophysiological mechanisms and a material structure (biologic life) and in relation to coexistence with other human beings (interpersonal and social life). (Orem, 1985, p. 174)

Orem (1985) considered nursing to be a helping service, "a creative effort of one human being to help another human being" (p. 132). The special concern of nursing is "the individual's need for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from

disease or injury, and cope with their effects" (Orem, 1985, p. 54). Nursing is characterized as action, as assistance. Orem (1985) stated that "a nurse's unit of service may be an individual or a multiperson unit" (p. 251). Individuals have self-care requisites to be met and the capabilities for meeting them.

> Individuals who receive help and care from persons qualified as nurses are referred to as nurses' patients. The term symbolizes the social status and roles of persons under the care of nurses. From a sociological perspective, the terms nurse and nurse's patient signify related statuses or positions in social groups. Each status carries with it a role, that is, a set of prescriptions for organized action through which the status is filled. (Orem, 1985, p. 56)

If the DES daughter is to take active control of her health, the nurse must share knowledge openly, reinforce independent behavior, and provide an environment for health care delivery in which the uniqueness of each self-care agent is recognized, accepted, and enhanced. The nurse must assess the abilities of an individual to engage in self-care. Self-care is both an ongoing activity and a confidence to be developed. Thus, the professional nurse has a major responsibility for enhancing the DES daughter's capacity for self-care. The nurse is practicing within an educational and developmental system functioning in a consultative capacity, thus giving the self-care agent primary responsibility for personal health.

The preceding description of Orem's self-care theory is used as a building block for construction of a conceptual framework specific to the care of DES daughters (see Figure 1). An overview of this model will now be presented.

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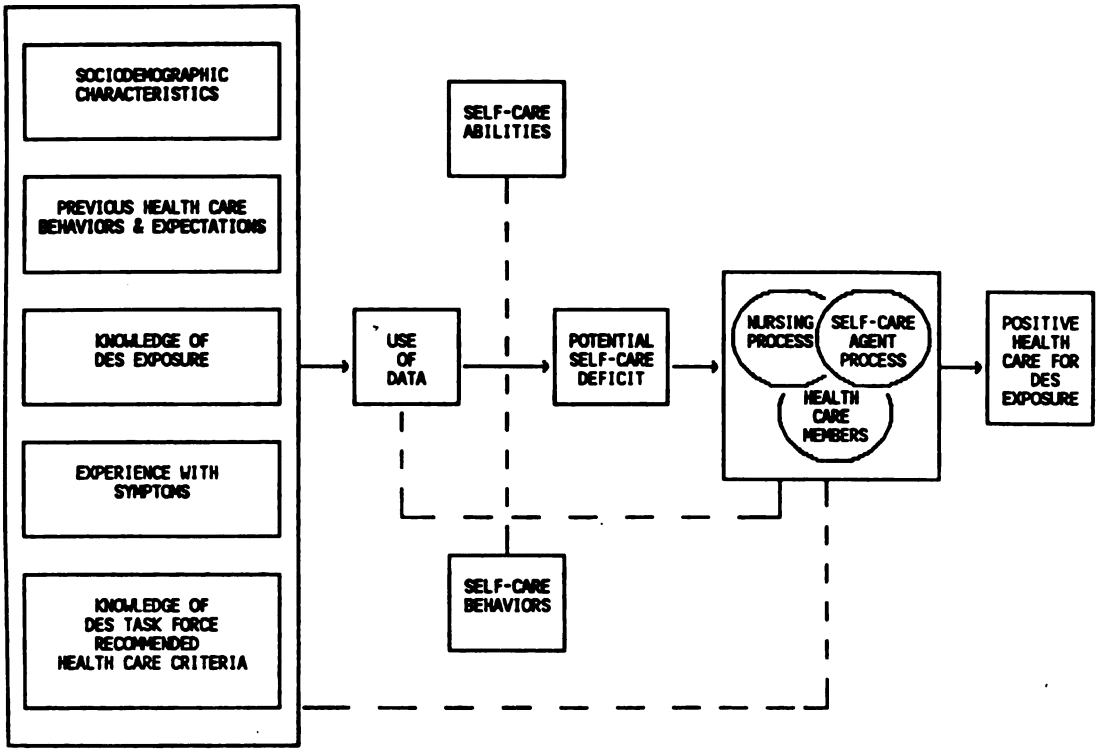

SELF-CARE CONCEPT FOR DES EXPOSED FEMALE OFFSPRING
FIGURE 1

Theoretical Framework

The DES daughter, the self-care agent, has the innate ability to care for herself. She is capable of goal-directed activity and possesses decision-making capabilities. It is through the use of deliberative action that the individual ultimately obtains positive health outcomes related to DES exposure. Positive health care related to DES exposure includes adherence to the DES Task Force recommended health care criteria; and knowledge and understanding of DES exposure, management, and treatment options.

The self-care agent is affected by many variables in the quest for meeting her health care needs. The individualized factor of sociodemographic data is one variable that will often determine the scope of self-care activities a person can perform (e.g., factors of age and developmental state). Other variables include previous health care behaviors and expectations, knowledge of being exposed to DES in utero, the experiencing of symptoms, and knowledge of DES Task Force recommended health care criteria; these serve as forces motivating individuals to focus their attention on present conditions and reflect upon their meaning. These variables, interacting within the DES daughter, affect the degree to which she will receive the recommended health care she needs specific to her DES exposure.

Demographic variables, such as age, sex, race, ethnicity, education, and income, may impact health care behaviors. The importance of ethnicity cannot be overlooked when trying to understand the impact of their culture on the health behaviors of a given population. Ability to comprehend instructions and health recommendations varies with educational level, as does the background

of knowledge and skills on which the DES daughter can draw in carrying out self-care. Income will affect health priorities and the accessability of services to follow through with recommended health behaviors. Demographic variables in DES daughters will result in the identification of significant differences in age, race, ethnicity, education, and income which must be considered when formulating specific nursing strategies.

Previous health care behaviors and expectations can affect an individual's pattern of health care. Personal factors that can facilitate or sustain health-promoting behavior include: the importance of health, definition of health, and perceived benefits of health-promoting behaviors.

The degree to which a DES daughter places a value on the importance of health will result in the degree of information-seeking behavior directed toward becoming more knowledgeable of her DES exposure and identifying required health care practices.

The DES daughter's definition of health will result in the extent to which she engages in health behaviors. Different definitions of health will predict differing patterns of health-related behaviors.

The DES daughter's perception of benefits from health-promoting behaviors will appear to facilitate continued practice of recently acquired behaviors. Repetition of the behavior itself will reinforce and strengthen beliefs about benefits.

Knowing whether one is DES exposed is the stepping stone needed in acquiring recommended health care. If a female is unaware that she is DES exposed, she is unable to choose whether to initiate the needed health care activities specific to her exposure. Knowledge of her

exposure may act as a motivational force to acquire knowledge, resources, and skills that will enhance her health status.

A cue, that is symptoms experienced by DES daughters, may affect the incidence of health behavior by triggering appropriate overt actions. If the symptoms are affecting her sexuality and ability to bear children, the DES daughter, whether or not she knows of her exposure, may seek medical attention. Intensity of cues, as well as level of readiness to engage in health care activities, will play a role in acquiring needed health care. Thus, perceived health status appears to play a role in the frequency and intensity of health-promoting behaviors.

Knowledge of the DES Task Force recommended health care criteria provides a knowledge base by which the DES daughter can initiate the recommended health care and monitor that proper medical care is being provided. This knowledge base enables the DES daughter in becoming her own self-care agent.

In summary, individual perceptions that are proposed as affecting the decision-making phase (i.e., use of data) of health-promoting behavior include: sociodemographic characteristics; previous health care behaviors and expectations; knowledge of DES exposure; experience with symptoms; and knowledge of DES Task Force recommended health care criteria. It is proposed in this model that each factor will influence readiness to engage in health-promoting behaviors. Further research is needed to ascertain what extent each factor contributes to readiness to engage in health-promoting behaviors. Future research is also needed to determine quantitative and qualitative relationships between level of readiness, cue intensity, and barriers.

Use of preceding data (i.e., sociodemographic characteristics; previous health care behaviors and expectations; knowledge of DES exposure; experience with symptoms; and knowledge of DES Task Force recommended health care criteria) by the DES daughter will or will not result in taking deliberative action, depending upon her self-care abilities and self-care behaviors. Self-care is a deliberative action.

The degree of self-care competencies, that is knowledge, motivation, skills, and orientation that an individual possesses, will influence her self-care abilities and behaviors. Her self-care abilities are reflected through the DES daughter's knowledge of herself; knowledge of her functional state; knowledge regarding the care that she needs; and the knowledge and skills necessary to appraise, investigate, and make judgments and decisions regarding her health and management of her DES exposure. Restrictions in her knowledge base, judgments and decision-making, and result-achieving actions in self-care would affect her ability to initiate self-care. Self-care deficits are associated with an individual's limitations, lack of validity, or effectiveness of self-care in which she engages.

Self-care behavior can inhibit or facilitate the obtaining of needed health care through self-care. Self-care behaviors place emphasis upon the self-direction, self-responsibility, and control of learning experiences of the individual self-care agent. Deficits in these areas can inhibit the initiation of self-care behaviors. It is the inability to initiate self-care that requires the intervention of health care professionals, in particular, the nurse.

Through the intervention of health care professionals, attention is sometimes directed back to the variables affecting the DES daughters' perceptions that are proposed as affecting the decision-making phase (i.e., use of data of health-promoting behavior). Thus, an opportunity is provided to initiate interventions that will assist a client in reflecting on or in modifying factors that influence their ability to engage in health-promoting behaviors. For example, the nurse may facilitate the DES daughter in acquiring the knowledge of health care recommended by the DES Task Force. If the DES daughter is knowledgeable about the health care recommended by the DES Task Force, but for some reason is not receiving the appropriate care, the nurse can help the DES daughter establish strategies to effectively acquire the care that she needs. Thus, the DES daughter will make use of the data she already possesses, and will acquire problem-solving skills that will influence her ability to initiate self-care in the future.

Thus the nurse, through the use of the nursing process, acts as a facilitator in assisting and supporting a client in self-care achievement. Nursing care is directed toward mitigation or elimination of self-care deficits initiated by identification of the client's ability and strengths. The nurse helps the client to identify strengths and develop them. Reinforcement of self-care abilities and potentials helps to decrease the client's anxieties. Decreased anxiety aids the client in obtaining health care goals and receive the lifelong health care she needs. Health care can then be sought directly through the self-care agent. The ultimate goal of

self-care is to acquire positive health care of DES exposure, that is, health care recommended by the Federal Government's DES Task Force.

Summary

To summarize, Orem's theory of self-care provides the framework for this study. It is beyond the scope of my proposed framework to identify cause and effect relationships related to the DES daughters' extent to which they are receiving the recommended health care prescribed by the DES Task Force. This framework proposes the relationship of the self-care concept entirety for DES female offspring. Thus, further research is needed in developing hypotheses concerning potential sources of motivation for preventative behavior, testing hypotheses, and integrating the findings of an explanative/predictive framework which demands considerable investigative effort. In Chapter III, a review of literature will be presented.

CHAPTER III

REVIEW OF LITERATURE

Overview

A review of literature will be presented in this chapter inclusive of the results of early studies related to the use of DES; the inception and study results of the DESAD Project; formation of the DES Task Force; subsequent establishment of the DES Task Force recommended health care, with reference to recommendations made by researchers other than members of DES Task Force in relation to necessary screening and management of DES daughters; and health behaviors of women in relation to BSE and Papanicolaou smear.

To obtain the full essence of the DES issue, it is important to review the drug's historical heritage. DES was known as the "miracle drug" during its inception into the pharmacological marketplace, until devastating side effects began affecting the lives of offspring exposed in utero to DES. Inquiries into the efficacy of DES in pregnancy was the foci of research. Controversy on the DES issue permeated its livelihood, but the drug continued to be manufactured and distributed in massive amounts during the baby-boom era. Many physicians used DES prophylactically, just as they would prescribe the use of prenatal vitamins.

Early Studies

In a study by Smith and Smith (1949) comparing the late pregnancies of primigravidas treated with DES to synchronous control primigravidas, it was determined that DES had value in reducing the usual incidence of late pregnancy complications and fetal loss.

Dieckmann, Davis, Rynkiewicz, and Pottinger (1953) indicate that one of the most serious criticisms of the Smith and Smith (1949) study is the lack of adequate controls to substantiate the clinical data (p. 1063). Also of significance is the fact that the control sample is 43 percent larger than the experimental sample. One further point to ponder is the fact that there was no sure way to tell if the patients who were treated with DES took the prescribed dosage or the drug at all.

In response to inquiries made by Drs. G. V. and O. W. Smith, researchers Sommers, Lawley, and Hertig (1949) performed a statistical investigation of the effects of stilbestrol therapy in pregnancy upon weights of baby and placenta. The results of the study by Sommers et al. (1949) reported that stilbestrol stimulates an increase in weight and presumably size of both infant and placenta. The results of the study also reported that no nontoxic premature separations were encountered after stilbestrol therapy.

In contrast to the findings obtained by Smith and Smith (1949), a double-blind prospective controlled study by Dieckmann and associates (1953) found no benefits of stilbestrol use in DES patients between 840 women receiving DES and 806 receiving a placebo. This experiment was designed in an attempt to learn whether DES had therapeutic value. The results of the study indicated that stilbestrol did not reduce the incidence of abortion, prematurity, or postmaturity. Premature babies of stilbestrol-treated mothers were no longer nor more mature for their gestational ages than comparable prematures in the control group of placebo-treated mothers. DES did not decrease

the incidence of perinatal mortality nor did it decrease the frequency of the toxemias of pregnancy.

Davis, an associate of Dieckmann, stated:

> We think that the number of patients studied and the methods used showed that stilbestrol has no therapeutic value in pregnancy. It is possible that that answer may not be correct, but it will take at least as many more patients just as carefully controlled to prove that stilbestrol administered prophylactically to normal or abnormal pregnant patients has any value in the prevention of the specific complications of pregnancy. (Dieckmann et al., 1953, p. 1081)

Ferguson (1953) concluded that DES had no effect on the incidence of pre-eclampsia, prematurity, perinatal mortality, fetal weight, and the size of the placenta. Brackbold and Berendes (1978) reported a recalculation of the statistics from the 1953 study of Dieckmann and associates and found that DES was associated with significant increases in abortions, neonatal deaths, and premature births.

In summary, there were supporters and avid believers in the results of both the Smith and Smith studies as well as the Dieckmann and associates studies. The results of the studies conducted by these two groups of researchers were at opposite ends of a spectrum. The controversies on the therapeutic use of DES in pregnancy continued over the years, until in 1971 the FDA banned the use of DES in pregnancy in response to reports by Herbst, Ulfelder, and Poskanzer (1971) that clear cell adenocarcinoma of the vagina was occurring in girls aged 14 to 22. This demonstrated the link of vaginal clear cell adenocarcinoma to in utero DES exposure that had occurred one and a

half to two decades earlier. The legacy of DES exposure has since continued to expand. "In addition to this lack of efficacy, severalserious long-term consequences of in utero exposure to DES have and continue to come to light" (Stillman, 1982, pp. 905-906).

DES Adenosis (DESAD) Project

The FDA approved DES for use in humans in 1941 when few criteria existed for judging new drugs. Once DES was approved, the FDA was slow to restrict the use of DES in the future.

Federal guidelines were drawn up in 1938 by the FDA to help assure that food and drugs were safe for human consumption, but did not require drug companies to demonstrate long-range safety or proof of effectiveness. It was not until new Congressional drug regulation laws in 1962 required that manufacturers prove effectiveness and safety. For nearly three decades following the FDA's initial approval of DES, the FDA never questioned the drug, despite the fact that the University of Chicago study published in 1953 demonstrated that DES was useless in preventing miscarriage (Orenberg, 1981, pp. 122-123).

In 1962, drug regulations were tightened. Proof of effectiveness was placed on the drug manufacturer. If proof of effectiveness was not submitted in six months, the FDA was empowered to restrict the use of that drug. Six months came and went, and the manufacturers of DES still did not submit proof of its effectiveness in preventing miscarriage. For reasons that are not clear, the FDA did not restrict the use of DES during pregnancy despite its own six-month time limit. In addition, the FDA was slow to act after Herbst and his colleagues gave proof early in 1971 to the FDA that DES given during pregnancy could cause cancer in the female offspring. Seven months after

receiving the Herbst report which linked DES given during pregnancy with vaginal cancer in the DES daughters, the FDA requested drug companies to issue a warning against the use of DES during pregnancy. This was 18 years after the Dieckmann study (1953) showed DES to be ineffective as an anti-abortive agent.

In November 1971, the FDA issued a drug bulletin, "Diethylstilbestrol Contraindicated in Pregnancy", thus bringing to the attention of health care providers an important possible toxic effect of DES. By this time, 21 cases of clear cell adenocarcinoma in DES-exposed daughters had already been reported to the Registry of Clear Cell Adenocarcinoma of the Genital Tract in Young Females.

In December 1973, the National Cancer Institute (NCI), a branch of the Department of Health, Education and Welfare (now known as the Department of Health and Human Services), began formulating a formal study of DES use during pregnancy. The resulting study was termed the DESAD project, short for DES Adenosis. "The basic purpose of the study was and remains 'to assess the magnitude and severity of the health hazard to DES-exposed female offspring'" (Orenberg, 1981, p. 124).

The DESAD project was proposed by Kurland, after the Herbst et al. (1971) article first reported the DES cancer connection. Kurland and his staff, after reviewing their own DES-exposed population and realizing the large size of the exposed population and the potential seriousness of the medical consequences, wrote a letter to the FDA for funding to conduct a preliminary study. This funding would help pay for examinations of DES daughters and for the epidemiological evaluations. Funding was received, and based on the results of this

FDA-funded study, Kurland and his staff applied to the NCI in 1973 for funds for a much larger, multi-institutional study. The result of their preliminary study and their petition to NCI was the DESAD project. In March 1974, the contracts for the study were awarded and a multi-institutional coordinated research project, "Study of the Incidence and Natural History of Genital Tract Anomalies and Cancer in Offspring Exposed In Utero to Synthetic Estrogens", began.

"The DESAD project was set up as a 'field test to answer questions concerning incidents, prevalence, and natural history' of changes in the vaginal tissues of DES daughters. This was to include a study of benign as well as malignant changes" (Orenberg, 1981, p. 125). "Information obtained by the institutions collaborating in the study would form the basis for advising offspring concerning risks of developing DES-associated abnormalities and proper management of such abnormalities" (Hamm, 1983, p. 2).

The NCI selected four health care institutions as the DESAD Project's field participants to perform the clinical examinations and tissue evaluations for its study: Baylor College of Medicine; Massachusetts General Hospital; the Mayo Clinic; and the University of Southern California. The Mayo Clinic was chosen to be the coordinating center for data collection analysis; Kurland and his staff were appointed as the coordinating unit for the entire project. The following year a fifth institution, the Gunderson Clinic in LaCrosse, Wisconsin became part of the project as a subcontractor to Mayo Clinic. The DESAD project was funded for three years for three million dollars.

In 1979, two scientific papers by DESAD investigators on the first results of the DESAD project were published in the March issue of Obstetrics and Gynecology (Robboy, Kaufman, et al., 1979; O'Brien et al., 1979). Briefly, the results of these two studies showed that DES, while still a cancer threat to daughters exposed to DES in utero, may pose less risk than earlier anticipated.

Initial clinical findings were reported for 3,339 young women enrolled in the DESAD project. Four cancers of the genital tract were found among the total of 3,339 DES daughters in the study. Among the 1,275 daughters identified through prenatal record reviews, who were most representative of the total population of women exposed to DES before birth, no cancers were found. Occurrence of abnormal squamous cells in either the vagina or cervix was rare. Changes in the lining or wall of the vagina, including adenosis, were found in 34 percent of the record review group, 65 percent of the referrals, and 59 percent of the "walk-ins". Among the record review group, women 26 years of age or older had changes in the vagina less frequently than did younger participants, thus suggesting that some effects of DES exposure may have less consequence as women grow older. Also, the DESAD investigators reported that the degree of benign changes of the vaginal and cervical tissues was associated with the week during pregnancy in which the mothers began taking DES (Robboy, Kaufman, et al., 1979; O'Brien et al., 1979; Orenberg, 1981; Hamm, 1985; and NCI, 1985).

Barnes et al. (1980) published a DESAD report, "Fertility and Outcome of Pregnancy in Women Exposed in Utero to Diethylstilbestrol", stating that women exposed to DES before birth were found to have some

increased risk to pregnancies of their own. The risk of an unfavorable pregnancy outcome in comparison with a group of similar women not exposed to DES indicated a risk of nearly one and three-quarters times that of the comparison group. However, no difference in the ability to conceive a child was found.

Robboy, Szyfelbein, et al. (1981) reported the results of a study in which the data suggested that as DES-exposed women grow older, vaginal adenosis regresses to squamous metaplasia. Until that time, the data suggested that there was no difference in the rates of squamous cell dysplasia among exposed and unexposed women. The authors however cautioned that this issue can only be resolved as these patients are followed over the next decades.

In December 1984, "Increased Incidence of Cervical and Vaginal Dysplasia in 3,980 Diethylstilbestrol-Exposed Young Women" was published indicating that the investigators (Robboy, Noller, et al.) found the incidence rate for dysplasia was significantly higher among women exposed prenatally to DES than among the matched controls (15.7 cases vs. 7.9 cases per 1,000 person-years of follow-up). Both DES-exposed and unexposed daughters were given initial examinations, when entered in the DESAD project, which showed similar rates of dysplasia. Over several years, dysplasia had developed in the DES-exposed women at twice the rate of the unexposed group. According to the DESAD researchers, dysplasia rarely occurs in women who have never had sexual intercourse. The current study found a definite connection in both the DES-exposed daughters and the unexposed daughters between dysplasia and an early age of first intercourse (before 20), multiple sex partners, multiple pregnancies, and exposure

to a male sexual partner who had had several sexual partners. The same researchers also discovered that genital herpes occurred twice as often in DES-exposed daughters but do not know the reason. Some of these factors are associated with subsequent development of cervical cancer, that is, early age of first intercourse, multiple sexual partners, and herpes. Robboy, Noller, et al. (1984) postulated the two-fold incidence of dysplasia observed in the DES-exposed daughters in this study made them at greater risk in later life of developing cervical cancer than unexposed daughters. Too few cases of carcinoma in situ however have been observed to date to reach any conclusions about the risk of cervical cancer.

DESAD investigators, as well as other interested researchers, have published additional scientific reports on many aspects of the problems of DES exposure. The information gained by the DESAD project helped to form the basis for advising offspring concerning risks of developing DES-associated abnormalities and the proper management of such abnormalities. A five-year grant, entitled "In Utero DES Exposure: Cancer and Medical Illness", was awarded in 1984 to the Mayo Clinic, with Dr. Kenneth Noller appointed as project director. This grant was awarded after the NCI funding for the DESAD project had ended. One of the principal aims of Noller's grant is to maintain contact with the previously assembled DESAD cohort of the 3,980 DES-exposed daughters and 1,033 controls by obtaining information annually through mailed questionnaires (NCI, 1985, p. 2).

> Dr. Kurland said during an interview that new problems, including a second peak incidence of invasive clear cell cancer in DES daughters, might occur as the DES-exposed population grows older,

and that such a trend could only be accurately assessed and appropriate treatments developed through a study such as the DESAD Project. (Orenberg, 1981, p. 127)

DES Task Force

Coincident with the publication of the DESAD Project's first findings was the formation of the DES Task Force. In February 1978, the DES Task Force was established by Dr. Julius B. Richmond, Surgeon-General of the United States, at the behest of Joseph Califano, then Secretary of the DHEW. Diane J. Fink, M.D., director of the Division of Cancer Control and Rehabilitation of the NCI, was appointed chairperson of the Task Force. The Task Force was composed of 14 physicians and researchers of the NCI whose mission was to review all aspects of the DES problem, to make recommendations for health care of the exposed, and to research directions for medical investigators. The Task Force was asked to specifically investigate the possibility of an increased risk of breast cancer and other tumors in DES mothers; the use of DES as a postcoital contraceptive; abnormalities of the urogenital tract in DES male offspring; abnormalities of the vaginal and cervical tissue in DES female offspring; and other early observations on the health effects of DES.

On September 21, 1978, six months after the DES Task Force began its investigation, their findings were announced. DES Task Force members were guided by scientific papers about various aspects of DES and by consultants with expertise about DES. The Task Force findings were presented in a summary report beginning with an introduction and followed by discussions of DES daughters; DES mothers; DES sons; psychosocial implications of DES exposure; current uses of DES (and

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other estrogens); and recommendations for public and professional education. Secretary Califano in a press release with the summary of the DES Task Force Report stated, "For DES-exposed daughters, a clear association between exposure before birth to DES and clear cell adenocarcinoma of the vagina or cervix is established. Estimates of incidence of clear cell adenocarcinoma are between 1.4 per 1,000 and 1.4 per 10,000 through age 24" (Hamm, 1985, p. 3).

On October 4, 1978, within two weeks of the Task Force release of its findings, Surgeon-General Julius Richmond issued a physician advisory summarizing the Task Force findings. "This advisory was remarkable because it was only the third cancer warning ever issued by the Surgeon-General, the first two involving cigarettes and asbestos" (Orenberg, 1981, p. 134). This advisory was sent to every physician and osteopath in the country as a result of recommendations made in the report. The six-page advisory contained a recommendation that all physicians notify women to whom they had prescribed DES of their exposure and advise them about the need for follow-up medical care for themselves and their offspring, and to provide this information without charge to the patient. Also included in this advisory were specific recommendations concerning examinations of DES daughters, sons, and mothers, and concerning the further use of estrogens. The importance of regular follow-up examinations for DES-exposed women was stressed. Orenberg (1981) stated in regards to the enforcement of recommendations in the physician advisory that, "..., few seem to have complied. Most women have learned of the DES problem through magazines, newspapers, and public service campaigns" (p. 134).

The Task Force reconvened in January 1985 to discuss the 1978 DES Task Force report and to review the results of investigations which had been published since the report of the 1978 DES Task Force, and to update any conclusions and recommendations from that report as appropriate. In summary, the 1978 Task Force addressed recommendations for screening to detect early occurrence of clear cell adenocarcinoma and non-cancerous epithelial changes of the vagina and cervix. It was determined by the 1985 DES Task Force that the screening procedures established in 1978 are still appropriate. Thus, the recommended health care established by the DES Task Force will now be addressed.

DES Task Force Recommended Health Care for DES Daughters

The DES Task Force has published recommendations for health care providers to follow in screening DES daughters to detect early occurrence of clear cell adenocarcinoma and non-cancerous epithelial changes of the vagina and cervix. DES-exposed daughters have a tendency for the development of areas of cervical and vaginal metaplasia. Thus, the sampling of tissue to establish a diagnosis of dysplasia by colposcopy and biopsy is somewhat complicated. It is important that the DES daughter be examined periodically by a physician who can detect subtle changes in the cervix and vagina. The DES daughter should have an annual pelvic examination, Pap smear, iodine staining, and a colposcopy and/or biopsy if indicated. If any abnormalities are found in the DES daughter, she should see a physician experienced in examinations using colposcopes. If treatment is indicated, second opinions from physicians knowledgeable about DES

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exposure should be sought before a decision is made (U.S. Department of Health and Human Services, 1985).

> Periodic screening examinations should begin at age 14 or at the onset of menses, whichever is earlier, unless there is vaginal bleeding or discharge; bleeding or discharge should be evaluated without delay. Exposed daughters and their families should have adequate explanation and consideration of the physical and emotional aspects of this examination. (U.S. Department of Health and Human Services, 1985, p. 22)

Anderson et al. (1979) reported the individual at high risk for development of adenocarcinoma is under the age of 24, has symptoms of abnormal bleeding or discharge, or has extensive columnar ectopy on the cervix or in the vagina. These researchers indicated that the most intense search for malignancy should be conducted in women meeting one or more of these criteria. The vast majority of DES-related malignancies occur between the age of 14 and the mid-twenties, with a peak incidence of 19. Although the mechanism of development of malignancy is not known, one theory has been that endogenous hormones secreted by the ovaries may play a role in the subsequent development of adenocarcinoma.

The presence of abnormal bleeding or discharge should be investigated immediately at any age. Fuller (1978) reported that, "Bleeding or discharge has been the presenting symptom in more than 80% of patients; less than 20% have been asymptomatic at the time of diagnosis" (p. 204). "Abnormal bleeding in adolescent girls can no longer be assumed to be due to anovulation, and the possibility of

vaginal tumor should be excluded by a physician's examination" (Herbst et al., 1971, p. 880).

> The screening procedure should include a thorough pelvic examination using careful palpation (feeling), cytology test (the Pap or Papanicolaou smear), and tissue inspection including the use of one-half strength aqueous Lugol's (iodine) solution for cervical and vaginal staining. (Nonstained areas of the vagina may indicate adenosis.) (U.S. Department of Health and Human Services, 1985, p. 22)

The importance of including all of the components of the examination has been stressed by many researchers. Robboy, Friedlander, et al. (1976) reported their study indicated that the presence of mucinous columnar or metaplastic squamous cells in vaginal scrapes is suggestive of vaginal adenosis, but that vaginal cytology cannot be considered an uniformally reliable screening technique for detecting the presence of this disorder.

Bibbo et al. (1977) reported in their follow-up study that cytology results reflect the appropriate sampling technique of taking four separate scrapings from the walls of the vagina, in addition to the ectocervical and endocervical smears. These researchers stated that the cytologic findings indicate that the technique is reliable as a screening test for vaginal epithelial changes in the DES-exposed females.

Fuller (1978) reported that cytology alone will detect approximately 80 percent of clear cell adenocarcinomas. The decrease in sensitivity of detection is attributed to the presence of large numbers of inflammatory cells or to the well-differentiated nature of the tumor.

On the other hand, Anderson et al. (1979) stated, "Frequent Papanicolaou vaginal smears, along with regular, careful palpation, and biopsy of all suspicious cystic or nodular vaginal masses, are minimum requirements for screening high-risk patients" (p. 298). Pap smears have been successful in detecting only 73 percent of known clear cell adenocarcinomas. Factors that have been identified to be responsible for false negative smears may be due to inadequate sampling, subepithelial location of the tumor and delicate nuclear chromatin pattern seen in some tumor cells. Anderson et al. (1979) indicated that submucosal malignancies that may not be detected by cytology may be detected upon careful palpation as a tumor nodule. They also indicated that iodine staining is helpful in identifying the extent of the immature transformation zone. Caution should be exercised when interpreting biopsies, since tissue obtained from the periphery of a tumor nodule may have a less malignant appearance and thus be confusing.

Schiller's iodine staining is significant in the examination of a DES daughter. Normal squamous epithelium of the vagina contains glycogen. When glycogen reacts with the iodine-containing solutions, a uniform brown color on the normal cervix and vagina is produced. Iodine stains only the normal (highly glycogenated) squamous epithelium that lines the vagina and cervix. Areas of columnar epithelium including areas undergoing squamous metaplasia do not possess glycogen and thus do not stain. Also, malignant changes in the cervicovaginal epithelium do not react with iodine and therefore are able to be detected by biopsy of the non-staining epithelium. Biopsies of all red or non-staining areas of the cervicovaginal

epithelium must be included in the initial evaluation of the DES daughters. Use of a colposcope for this evaluation will assist the physician by showing gradations of change and targeting biopsies to the most abnormal areas. Colposcopy is useful in patients with abnormal iodine staining or cytology. The required frequency of colposcopic examinations varies with the degree of columnar ectopy and immature metaplasia encountered (Fuller, 1978; Anderson et al., 1979; Goroll, May, and Mulley, 1981).

> Use of a colposcope (an instrument for examination of vaginal and cervical tissues by means of magnifying lenses) is not required at every examination of DES daughters. Colposcopy should be utilized: (a) in all cases where abnormal cytology (Pap smear) is observed; (b) in cases of extensive or widespread epithelial changes (such as squamous metaplasia); and (c) where feasible as part of the initial examination. It must be recognized that colposcopy may be a relatively expensive procedure, and most physicians do not have colposcopes or the special training needed for their use. Many of the changes which can be observed with the colposcope can also be detected by use of the much simpler and less traumatic technique of iodine staining.
>
> Biopsies should not be done routinely, but should be reserved for specific indications such as abnormal Pap tests or other evidence of significant epithelial abnormalities. (U.S. Department of Health and Human Services, 1985, pp. 22-23)

Orr et al. (1981) reported the anatomic, colposcopic, cytologic, and histologic findings of the cervix in 300 women exposed to DES in utero. In 14 patients, marked dysplasia-carcinoma in situ was found.

Their data strongly suggested that women exposed to DES may be followed safely with Papanicolaou smears and colposcopic examinations provided that both the cytopathologists and colposcopists are aware of the metaplastic changes in the DES progeny that distinguishes them from women who were not exposed to DES with cervical intraepithelial neoplasia (CIN). These researchers also indicated that a biopsy should only be performed if indicated by cytologic atypia, evidence of advanced CIN by colposcopic examination, or presence of an invasive lesion. Colposcopic examination of DES-exposed women can be confusing due to active metaplasia that mimics the patterns of CIN.

The DES Task Force has recommended that DES daughters should be examined minimally, at least once a year, with more frequent examinations for those with extensive or atypical epithelial changes (U.S. Department of Health and Human Services, 1985, p. 22).

Prominent DES researchers (Fuller, 1978; Herbst, 1984; Johnston, 1983; Robboy, Noller, et al., 1984; and U.S. Department of Health and Human Services, 1983) are in agreement that routine examination of the daughters exposed to DES in utero can be performed at yearly intervals, unless more frequent evaluation is indicated in the presence of cytological or histologic changes.

Much attention has been given to the examination and monitoring of the DES daughter's genital tract anomalies. In addition to close screening of the vagina and cervix, the DES Task Force (1985) recommends breast examinations of DES daughters to conform with current NCI guidelines (U.S. Department of Health and Human Service, 1985, p. 23). Many questions remain to be answered about the health risks related to DES exposure. DES daughters are just now reaching

the age when breast cancer begins to appear among all women. As an NCI document noted, ". . . the biological rationale for increased risk of breast cancer from DES exposure exists for daughters exposed in utero, as well as for mothers" (DES Action Voice, Summer 1986, p. 1). Thus, the importance for further research to determine the DES daughter's risk for breast cancer is stressed, as such information will aid the DES daughters in seeking appropriate breast screening as they grow older.

Greenberg et al. (1984), in an NCI-supported study of 6,000 DES-exposed and non-exposed mothers, found the DES-exposed mother to have a moderate increase in breast cancer incidence. They were observed to develop breast cancer at a rate of almost one and one-half times more frequently than comparable non-exposed mothers. The investigators were unable to discern with certainty that DES itself accounts for such elevated incidence, and not some other unrecognized factor in the DES-exposed women. The risk of breast cancer in the DES-exposed women appears to be less than that associated with a positive family history of breast disease. According to these investigators, the risk in DES-exposed mothers was the same as the risk in non-exposed women until approximately 22 years after exposure. The exposed women's risk becomes progressively greater and pronounced with time, with the highest risk in DES-exposed mothers 60 years and older. Mortality from breast cancer did not appear to be significantly higher in this study.

The oldest DES daughters are approaching their early 40's. Many questions remain unanswered regarding the health risks related to DES exposure as these women approach their 40's and 50's, ages at which

the incidence of cancer increases sharply in the general population. As Orenberg (1981) states,

> In the DES-unexposed population, invasive carcinoma of the vagina comprises about 2% of all female genital cancers. The mean age of women who get it is 56 years. Will the normal aging process trigger a second wave of invasive vaginal cancer in the already sensitized tissue of DES daughters?
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> Unfortunately, this is a question only the passage of time can answer. (p. 53)

In summary, the DES Task Force established recommendations for health care providers to follow in screening DES daughters based on reports from DESAD studies. Controversy between researches as to the efficiency of screening procedures (i.e., Pap smear) remains prevalent in the literature, but the guidelines are clear.

Health Behavior

Historically, the woman patient, because of prevailing theories about woman's nature and place, was treated in a subordinate manner by the predominantly male medical profession who were ascribed with a high degree of power. Women were limited by the Victorian mentality that prescribed unequal status for women in society. During the past century, the woman has evolved from patient to consumer. Since the women's movement of the 1970's, women have become increasingly involved in health-related concerns including a growing number of critiques of medical services reflecting consumer dissatisfaction with conventional health care. "Indeed, some credit the woman's movement in the United States with the original consciousness about self-care" (Woods, 1985, p. 227).

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"As women become more competent as advocates for themselves, they will become stronger advocates for an improved health care system" (Choi, 1985, p. 15). The attainment and retention of good health often rests with the woman's own behavioral practices. "People choose to engage in given behaviors from a range of options based on their perception of the behaviors and of the options available to them" (Laffrey, 1985, p. 279).

Women make more visits to physicians and use hospitals more often than men (even when hospitalization for delivery is excluded). Women throughout their life span, but particularly women in their middle years, are more likely to utilize a regular source of care, to obtain this from a private physician, and to visit the physician more often than men. Increased health care utilization may contribute to women's longevity as more frequent contact can allow for early diagnosis and treatment (Rice, Hing, Kovar, & Prager, 1984, pp. 17-18).

Mortality statistics reflect a partial picture of health care needs for a given population. Health care needs specific for women, as well as specific to a particular portion of the life cycle, can be identified.

In summary, women's role in society has changed and contributed to her advocacy for self-care. Cited throughout literature is the women's increased utilization of health care. If proper screening procedures were employed, her frequent contact with the health care system could allow for early diagnosis and treatment. No literature focusing on the health behavior of DES daughters could be found.

Breast Self-Examination

For women aged 25-64 years, breast cancer and lung cancer are the leading causes of death due to malignant neoplasms (American Cancer

Society [ACS], 1985). Therefore, early detection is of particular importance to women of this age group.

Since most breast cancers are found by women themselves, monthly BSE is an important preventative measure. Consequently, there are many studies that research the factors that influence the performance of BSE.

"Breast self-examinations by health professionals, and mammography are associated with the greater likelihood of detecting lesions of small size. . . . The best hope for breast cancer today lies in secondary prevention specifically, early detection and treatment" (Ernster, 1984, p. 196).

Woods (1985) reported that self-care patterns revealed a variety of self-care measures and coping with systems in ways specific to the systems. The purpose of Wood's study was to explore the universal and illness-related, self-care activities employed by young adult married women. Ninety-six women 20 to 40 years of age kept a daily health diary for three weeks. In this diary they reported their regular health care, symptoms experienced each day, and self-care actions in response to symptoms. A total of 1,140 universal self-care activities was reported over the three-week period. BSE was reported as a universal self-care activity by only one woman of the 96 in this study.

Amsel, Grover, and Balshem (1984) studied the relationship of physician reinforcement with BSE behavior. Inasmuch as BSE is a health-related behavior and that the physician is considered the main source of credibility in health matters, the researchers hypothesized that reinforcement by the physician would be highly effective in

motivating women to do BSE. Fifty-nine percent of the women in the sample were aged 40 years or younger. The data showed a positive relationship between physician reinforcement of BSE behavior and BSE practice among the subjects. Similarly, the higher the level of reinforcement from the physician, the greater the probability a woman would practice BSE regularly (at least once a month). Also, self-confidence in performance of BSE, knowledge of breast cancer etiology, and knowledge of risk factors of breast cancer were associated with practice of BSE at a statistically significant level. Although the data is indicative of a statistically significant positive correlation between physician reinforcement and BSE practice, the role of physician as motivator for BSE within the context of routine medical practice has been dealt with superficially and not adequately investigated. A prospective study could conclusively demonstrate whether a causal relationship exists between physician reinforcement and BSE practice.

A study by O'Malley, Fletcher, and Bunce (1985) surveyed 80 physicians from four specialities (Family Medicine, General Medicine, General Surgery, and Obstetrics and Gynecology) to investigate how these physicians taught BSE. Only half reported personally teaching BSE. Few physicians reported routinely using techniques to assess BSE competency. Seventy-two percent had no formal training in teaching BSE, while 10 percent claimed no training at all. Techniques used to teach BSE vary, and some physicians lack the training to teach BSE.

Mamon and Zapka (1985) performed a randomized trial to improve BSE performance among college-age women. The major intervention was a BSE group education session conducted in classroom and workshop

settings. The pre-intervention and six-month-after experimental control comparisons from the study suggest that properly targeted educational programs can significantly improve early detection behavior in women.

In summary, researchers have reiterated the importance of the monthly BSE as a preventative measure. Also, researchers have reported that there are many factors that influence the health behavior of a woman in practicing monthly BSE. Thus, although studies have repeatedly shown a positive correlation between BSE and early detection of breast cancer, it is the woman who chooses whether or not to perform the BSE or positive health behavior. The reason(s) a woman performs or does not perform BSE continues to be explored. Ongoing research, assessment, and intervention need to be continued if the performance levels for BSE are to increase.

Papanicolaou Smear

According to the ACS (1985), there are 14,000 estimated cases of invasive cancer of the cervix and 45,000 estimated cases of cancer in situ annually. The Pap smear is an inexpensive reliable test to screen for cervical cancer. There are different opinions as to how often a Pap smear needs to be done. The ACS prescribes that asymptomatic women between 20 and 65 years of age are to receive a Pap smear every three years after two negative smears one year apart. An initial Pap smear should be obtained by age 20 or at the onset of sexual activity.

Needle (1976) reported that 33.9 percent of college women seek gynecological services for check-up and Pap smear. Petravague, Reynolds, Gardner, and Reading (1979) studied the attitudes of women

toward gynecologic examination. These researchers found that women are uncomfortable with the physical discomfort of pelvic examinations. Also, these researchers found that women need andwant to be educated about the gynecologic examination. Thus, knowing more about the gynecologic examination would make the women more comfortable during the procedure.

Michielutte, Diseker, Young, and May (1985) investigated the extent of noncompliance with follow-up to screening for cervical dysplasia at a public health family-planning clinic. Noncompliance in the study was defined as failure to respond to notification of an abnormal cervical smear (Class III, IV, or V) by failing either to make a follow-up appointment or to keep such an appointment after it was scheduled. The sample consisted of 177 women, of which approximately 17 percent of the sample were noncompliant. It was found that noncompliant patients were more likely to be unmarried, less educated, younger, and to have fewer total health problems than women who returned for follow-up. Logistic regression analysis revealed that the number of health problems and educational attainment were the most important predictors of noncompliance.

In summary, the Pap smear, an inexpensive and reliable test to screen for cervical cancer, is not routinely used by many women. Barriers to receiving screening for cervical cancer and noncompliance with follow-up of abnormal Pap smear results continue to be explored. There are many factors that affect whether a woman will comply with set standards of care regarding Pap smears. Ongoing research, assessment, and interventions need to continue if a higher rate of compliance in seeking routine Pap smears and follow-up of abnormal results is to be obtained.

Summary of Review of Literature

A review of the existing literature has been presented on the following areas: early studies, DESAD project, DES Task Force, DES Task Force recommended health care for DES daughters, health behavior, BSE, and Papanicolaou smear. Literature was found that addressed the physical abnormalities and screening procedures resulting from DES exposure in utero. The area inadequately addressed in the scientific literature was health behavior specific to those women exposed to DES in utero. Women in general were addressed regarding health behavior specific to screening procedures and health care. There is lack of quality research addressing the health behavior of the DES population as well as what health care the DES daughter is receiving. The researcher in this study will attempt to contribute to the small body of scientific knowledge that exists relative to the extent of health care received by DES daughters. In Chapter IV, the research design and methods used to guide the study will be presented.

CHAPTER IV

METHODOLOGY AND PROCEDURE

Overview

This descriptive study examined the extent to which DES daughters received the health care recommended by the Federal Government's DES Task Force. Criteria for health care of DES daughters were ascertained through a review of literature and established DES Task Force guidelines. The goal of the study was to provide a description of the characteristics of female offspring exposed to DES in utero, and to describe the pattern and type of health care received specific to monitoring the potential effects of DES exposure in utero.

The purpose of this chapter is to present the research design and methods that were used to guide this study. The data collection procedure, operational definitions, scoring, reliability and validity, analysis of data, and protection of human rights will be described.

Data Collection Procedure

A self-administered questionnaire was developed for this study which included both closed-ended and open-ended items. Before developing the initial questionnaire, questions were formulated specific to the 1985 DES Task Force recommendations (U.S. Department of Health and Human Services, 1985). These questions were designed to answer the overall question addressed in this study: To what extent do DES daughters receive the health care recommended by the Federal Government's DES Task Force? Thus, the formulation of specific subquestions to be answered provided the starting point for developing the questionnaire.

The survey data in this study were obtained using both open-ended and closed-ended questions. Open-ended questions were used if responses could not be adequately anticipated, and thus to provide for a richer and fuller perspective, and response from subjects on the topic of interest. The first draft of the questionnaire was constructed after the researcher acquired some idea what questions and response choices were needed to answer each of the subquestions stated.

A pilot study was conducted using eight DES daughters who responded to a notice which was posted and distributed in the College of Nursing at Michigan State University requesting their voluntary participation to fill out a self-administered questionnaire for a pilot study (see Appendix C for questionnaire). The respondent was also asked to add comments and suggestions regarding the questionnaire's construction and content. At the end of the questionnaire, the respondents were asked to give the approximate time needed to complete this questionnaire. These respondents did not participate in the full-scale study.

After the pilot study was completed, the questionnaire was revised. Pilot study comments were taken into consideration, as well as suggestions made by DES Action National Organization consultants.

Changes in the format and order of questions were made, that is, sociodemographic questions were moved from the beginning to the end of the questionnaire. The format of Likert-type responses was changed from checking on a scale to checking one of five responses in a parenthesis. DES screening examination was defined early in the questionnaire as the participants were not certain what was meant by a

DES screening examination. Reference to physician in the questionnaire was modified to include health care provider. A question regarding a change in vaginal lining/tissue with the same format as used in the question addressing abnormal Pap smear was added. In the question regarding abnormal Pap smear, the question was modified so that the respondent was given the option of stating her approximate age or year of occurrence of the abnormal Pap smear, since the pilot participants felt the option would make the question easier to answer. A question was added regarding marital status. It was suggested by a pilot participant that the DES daughter should cite the area of the country in which she resides; thus, a question was added to specify a state of residence.

The final draft of the questionnaire was completed after final approval from the members of the thesis committee, statistical consultant, and the DES Action National Organization consultants. The study was then conducted utilizing the format described in this chapter.

Population and Sample

The population under consideration in this study was female offspring conceived between 1947 and 1971 whose mothers took Diethylstilbestrol (DES) for any period of time during any of the three trimesters. A convenience sample was drawn from those members of the population who belonged to DES Action USA, and who subscribed to the quarterly newsletter DES Action Voice. The DES Action is an international group (consisting of local chapters) made up of volunteers dedicated to identifying DES-exposed persons, assisting them in finding appropriate care, and providing such counseling and

referrals as are available. The sample consisted of literate, English-speaking women who voluntarily responded to the self-administered questionnnaire published in the DES Action Voice, Issue 31, and who mailed back the questionnaire.

DES daughters associated with DES Action were selected as a sample for the study, as this group knows of their DES exposure, were most representative of daughters highly interested in their condition, and typify self-care agents. The sample for the study was self-selected. It was speculated that, if a problem in health care was identified in this group of DES daughters who had taken action to gain control and knowledge of their condition, there exists a high probability that there was a problem in the DES-daughters' population as a whole. The sample selected for the study is likely to represent a group biased toward seeking care. Publishing the questionnaire in the DES Action Voice provided a means by which to collect data on a sample of DES daughters who were receiving care from a variety of health care providers throughout the United States, therefore not limiting it to one specific geographical area.

A nonprobability sample was utilized for its convenience and economical advantages. Probability sampling would be more representative of the population, but such sampling for this population would require a great deal of resources and time; therefore, such an option was not available at that time.

In accordance with the DES Action International liaison consultant, 2,058 copies of DES Action Voice, Issue 31 had been mailed directly to subscribers. DES Action's figure for identified daughters of the 2,058 publications mailed in the United States was quoted as

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826; however, this was not an exact count as the subscriber was coded as a DES daughter only when she so identified herself, thus the count could be higher.

A self-selection bias may exist in this study. The sample may represent a group biased toward seeking care as the voluntary respondents were generally active, motivated, and concerned females. Thus, there is a possibility that the sample for this study may differ in the extent to which it cannot be said to represent the population.

A total of 679 questionnaires was received; of those, 670 questionnaires were relevant for the sample used in this study. Of those samples not entered into the study, three consisted of women who lived in other countries, such as Israel, Switzerland, and Australia. DES Action is international and has chapters in Australia, Canada, and the Netherlands, as well as the U.S.A. Three of the questionnaires were late responses and were received after the data was entered into the computer. One questionnaire was returned unanswered with the notation "DES son". The remaining two questionnaires were returned with notations that the questionnaire did not apply to them since they received surgery (i.e., hysterectomy) prior to care received since 1978.

The questionnaire developed for the purpose of this study was based upon the guidelines set by the 1985 DES Task Force in reference to recommended health care for DES daughters. The recommended health care was measured as the components of screening procedures specified by the 1985 DES Task Force. Each screening procedure was addressed as a question(s) in the questionnaire (see Appendix D). Respondents were given additional space to make comments if they so chose.

Close-ended questions were presented in Likert-type questions, yes/no questions, and pre-established alternative questions. Open-ended questions were also used to elicit additional information. This information when analyzed was listed and then placed into categories as appropriate, so that this data could be used in statistical analysis procedures and with other variables in overall scoring.

The questionnaire objectives were:

- - To determine current health practices utilized by DES daughters.
- - To determine current health care received by DES daughters.
- - To identify respondent's socioeconomic characteristics.

Data Handling

Respondents mailed the completed questionnaires to a post office box. Completed questionnaires were first coded by the researcher onto predesigned numbered coding sheets. Once all of the questionnaires were coded onto the form, the results were then entered onto a floppy disk via a personal computer using EDLIN. Once all the data were entered using EDLIN, the data were uploaded from the floppy disk to the IBM mainframe at Michigan State University. A printout of the data file was then made and a careful case-by-case verification between the data file and coding sheets was performed. Mistakes were corrected and appropriate statistical runs completed.

Operational Definitions

Recommended Health Care

Recommended health care was defined as the screening procedure advocated by the DES Task Force for daughters exposed in utero. Recommended health care was divided into seven areas (subquestions)

which were operationalized as: initiation of periodic screening examinations, screening procedure, examination schedule, indication for more frequent screening examinations, use of colposcopy, use of biopsies, and breast examination (see Appendix E for a listing of specific questions in the questionnaire that were used to evaluate each of the seven areas, subquestions, that comprise recommended health care).

Initiation of Periodic Screening Examinations

Initiation of periodic screening examinations was defined as the first screening examination done for those DES daughters who were told of their exposure during puberty. This initial screening examination should have been done beginning at age 14 or at the onset of menses (whichever was earlier). Once the initial examination was done, periodic screening examinations were to be done minimally once a year. Adherence to this guideline was measured by responses to Questions 4, 7, 9, 21.

Screening Procedures

Screening procedures were defined as procedures performed at each DES daughter's examination which minimally included a pelvic examination, cytology test, and iodine solution for cervical and vaginal staining. Appropriate screening procedures were evaluated by responses to Question 13.

Examination Schedule

The examination schedule states that DES daughters were being examined at least once a year. The frequency of DES examinations was evaluated by responses to Questions 9 and 11.

Indication for More Frequent Examinations

To monitor if more frequent examinations were done for women with extensive atypical epithelial changes, responses to Questions 11 and 12 were evaluated.

Use of Colposcopy

The use of a colposcopy was not to be a routine procedure at every DES examination but used only in specific circumstances, such as an abnormal cytology, extensive or widespread epithelial changes, or in the initial examination (for baseline data). To monitor if a colposcopy was being utilized in all cases where abnormal cytology was observed, response to Question 17 was evaluated. To monitor if a colposcopy was being utilized in cases of extensive or widespread epithelial changes, response to Question 18 was evaluated. To monitor if a colposcopy was being utilized in the initial examination (for baseline data), the response to Question 8 was evaluated.

Use of Biopsies

The use of a biopsy was not to be a routine procedure at every DES examination, but used only in specific circumstances when indicated by abnormal Pap tests, and when there was other evidence of significant epithelial abnormalities. To monitor if a biopsy was being utilized when indicated by abnormal Pap tests, the response to Question 17 was evaluated. To monitor if biopsies were being performed when there was evidence of significant epithelial abnormalities, the response to Question 18 was evaluated.

Breast Examination

The frequency of breast examinations of DES daughters was defined in accordance with the current National Cancer Institute guidelines

(U.S. Department of Health and Human Services, 1986). Adherence to breast examinations was evaluated by responses to Questions 22, 23, 24.

Modifying Factors

Modifying factors were those sociodemographic and general background questions which characterize the nature of the sample. Modifying factors were identified by the DES daughters' responses to Questions 1, 2, 3, 5, 6, 19, 20, 25, 26, 27, 28, 29, 30, 31.

Scoring

The subquestions were used once the questionnaires were coded as decision variables. The respondents were required to meet a combination of responses to fulfill each subquestion criteria. Nominal measurement of met and not met was used. If a respondent met the subquestion criteria, she was assigned a "1", otherwise a "0". For example, subquestion 2 assessed whether DES daughters were receiving the appropriate screening procedure at each examination which minimally included a thorough pelvic examination, cytology test, and cervical and vaginal iodine staining. In the questionnaire, Question 13 was used to answer subquestion 2. In order for the respondent to be assigned a "1", she must have answered "always" to each of the procedures routinely being done at her DES examinations (i.e., pelvic examination, Pap smear, and iodine staining).

Once this scoring procedure was used for all subquestions, it was determined how many subquestion criteria each respondent met. The sum of these scores provided an answer to the question: To what extent do DES daughters receive the health care recommended by the Federal Government's DES Task Force?

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Reliability and Validity

The reliability of an instrument reflects the degree of consistency or accuracy with which an instrument measures an attribute. The internal consistency or homogeneity aspect of reliability of the self-administered questionnaire used in this study was ascertained by the coefficient alpha (Cronbach's alpha method). This technique was employed on Question 13 which dealt with the procedures which were done routinely at each DES examination. Coefficient alpha produced a reliability coefficient that estimated the extent to which the subparts of the instrument (i.e., pelvic examination, Pap smear, iodine staining, colposcopy, and biopsy) are equivalent in terms of measuring the critical attribute, recommended health care.

The purpose of a reliability test, with respect to the items in Question 13, is to find out if the procedures addressed in the questionnaire tend to be performed together at DES examinations, or if there are certain groups of procedures typically performed together. The range of values for coefficient alpha is between 0.00 and +1.00, the higher values reflecting a higher degree of internal consistency. Coefficient alpha was 0.71.

Validity of an instrument was defined by Polit and Hungler (1983) as "the degree to which an instrument measures what it is supposed to be measuring" (p. 394). In this study, content validity is the most pertinent.

Content validity was concerned with the sampling adequacy of the content area being measured (Polit & Hungler, 1983). That is, how representative were the questions compared with all questions that

might be asked on this topic? Since there were no objective methods for measuring content validity (Polit & Hungler, 1983), content validity could be judged to be adequate by examining the methods used to develop the questions on the instrument. In this study, experts in the content area were called upon to analyze the items to see if they adequately represented the content universe. The formulation and selection of questions for inclusion in the instrument were based upon a thorough review of the literature and set guidelines by the DES Task Force.

Analysis of Data

Several statistical techniques were used to analyze the data: frequency distributions, percentages, measures of central tendency, chi-square, cross tabulations and correlations. Each subquestion was analyzed using frequency distribution, percentages, and measures of central tendency.

Statistical procedures used on the socioeconomic data included frequency distributions, percentages and means. Cross tabulations and correlations between socioeconomic variables, as well as between these variables and variables in the subquestions, were made.

In Chapter V, a presentation of the findings obtained in this study will be made. Tables will be used to aid in illustrating the results of this data.

Protection of Human Rights

The rights of the respondents were protected through adherence to established standard criteria set forth by the University Committee on Research Involving the use of Human Subjects (UCRIHS) and also by approval of representatives of DES Action. Approval of the human

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rights protection procedures was granted by UCRIHS on November 19, 1986 (see Appendix F). Approval by the DES Action Research Committee was also granted for inclusion of the questionnaire in DES Action Voice.

A brief explanation of the research study and objective, voluntary participation, time involved in participation, instructions, and assurances of anonymity were provided in an explanation at the beginning of the self-administered questionnaire. Confidentiality and anonymity were maintained as the reasearcher did not have access to the names of respondents, as the DES Action group mailed the Voice in which the questionnaire was included. The questionnaire was returned to a rented-Post Office box. Since there was no access to the names of respondents, follow-up of returned questionnaires was not possible.

Summary

The proposed research design has been described. The data gained by the survey research will aid in the identification of potential deficiencies in health practices of DES daughters. Data analysis will be presented in Chapter V, followed by implications of the study results and recommendations for further research as proposed in Chapter VI.

CHAPTER V

DATA PRESENTATION AND ANALYSIS

Overview

The purpose of this study was to examine the extent to which DES daughters receive the health care recommended by the Federal Government's DES Task Force. In this chapter, data which describe the study sample and address the research question will be presented. Additional descriptive data, although not directly related to the study variables, will be presented to broaden the description of the sample. Data pertaining to the research question are based on the scores generated for compliance with predetermined criteria associated with each subquestion.

Several statistical techniques were used to analyze the data: frequency distributions, percentages, measures of central tendency, chi-square, cross tabulations, and correlations. The data will be presented as follows: descriptive data pertaining to the sample, and descriptive and inferential data pertaining to the research question. Presentation of the data is the focus of this chapter, while an interpretation of the results of the statistical analyses and summary are presented in Chapter VI.

Data from the 670 DES daughters were used to answer the following research question: To what extent do DES daughters receive the health care recommended by the Federal Government's DES Task Force?

Subquestions

1. For those DES daughters who were told of their exposure during puberty, are periodic screening examinations being done beginning at age 14 or at the onset of menses (whichever is earlier)?

2. Are DES daughters receiving the appropriate screening procedure at each examination which minimally includes a thorough pelvic examination using palpation, cytology test, and tissue inspection including the use of one-half strength aqueous Lugol's solution for cervical and vaginal staining?

3. Are DES daughters being examined at least once a year?

4. Are more frequent examinations being done for women with extensive atypical epithelial changes?

5. Is colposcopy being utilized in:
   a. all cases where abnormal cytology (Pap smear) is observed?
   b. cases of extensive or widespread epithelial changes (such as, squamous metaplasia)?
   c. the initial examination (for baseline data)?

6. Are biopsies being performed only:
   a. when indicated by abnormal Pap tests?
   b. when there is other evidence of significant epithelial abnormalities?

7. Are breast examinations of DES daughters being performed according to the current National Cancer Institute (NCI) guidelines regarding the frequency of screening examinations?

Descriptive Findings of the Study Sample

Sociodemographic Variables

The sociodemographic variables examined in the present study were age, race, education, marital status, family income, state of residence, health insurance coverage, verification of DES exposure, and how informed of exposure.

Age. The age of the study participants ranged from 16 to 40; this is congruent with the definition of DES daughters utilized in the present study. The mean age of the subjects was 31.7 years. The age distribution and percentages are illustrated in Table 1.

Table 1. Number and Percentage of Participants by Age (n = 668).

Age	Number of Responses	Percentage
16-19	14	2.1
20-23	27	4.0
24-27	43	6.4
28-31	190	28.5
32-35	275	41.2
36-40	119	17.8
	668*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

Race. The majority of participants in this study, 662 (99.0%), were white. The remaining participants in this study consisted of: 2 (0.3%) black, 1 (0.1%) American Indian, and 4 (0.6%) other.

Education. The majority of participants in this study, 665 (99.3%), were high school graduates and of these, 481 (72.3%) had a four-year college degree or higher. The mean educational level of the sample was 16.4 years. The number and percentage of the DES daughters by years of education can be seen in Table 2.

Table 2. Number and Percentage of Participants by Years of Education (n = 670).

Years of Education	Number of Responses	Percentage
High School		
10	1	0.1
11	4	0.6
12	40	6.0
College		
13	46	6.9
14	65	9.7
15	33	4.9
16	181	27.0
Graduate School		
17	67	10.0
18	107	16.0
19	40	6.0
20+	86	12.8
	670	100.0

Marital Status. The distribution and percentage of DES daughters by marital status may be seen in Table 3. Of the women in this study, 468 (70.0%) were married.

Table 3. Number and Percentage of Participants by Marital Status (n = 670).

Marital Status	Number of Responses	Percentage
Single	163	24.3
Married	468	70.0
Separated	9	1.3
Divorced	29	4.3
Widowed	1	0.1
	670	100.0

Family Income. Yearly total family income was obtained from 653 respondents. The distribution and percentage of respondents according to income can be seen in Table 4. Of the women responding, 525 (80.4%) reported a family income of $25,000 and above, and of these, 281 (43.0%) had a total family income of $50,000 or more.

Table 4. Number and Percentage of Participants by Yearly Family Income (n = 653).

Income	Number of Responses	Percentage
Less than $9,999	15	2.3
$10,000 - $14,999	17	2.6
$15,000 - $19,999	30	4.6
$20,000 - $24,999	66	10.1
$25,000 - $49,999	244	37.4
$50,000 or more	281	43.0
	653*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

Health Insurance. In this sample, 657 (98.2%) of DES-exposed daughters have health insurance and of these, 479 (72.9%) have health insurance that covers their DES examinations.

State of Residence. Of the sample in this study, 165 (24.6%) were from the Pacific Coast States, 158 (23.6%) from the Middle Atlantic States, 125 (18.7%) from Midwestern States, 105 (15.7%) from Southern States, 62 (9.2%) from New England States, 38 (5.7%) from Southwestern States, 12 (1.8%) from Rocky Mountain States, and 5 (0.7%) from Alaska and Hawaii. Refer to Table 5 for the distribution and percentage of participants by state of residence.

Verified Exposure. Of the 669 participants in the study who responded to DES-exposure verification, 590 (88.2%) reported that they knew for sure they were a DES daughter, 79 (11.8%) reported they thought they were exposed, but it was not verified by medical records. When asked if they had ever tried to obtain medical records to verify DES exposure, 453 (67.7%) responded "yes".

Informed of Exposure. How the DES daughter was informed that she was exposed to DES was ascertained for each participant in the study. The number and percentage of participants according to the manner in which they were informed of their DES exposure is included in Table 6. The majority of participants in the study, 436 (65.1%) were informed of their DES exposure by their mother.

Summary of Sociodemographic Variables

Descriptive findings about the study population were presented in the previous section. The description of the sample included the following sociodemographic variables: age, race, education, marital status, family income, state of residence, health insurance coverage,

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Descriptive findings about the study population were presented in the previous section. The description of the sample included the following sociodemographic variables: age, race, education, marital status, family income, state of residence, health insurance coverage,

Table 5. Number and Percentage of Participants by State of Residence (n = 670).

Region/State		Number of Responses	Percentage
New England States:	Connecticut	21	3.1
	Maine	3	0.4
	Massachusetts	33	4.9
	New Hampshire	3	0.4
	Rhode Island	1	0.1
	Vermont	1	0.1
Middle Atlantic States:	New Jersey	38	5.7
	New York	87	13.0
	Pennsylvania	33	4.9
Southern States:	Delaware	1	0.1
	District of Columbia	7	1.0
	Florida	13	1.9
	Georgia	15	2.2
	Kentucky	1	0.1
	Louisiana	3	0.4
	Maryland	26	3.9
	North Carolina	11	1.6
	South Carolina	1	0.1
	Tennessee	5	0.7
	Virginia	20	3.0
	West Virginia	2	0.3
Midwestern States:	Illinois	18	2.7
	Indiana	2	0.3
	Iowa	8	1.2
	Kansas	7	1.0
	Michigan	31	4.6
	Minnesota	18	2.7
	Missouri	6	0.9
	Nebraska	3	0.4
	North Dakota	1	0.1
	Ohio	21	3.1
	Wisconsin	10	1.5
Rocky Mountain States:	Colorado	8	1.2
	Montana	2	0.3
	Nevada	1	0.1
	Utah	1	0.1
Southwestern States:	Arizona	5	0.7
	New Mexico	2	0.3
	Oklahoma	1	0.1
	Texas	30	4.5
Pacific Coast States:	California	143	21.3
	Oregon	8	1.2
	Washington	14	2.1
Alaska		4	0.6
Hawaii		1	0.1
		670	100.0

Table 6. Number and Percentage of Participants by Manner in Which Informed of DES Exposure (n = 670).

Informed By	Number of Responses	Percentage
Letter or Phone Call	38	5.7
Mother	436	65.1
Physical Examination Diagnosis	159	23.7
Father	7	1.0
Relative (Other than Mother or Father)	5	0.7
Personal Inquiry	16	2.4
News Media	9	1.4
	670	100.0

verified DES exposure, and how informed of exposure. An examination of the descriptive statistics showed that the majority of subjects in the sample consisted of white, middle to upper class, college-educated, married females who were covered by health insurance.

Extraneous Variables

Sociodemographic variables were cited as extraneous variables in the study. Multiple regression revealed that there was no significant relationship between how often a DES daughter sees a health care provider for DES examinations and her educational level, total family income, health insurance, age, and marital status.

Data Presentation for Research Question and Subquestions

Subquestion 1

For those DES daughters who were told of their exposure during puberty, are periodic screening examinations being done beginning

at age 14 or at the onset of menses (whichever is earlier)?

The mean age at which the DES daughters in this sample learned they were exposed was 20.5 years. Of the sample (n = 667), 80 (12.0%) respondents learned they were a DES daughter at 14 years of age or younger.

Of the sample (n = 665), 640 (96.2%) DES daughters had a first DES screening examination. Of those daughters who stated the age at which they received their first DES screening examination (n = 623), 54 (8.7%) had had their first DES screening examination at 14 years or younger. The mean age of those who had their first DES screening examination was 21.2 years. In this study, 528 (83.1%) DES daughters reported having a screening examination done at least once a year once they had their first DES screening examination (n = 635).

Of the sample (n = 669), 666 (99.6%) had or previously had a menstrual period. The mean age at which this sample started menses was 12.8 years. Of the 80 (12.0%) DES daughters who were told of their exposure during puberty, 23 (30.3%) had periodic screening examinations done beginning at age 14 or at the onset of menses (whichever came earlier).

Subquestion 2

Are DES daughters receiving the appropriate screening procedure at each examination which minimally includes a thorough pelvic examination using palpation, cytology test, and tissue inspection including the use of one-half strength aqueous Lugol's solution for cervical and vaginal staining?

In this study, 599 (95.5%) DES daughters reported having a pelvic examination at each DES screening examination (n = 627); 621 (97.3%)

reported having a Pap smear (n = 638); and 144 (24.7%) reported always having iodine staining (n = 583). The distribution and percentage of participants according to each particular procedure and frequency of this procedure is illustrated in Tables 7-9. Only 133 (20.8%) DES daughters in this study who had DES screening examinations (n = 640) were receiving the appropriate screening procedure at each examination which minimally included a pelvic examination, cytology test and tissue inspection which included iodine staining of cervical and vaginal tissues.

Table 7. Number and Percentage of Participants by Frequency of Pelvic Examinations at DES Screening Examinations (n = 627).

Frequency of Pelvic Examination	Number of Responses	Percentage
Always	599	95.5
Sometimes	18	2.9
Never	1	0.2
Don't Know	9	1.4
	627*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

Table 8. Number and Percentage of Participants by Frequency of Pap Smears at DES Screening Examinations (n = 638).

Frequency of Pap Smear	Number of Responses	Percentage
Always	621	97.3
Sometimes	14	2.2
Never	2	0.3
Don't Know	1	0.2
	638*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

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Frequency of Pelvic Examination	Number of Responses	Percentage
Always	599	95.5
Sometimes	18	2.9
Never	1	0.2
Don't Know	9	1.4
	627*	100.0

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Frequency of Pap Smear	Number of Responses	Percentage
Always	621	97.3
Sometimes	14	2.2
Never	2	0.3
Don't Know	1	0.2
	638*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

Table 9. Number and Percentage of Participants by Frequency of Iodine Stainings at DES Screening Examinations (n = 583).

Frequency of Iodine Staining	Number of Responses	Percentage
Always	144	24.7
Sometimes	233	40.0
Never	126	21.6
Don't Know	80	13.7
	583*	100.0

* Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

Subquestion 3

Are DES daughters being examined at least once a year?

In this study (n = 643), 15 (2.3%) DES daughters are presently seeing a health care provider for DES examinations more often than every six months, 276 (42.9%) every six months, 312 (48.5%) once a year, 26 (4.0%) more than one year apart, 7 (1.1%) erratic, and 7 (1.1%) reported they no longer see a health care provider for DES examinations. In this study (n = 635), 528 (83.1%) DES daughters reported that they had a screening examination done at least once a year after they had their first DES examination.

Subquestion 4

Are more frequent examinations being done for women with extensive atypical epithelial changes?

Of those women who were currently seeing a health care provider more than once a year, the following reasons (indicative of extensive

atypical epithelial changes) were reported: 110 (21.7%) - abnormal Pap smear, 42 (8.2%) - results of iodine staining, 88 (17.3%) - results of colposcopy, 54 (10.6%) - results of biopsy, 12 (2.4%) - adenosis, and 14 (2.8%) for follow-up (i.e., carcinoma in situ, past history of cancer, hysterectomy). Refer to Table 10. Of those DES daughters who stated they were seeing a health care provider every six months or more frequent than every six months, one of the above-stated reasons was given in 320 (63.0%) of 508 reasons given. In this study (n = 664), 399 (60.1%) DES daughters had been told by their health care provider that they had had changes in their vaginal lining/tissue (i.e., epithelial changes, dysplasia, adenosis). Of the entire sample (n = 670), 175 (26.1%) DES daughters were receiving examinations more frequent than once a year for extensive atypical epithelial changes.

Subquestion 5

Is colposcopy being utilized in:

a. all cases where abnormal cytology (Pap smear) is observed?

b. cases of extensive or widespread epithelial changes (such as, squamous metaplasia)?

c. the initial examination (for baseline data)?

Colposcopies were not utilized in all cases where abnormal Pap smears were observed. An abnormal Pap smear had been reported in 280 (42.3%) DES daughters in this study (n = 662). Of those females, 26 (9.3%) reported a colpscopy in all cases where abnormal cytology was observed.

Changes in the vaginal lining/tissue have been reported by 399 (60.1%) DES daughters in this study (n = 664). Of these females, 62 (15.5%) reported a colposcopy being utilized in cases where extensive

Table 10. Number and Percentage by Reason for Seeing Health Care Provider More Than Once a Year (n = 508).

Reason	Number of Responses	Percentage
Abnormal Pap Smear	110	21.7
Results of Iodine Staining	42	8.2
Results of Colposcopy	88	17.3
Results of Biopsy	54	10.6
Adenosis	12	2.4
Endometriosis	8	1.6
Estrogen Replacement Therapy/Menopause	4	0.8
Followup — carcinoma-in-situ	14	2.8
General GYN Problems*	25	4.9
Infertility	35	6.9
Monitoring of DES Exposure	75	14.8
Other Health Problems (other than GYN related)	5	1.0
Personal Preference/Concern	21	4.1
Prenatal Care	15	2.9
	508**	100.0

* PMS, menstrual cramps, cervicitis, ovarian cyst, cervical stenosis, ovarian dysfunction, uterine polyps, fibroid growth, cervical scarring, cervical growths, STD (i.e., herpes type II, condyloma), vaginal bleeding, recurrent vaginitis

** Variation between the study sample (n = 670) and the total number of responses is due to "no answer" responses.

or widespread epithelial changes were observed. The mean age of the DES daughters who reported abnormal Pap smears and changes in vaginal lining/tissue was 28.8 years and 28.5 years of age respectively.

A colposcopy was utilized in the initial DES examination for baseline data in 480 (77.7%) of the sample (n = 618). Of those females in the sample who reported ever having a DES screening examination (n = 640), 480 (75%) reported a colpscopy being done on their first or second DES examination.

Subquestion 6

Are biopsies being performed only:

a. when indicated by abnormal Pap tests?

b. when there is other evidence of significant epithelial abnormalities?

Of the 280 (42.3%) DES daughters who reported abnormal Pap smears (n = 662), 18 (6.4%) reported a biopsy being performed when indicated by abnormal cytology. Of the 399 (60.1%) DES daughters who reported a change in vaginal lining/tissue (n = 664), 29 (7.3%) reported a biopsy being performed where there was evidence of significant epithelial abnormalities.

Subquestion 7

Are breast examinations of DES daughters being performed according to the current National Cancer Institute guidelines regarding the frequency of screening examinations?

Of the sample in the study (n = 670), 184 (27.5%) reported performing BSE monthly; 396 (59.1%) reported not performing BSE routinely (but check on occasion); 87 (13.0%) reported not doing BSE monthly; and 3 (0.4%) did not answer the question. In the sample (n = 670), 616 (91.9%) reported that the DES daughter's health care provider examined her breasts at least once a year; 30 (4.5%) reported not routinely once a year; 21 (3.1%) reported that their health care

provider did not examine their breasts once a year; and 3 (0.4%) did not reply to this question.

A mammography has been performed at least once in 158 (23.7%) of the sample (n = 667). The age at which these women received a mammography ranged from 18 to 40 years. The mean age of the first mammography was 30.7 years, and 31.7 years and 36.3 years for additional mammographies respectively. The number and percentage of participants by age when mammography was performed was reported in Table 11.

Table 11. Number and Percentage of Participants by Age When Mammography was Performed.

Age	Number of Responses			Percentage		
	*I	**II	***III	I	II	III
Less than 20	6	0	0	3.9	0.0	0.0
20 - 24	18	1	0	11.7	6.2	0.0
25 - 29	29	3	0	19.0	18.8	0.0
30 - 34	52	8	0	34.0	50.0	0.0
35 - 40	48	4	3	31.4	25.0	100.0
	153+	16	3	100.0	100.0	100.0

*First Mammography (n = 153)

**Second Mammography (n = 16)

***Third Mammography (n = 3)

+Variation between the number who stated that they had a mammography done (n = 158) and the number of reponses by age when mammography was performed is due to "no answer" respones to age.

provider did not examine their breasts once a year; and 3 (0.4%) did not reply to this question.

A mammography has been performed at least once in 158 (23.7%) of the sample (n = 667). The age at which these women received a mammography ranged from 18 to 40 years. The mean age of the first mammography was 30.7 years, and 31.7 years and 36.3 years for additional mammographies respectively. The number and percentage of participants by age when mammography was performed was reported in Table 11.

Table 11. Number and Percentage of Participants by Age When Mammography was Performed.

Age	Number of Responses *I	**II	***III	Percentage I	II	III
Less than 20	6	0	0	3.9	0.0	0.0
20 - 24	18	1	0	11.7	6.2	0.0
25 - 29	29	3	0	19.0	18.8	0.0
30 - 34	52	8	0	34.0	50.0	0.0
35 - 40	48	4	3	31.4	25.0	100.0
	153+	16	3	100.0	100.0	100.0

*First Mammography (n = 153)

**Second Mammography (n = 16)

***Third Mammography (n = 3)

+Variation between the number who stated that they had a mammography done (n = 158) and the number of reponses by age when mammography was performed is due to "no answer" respones to age.

The three leading reasons for having a first mammography done were reported as: for baseline, fibrocystic breast disease, and suspicious lump, which was reported as 42 (26.9%), 39 (25.0%), and 36 (23.1%) respectively. Of the women who had more than one mammography done, fibrocystic breast disease was the reason given in 10 (58.8%) of those women who had a second mammography, and 2 (50.0%) of those who had a third mammography. The distribution and percentage of participants by reason for mammography can be seen in Table 12.

Table 12. Number and Percentage by Reason for Mammography.

Reason	Number of Responses			Percentage		
	*I	**II	***III	I	II	III
Baseline	42	0	0	27.1	0.0	0.0
Breast Discharge/Pain	15	1	0	9.7	5.9	0.0
DES Exposure	3	0	0	1.9	0.0	0.0
Employment Physical	1	0	0	0.6	0.0	0.0
Enlarged Lymph Node	2	0	0	1.3	0.0	0.0
Fibrocystic Breast Disease	39	10	2	25.2	58.8	50.0
Family History of Cancer	8	1	1	5.2	5.9	25.0
Personal Preference	3	1	0	1.9	5.9	0.0
Recommended by Physician	6	0	0	3.9	0.0	0.0
Suspicious Lump	36	4	1	23.2	23.5	25.0
	155+	17	4	100.0	100.0	100.0

*First Mammography (n = 155)

**Second Mammography (n = 17)

***Third Mammography (n = 4)

+Variation between the number who stated that they had a mammography done (n = 158) and the number of responses by reason why mammography is due to "no answer" responses to reason.

Breast examinations of DES daughters were being performed according to the current National Cancer Institute guidelines regarding the frequency of screening examinations in 146 (21.9%) of this sample.

Research Question

To what extent do DES daughters receive the health care recommended by the Federal Government's DES Task Force?

To answer the overall research question, the study sample was first broken down into eight groups according to a combination of three characteristics: whether the daughters found out about their exposure during puberty, whether they had experienced an abnormal Pap smear, and/or whether they had experienced epithelial changes. Each group had relevant subquestions that described what health care needed to be received by the DES daughters to conform to the Federal Government's DES Task Force recommendations. Refer to Appendix E.

The number and combination of relevant subquestions differed for each of these groups of DES daughters. For example, women who learned of their exposure during puberty and who did not experience an abnormal Pap smear or epithelial changes were referred to as Group 1. Women who learned of their exposure during puberty and who had an abnormal Pap smear but did not experience epithelial changes were referred to as Group 2. Group 1 had 5 subquestions which were relevant to the health care they were to receive to comply with their DES exposure, whereas Group 2 had 8 subquestions that applied. Therefore, to understand what extent of recommended health care they were receiving, each group was analyzed individually before an overall extent could be accurately determined for the sample (n = 670).

Of the DES daughters comprising Group 1 (n = 17), 10 (58.9%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 7 (41.1%) received less than 50.0%, as shown in Table 13. Of the DES daughters comprising Group 2 (n = 2), 2 (100.0%) received less than 50.0% of the health care recommended by the Federal Government's DES Task Force, as shown in Table 14.

Table 13. Number and Percentage of Group 1 Participants by Extent of Recommended Health Care Met (n = 17).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 5	0.0	-	0.0
1 of 5	20.0	3	17.6
2 of 5	40.0	4	23.5
3 of 5	60.0	8	47.1
4 of 5	80.0	2	11.8
5 of 5	100.0	-	0.0
		17	100.0

Group 3 consisted of DES daughters who learned of their exposure during puberty who did not have an abnormal Pap smear but did have epithelial changes. Of the DES daughters comprising this group (n = 22), 8 (36.4%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 14 (63.6%) received less than 50.0%, as shown in Table 15.

Table 14. Number and Percentage of Group 2 Participants by Extent of Recommended Health Care Met (n = 2).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 8	0.0	-	0.0
1 of 8	12.5	-	0.0
2 of 8	25.0	1	50.0
3 of 8	37.5	1	50.0
4 of 8	50.0	-	0.0
5 of 8	62.5	-	0.0
6 of 8	75.0	-	0.0
7 of 8	87.5	-	0.0
8 of 8	100.0	-	0.0
		2	100.0

Table 15. Number and Percentage of Group 3 Participants by Extent of Recommended Health Care Met (n = 22).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 8	0.0	-	0.0
1 of 8	12.5	1	4.5
2 of 8	25.0	5	22.7
3 of 8	37.5	8	36.4
4 of 8	50.0	6	27.3
5 of 8	62.5	2	9.1
6 of 8	75.0	-	0.0
7 of 8	87.5	-	0.0
8 of 8	100.0	-	0.0
		22	100.0

Group 4 consisted of DES daughters who learned of their exposure during puberty who had an abnormal Pap smear and had epithelial changes. Of the DES daughters comprising this group (n = 25), 25 (100.0%) received less than 50.0% of the health care recommended by the Federal Government's DES Task Force, as shown in Table 16.

Table 16. Number and Percentage of Group 4 Participants by Extent of Recommended Health Care Met (n = 25).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 10	0.0	-	0.0
1 of 10	10.0	1	4.0
2 of 10	20.0	8	32.0
3 of 10	30.0	13	52.0
4 of 10	40.0	3	12.0
5 of 10	50.0	-	0.0
6 of 10	60.0	-	0.0
7 of 10	70.0	-	0.0
8 of 10	80.0	-	0.0
9 of 10	90.0	-	0.0
10 of 10	100.0	-	0.0
		25	100.0

Group 5 consisted of DES daughters who learned of their exposure after puberty and did not have an abnormal Pap smear or epithelial changes. Of the DES daughters comprising this group (n = 95), 49 (51.6%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 46 (48.4%) received less than 50.0%, as shown in Table 17.

Table 17. Number and Percentage of Group 5 Participants by Extent of Recommended Health Care Met (n = 95).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 4	0.0	14	14.7
1 of 4	25.0	32	33.7
2 of 4	50.0	36	37.9
3 of 4	75.0	13	13.7
4 of 4	100.0	-	0.0
		95	100.0

Group 6 consisted of DES daughters who learned of their exposure after puberty and had an abnormal Pap smear but not epithelial changes. Of the DES daughters comprising this group (n = 30), 1 (3.3%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 29 (96.7%) received less than 50.0%, as shown in Table 18.

Table 18. Number and Percentage of Group 6 Participants by Extent of Recommended Health Care Met (n = 30).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 7	0.0	4	13.4
1 of 7	14.3	6	20.0
2 of 7	28.6	10	33.3
3 of 7	42.9	9	30.0
4 of 7	57.2	1	3.3
5 of 7	71.5	-	0.0
6 of 7	85.8	-	0.0
7 of 7	100.0	-	0.0
		30	100.0

Group 7 consisted of DES daughters who learned of their exposure after puberty and did not have an abnormal Pap Smear but did have epithelial changes. Of the DES daughters comprising this group (n = 113), 13 (11.5%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 100 (88.5%) received less than 50.0%, as shown in Table 19.

Table 19. Number and Percentage of Group 7 Participants by Extent of Recommended Health Care Met (n = 113).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 7	0.0	4	3.5
1 of 7	14.3	18	15.9
2 of 7	28.6	41	36.3
3 of 7	42.9	37	32.8
4 of 7	57.2	9	8.0
5 of 7	71.5	4	3.5
6 of 7	85.8	-	0.0
7 of 7	100.0	-	0.0
		113	100.0

Group 8 consisted of DES daughters who learned of their exposure after puberty and had an abnormal Pap smear and had epithelial changes. Of the DES daughters comprising this group (n = 199), 32 (16.0%) received 50.0% or more of the health care recommended by the Federal Government's DES Task Force, and 167 (84.0%) received less than 50.0%, as shown in Table 20.

Table 20. Number and Percentage of Group 8 Participants by Extent of Recommended Health Care Met (n = 199).

Number of Criteria Met	Percent of Criteria Met	Frequency	Percent of Sample
0 of 9	0.0	8	4.0
1 of 9	11.1	20	10.1
2 of 9	22.2	49	24.6
3 of 9	33.3	60	30.2
4 of 9	44.4	30	15.1
5 of 9	55.5	15	7.5
6 of 9	66.6	8	4.0
7 of 9	77.7	5	2.5
8 of 9	88.8	4	2.0
9 of 9	100.0	-	0.0
		199	100.0

In accordance with the Federal Government's DES Task Force, the extent of health care received by the sample in this study (n = 503) is reported as: 113 (22.4%) received 50.0% or more of the recommended health care, and 390 (77.6%) received less than 50.0% of the recommended health care. Of the sample, 30 (6.8%) did not receive any of the recommended health care; 0 (0.0%) met all of the recommended health care. Refer to Table 21 for the extent of recommended health care met. There were 167 DES daughters who were not accounted for in the final determination of the extent of recommended health care met, due to omitting answers to questions in the questionnaire that were critical in determining whether or not a specific aspect of her health care was received.

Table 21. Number and Percentage of DES Daughters in the Study by Extent of Recommended Health Care Met (n = 503)

Percent of Recommended Health Care	Frequency	Percent of Sample
0.0 - 25.0	174	34.7
26.0 - 50.0	258	51.2
51.0 - 75.0	60	11.9
76.0 - 100.0	11	2.2
	503	100.0

Summary of Research Question and Subquestions

Data presentation of the research question and subquestions was described in the previous section. In summary, of the DES daughters who were told of their exposure during puberty, 30.3% had periodic screening examinations done beginning at age 14 or at the onset of menses (whichever came earlier). Only 20.8% of DES daughters in this study who had DES screening examinations were receiving the appropriate screening procedure at each examination which minimally included a pelvic examination, cytology test, and tissue inspection which included iodine staining of cervical and vaginal tissues. In this study, 93.7% of DES daughters reported that they were presently seeing a health care provider for DES examinations at least once a year, and 83.1% of DES daughters reported having a screening examination done at least once a year after having their first examination. Of those DES daughters who were told by their health care provider that they had had changes in their vaginal lining/tissue, 26.1% were receiving more frequent examinations for extensive atypical epithelial changes. A colposcopy was utilized in

9.3% of DES daughters in all cases where abnormal cytology was observed. A colposcoppy was utilized in 15.5% of cases where extensive or widespread epithelial changes were observed. A colposcopy was utilized in the initial DES examination for baseline data in 77.7% of the sample. A biopsy was performed in 6.4% of DES daughters when indicated by abnormal Pap tests. Of the daughters who reported a change in vaginal lining/tissue, 7.3% reported a biopsy was performed where there was evidence of significant epithelial abnormalities. Breast examinations of DES daughters were being performed according to the current NCI guidelines regarding the frequency of screening examinations in 21.9% of this sample. In this study sample, it was determined that less than 25% of DES daughters were receiving 50.0% or more of the recommended health care in accordance with the Federal Government's DES Task Force guidelines.

Summary

In this section, data results and analyses were presented. In Chapter VI, a summary and interpretation of findings, and implications for nursing practice and education along with recommendations for future research will be presented.

CHAPTER VI

SUMMARY, INTERPRETATIONS, AND RECOMMENDATIONS

Overview

A summary and interpretation of the findings are presented in Chapter VI. This summary and interpretation include a discussion of the sociodemographic characteristics of the study sample and how these variables may have influenced the outcome of the study. Findings of the research question and subquestions are discussed. No reference to the findings of previous research studies will be made in the discussion due to lack of research in this area. Thus, no studies exist to refute or support the findings of the study. Limitations of the present study are cited, and implications of the study for nursing practice, education, and future research are presented. A review of the previous chapters is now being presented.

Review of Previous Chapters

In 1971, after 24 years in the drug marketplace, DES was banned in the United States for use in pregnancy. This once thought of "miracle drug" used in preventing miscarriages was now linked to vaginal cancer. The dissemination of DES left a large portion of the population exposed to the effects of this drug, including not only the women who initially took DES but their offspring and possibly subsequent generations to follow.

In response to the DES problem, the DES Task Force was formed. The Task Forces's mission was to review all aspects of the DES problem, to make recommendations for health care of the exposed, and to research directions for medical researchers. From these findings,

recommendations for screening procedures of the DES-exposed population were established.

The purpose of this research was to ascertain the extent to which DES daughters receive the health care recommended by the Federal Government's DES Task Force. Analysis of data indicated that 77.6% of the study sample received less than 50.0% of the recommended health care in accordance with the Federal Government's DES Task Force recommendations.

The goal of this study was to provide a description of the characteristics of female offspring exposed to DES in utero, and to describe the pattern and type of health care received specific in monitoring the potential effects of DES exposure in utero. This study was purely descriptive research and thus was not intended to explain why the recommended health care was or was not being obtained. The results of this study are intended to stimulate further interest in this area.

Summary and Interpretation of Findings

Sociodemographic Characteristics of the Study Sample

A summary of the sociodemographic characteristics of the study sample and comparison of these characteristics to the general population, where applicable, will be presented. Sociodemographic characteristics of the participants in this study may have affected the outcome of the study by influencing their behaviors and attitudes. The women in this sample were primarily white, highly educated and above average socioeconomically. The daughter's perceptions of the importance of health, perceived control, access to health care, and

perceived benefits to engage in health-promoting behaviors may vary between women of different socioeconomic and educational levels. The manner in which the sociodemographic variables could have influenced the results of the study will be presented in the discussion of findings for the research question.

The mean age of the study participants was 31.7 years, with a range from 16 to 40. This range is consistent with the definition of DES daughter. The inclusion of only female participants was inherent in the study design. The 1985 U.S. Census reports 47.8% of the female population range in age from 14 to 44 (U.S. Bureau of the Census, 1986, p. 14).

The majority of women in the study were white (99.0%). The remaining participants were: 0.3% black, 0.1% American Indian, and 0.6% other (i.e., Jewish and Asian). According to the 1985 U.S. Census, 83.7% of women between the ages of 15 and 44 were white; 13.0% were black; and 3.3% were other (U.S. Bureau of the Census, 1986, p. 18). Therefore, there was a larger proportion of whites in the present study than in the general population.

The majority of participants (99.3%) were high school graduates and of these, 72.3% had a four-year college degree or higher. According to the 1985 U.S. Census, in the general population for females 25 years of age or older, 41.3% were high school graduates and of these, 16.0% had four or more years of college (U.S. Bureau of the Census, 1986, p. 122). Therefore, the educational level attained in the study sample was higher than the educational level attained in the general population.

The majority of DES daughters in the study were married (70.0%), 24.3% single, 4.3% divorced, 1.3% separated, and 0.1% widowed. The 1985 U.S. Census reported the following percentages of marital status categories for females over 18 years of age: married, 60.5%; single, 18.2%; divorced, 8.7%; and widowed, 12.6% (U.S. Bureau of the Census, 1986, p. 38). Thus, the study sample had a higher percentage of married and single women, and less widowed and divorced women in comparison to the general population. Due to the relatively young sample, the same widow status would not be expected.

A total family income of $25,000 and above was reported in 80.4% of the study sample and of these, 43.0% had a total family income of $50,000 or more. The 1985 U.S. Census reported the median family income in the United States according to age of householder as: 15-24 years, $15,049; 25-34 years, $25,085; and 35-44 years, $31,066. Of the U.S. population 47.6% had a total family income of $25,000 and above and of these, 14.8% had a total family income of $50,000 or more (U.S. Bureau of the Census, 1986, p. 432). Therefore, the median family income for the study population was higher than the median family income for the general population.

The study sample represented care received in 45 states throughout the country. Of the sample in this study, 24.6% were from the Pacific Coast States, 23.6% from the Middle Atlantic States, 18.7% from the Midwestern States, 15.7% from the Southern States, 9.2% from the New England States, 5.7% from the Southwestern States; 1.8% from the Rocky Mountain States, and 0.7% from Alaska and Hawaii. A large percentage of the sample in the study were from California (21.3%) and New York (13.0%). The DES Action's west coast headquarters is located

in California and the east coast headquarters is located in New York. This, as well as the large population in these states, may have contributed to the response rate in these two states.

In summary, the sample in the present study was composed primarily of white, married women with a high school or greater educational attainment, and with a family income exceeding the median family income for the general population. No correlation between social class and rate of DES exposure was found in the literature. It may be hypothesized that DES exposure is a primarily middle-class phenomenon. DES was mainly given to women who were seen in private practice or clinic settings who were receiving the "best" prenatal care at the time. Thus, the women who obtained this health care were most likely from the middle to upper class. Therefore, it may be correct in assuming the majority of DES-exposed daughters in the United States today are white, middle or upper class, and college educated.

Other possible explanations why the DES daughters in this sample were primarily white, highly educated, and above average socioeconomically may include: women from the lower socioeconomical class did not seek or have access to prenatal care during the period when DES was being given to pregnant women; black women may have not received the standard of care or sought access to prenatal care; the black mother may have received DES but there are no known entities; another possible explanation to this phenomenon is that the majority of women who subscribe to the DES Voice are white, middle to upper class females. Thus, the characteristics of the study sample may or may not affect the applicability of the results of this study to the

general DES population. However, there is no data on the DES daughter with which to compare.

Extraneous Variables

Multiple regression revealed there was no significant relationship between the dependent variable, how often a DES daughter sees a health care provider for DES examinations, and the independent variables which consisted of the DES daughters' educational level, total family income, health insurance, age, and marital status. No significant relationship was shown as the dependent variable did not demonstrate a significant variation in examination frequency; 42.6% saw a health care provider for DES examinations every six months and 48.5% once a year which consisted of the majority of daughters seeing a health care provider at least once a year. Thus, there is insufficient variation in the dependent variable resulting in the independent variables showing low bivariate variation.

Also, correlation between independent variables was not significant and is due to the homogenous group or lack of sufficient variation in this study sample. Therefore, the multiple regression results could not be used to understand the effects of the extraneous variables on the dependent variable, as there was not sufficient variation between the dependent variable or variation between the independent variables to provide a significant relationship.

Research Questions and Subquestions

In the present study, the results of seven subquestions were utilized in answering the overall research question. To answer the overall research question, the study sample was divided into eight groups according to a combination of three characteristics: whether

general DES population. However, there is no data on the DES daughter with which to compare.

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Research Questions and Subquestions

In the present study, the results of seven subquestions were utilized in answering the overall research question. To answer the overall research question, the study sample was divided into eight groups according to a combination of three characteristics: whether

the daughters found out about their exposure during puberty; whether they had experienced an abnormal Pap smear; and/or whether they had experienced other epithelial changes (i.e., changes in vaginal lining/tissue). The number and combination of relevant subquestions that described what health care needed to be received by the DES daughters to conform to the Federal Government's DES Task Force recommendations differed for each of these groups of DES daughters (see Appendix G). The findings will be discussed in the following section.

It must be reiterated that some DES daughters were not accounted for in the final determination of the extent of recommended health care met, due to omitting answers to questions in the questionnaire that were critical in determining whether or not a specific aspect of her health care was received. Thus, only valid cases were included in the analyses.

The women comprising Groups 1 - 4 were DES daughters who learned of their exposure during puberty. The terms "during puberty" and "after puberty" were referenced in this study. Fourteen years of age is used to delineate the upper limit of puberty in this study; therefore, "after puberty" referred to women who learned of their exposure at 15 years of age or older. This age was chosen in accordance with the DES Task Force recommendation that periodic screening examinations should begin at age 14 or at the onset of menses whichever was earlier. The study sample consisted of 80 (11.9%) DES daughters who learned of their exposure during puberty. The number of participants in Groups 1 - 4 consisted of 66 DES daughters. Comprising the remainder of the study sample were

Groups 5 - 8 consisting of women who learned of their DES exposure after puberty.

Group 1: Women who learned of their exposure during puberty and who did not experience an abnormal Pap smear or other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising Group 1 (n = 17), 58.9% received 50% or more of the health care recommended by the Federal Government's DES Task Force. Five criteria were used to establish the extent to which the DES daughters in Group 1 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 1 were: 35.3% received a periodic screening examination beginning at age 14 or at the onset of menses whichever was earlier; 45.5% received the appropriate screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 94.1% received an examination at least once a year; 81.3% had a colposcopy during their initial examination for baseline data; and breast examinations were performed in 18.8% according to the current NCI guidelines regarding frequency of screening examinations.

Group 2: Women who learned of their exposure during puberty and who did experience an abnormal Pap smear but did not experience other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising Group 2 (n = 2), neither of these DES daughters received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Eight criteria were used to establish the extent to which the DES daughters in Group 2 received

the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 2 were: none received a periodic screening examination beginning at age 14 or at the onset of menses whichever was earlier. One of the two in the sample received the appropriate procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining). One of the two was examined at least once a year. More frequent examinations were done for women with extensive atypical epithelial changes in one DES daughter in this sample. Data were missing in regards to colposcopy utilization for this group. Biopsies were not performed in this group when indicated by abnormal Pap smears. In neither of the DES daughters comprising this group were breast examinations performed according to the current NCI guidelines regarding frequency of screening examinations.

Group 3: Women who learned of their exposure during puberty and who did not experience an abnormal Pap smear but did experience epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising this group (n = 22), 36.4% received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Eight criteria were used to establish the extent to which the DES daughters in Group 3 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 3 were: 35.0% received a periodic screening examination beginning at age 14 or at the onset of menses whichever was earlier; 62.5% received the appropriate

screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 95.5% received an examination at least once a year; 33.3% received more frequent examinations as a result of experiencing extensive atypical epithelial changes; 14.3% had a colposcopy as a result of experiencing extensive or widespread epithelial changes); 81.8% received a colposcopy during their initial examination for baseline data; 8.3% received biopsies when indicated by other evidence of significant epithelial abnormalities; and breast examinations were performed in 23.8% according to current NCI guidelines regarding frequency of screening examinations.

Group 4: Women who learned of their exposure during puberty and who did experience an abnormal Pap smear and other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising this group (n = 25), none received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Ten criteria were used to establish the extent to which the DES daughters in Group 4 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 4 were: 21.7% received a periodic screening examination beginning at age 14 or at the onset of menses whichever was earlier; 36.4% received the appropriate screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 92.0% received an examination at least once a year; 55.6% received more frequent examinations as a result of experiencing extensive atypical epithelial changes; 37.5% received a colposcopy as a result of experiencing

extensive or widespread epithelial changes; none of Group 4 received a colposcopy when indicated by an abnormal Pap smear; 70.8% received a colposcopy during their initial examination for baseline data; no biopsies were performed in this group when indicated by abnormal Pap smears or when indicated by other evidence of significant epithelial abnormalities; breast examinations were performed in 8.0% according to current NCI guidelines regarding frequency of screening examinations.

Group 5: Women who learned of their exposure after puberty and who did not experience an abnormal Pap smear or other epithelial changes (i.e., changes in the vaginal lining/tissue).

Of the DES daughters comprising Group 5 (n = 95), 51.6% received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Four criteria were used to establish the extent to which the DES daughters in Group 5 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 5 were: 18.3% received the appropriate screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 65.5% received an examination at least once a year; 72.0% received a colposcopy during their initial examination for baseline data; and breast examinations were performed in 18.9% according to the current NCI guidelines regarding frequency of screening examinations.

Group 6: Women who learned of their exposure after puberty and who did experience an abnormal Pap smear but did not experience other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising Group 6 (n = 30), 3.3% received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Seven criteria were used to establish the extent to which the DES daughters in Group 6 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 6 were: 13.3% received the appropriate screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 65.4% received an examination at least once a year; 42.3% received more frequent examinations as a result of experiencing extensive atypical epithelial changes; none of Group 6 received a colposcopy when indicated by an abnormal Pap smear; 74.1% received a colposcopy during their initial examinations for baseline data; none of Group 6 received a biopsy when indicated by an abnormal Pap smear; and breast examinations were performed in 23.3% according to the current NCI guidelines regarding frequency of screening examinations.

Group 7: Women who learned of their exposure after puberty and who did not experience an abnormal Pap smear but did experience other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising Group 7 (n = 113), 11.5% received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Seven criteria were used to establish the extent to which the DES daughters in Group 7 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 7 were: 30.1% received the appropriate screening procedure at each examination (i.e., minimally

included a pelvic examination, cytology test, and iodine staining); 78.4% received an examination at least once a year; 23.1% received more frequent examinations as a result of experiencing extensive atypical epithelial changes; 57.7% received a colposcopy as a result of experiencing extensive or widespread epithelial changes; 80.7% received a colposcopy during their initial examination for baseline data; 8.5% received biopsies when indicated by evidence of significant epithelial abnormalities; and breast examinations were performed in 21.4% according to current NCI guidelines regarding frequency of screening examinations.

Group 8: Women who learned of their exposure after puberty and who did experience an abnormal Pap smear and other epithelial changes (i.e., changes in vaginal lining/tissue).

Of the DES daughters comprising Group 8 (n = 199), 16.0% received 50.0% or more of the health care recommended by the Federal Government's DES Task Force. Nine criteria were used to establish the extent to which the DES daughters in Group 7 received the health care recommended by the Federal Government's DES Task Force.

The results of the criteria for Group 8 were: 25.5% received the appropriate screening procedure at each examination (i.e., minimally included a pelvic examination, cytology test, and iodine staining); 87.5% received an examination at least once a year; 58.2% received more frequent examinations as a result of experiencing extensive atypical epithelial changes; 31.3% received a colposcopy when indicated by an abnormal Pap smear; 55.1% received a colposcopy as a result of experiencing extensive or widespread epithelial changes; 77.7% received a colposcopy during their initial examination for

baseline data; 18.0% received a biopsy when indicated by an abnormal Pap smear; 30.4% received a biopsy when indicated by other evidence of significant epithelial abnormalities; and breast examinations were performed in 23.6% according to current NCI guidelines regarding frequency of screening examinations.

Interpretation of Group Subquestions

In summary, the study sample was divided into eight groups based upon a combination of whether the daughters found out about their exposure during puberty; whether they had experienced an abnormal Pap smear; and/or whether they had experienced other epithelial changes (i.e., changes in vaginal lining/tissue). Each group was analyzed according to relevant subquestions that described the health care needed to be received to conform to the Federal Government's DES Task Force recommendations. Once a percentage describing the extent to which each group of DES daughters received the health care recommended by the Federal Government's DES Task Force, the extent was calculated for the entire study sample.

In the previous section, the relevant criteria for each group were described according to the extent to which they were met. Patterns in criteria met and not met across the groups could be ascertained.

For those DES daughters who were told of their exposure during puberty, periodic screening examinations were not being done beginning at age 14 or at the onset of menses (whichever was earlier). The researcher feels a reason for this may be that the mother did not want to bring her daughter for an examination which is normally initiated later in the teens or after becoming sexually active. This may be

that the mother felt guilty about exposing her child to DES, fear of the unknown, and/or feelings that her child was becoming a woman. The DES daughter at this age was not responsible for initiating her health care.

Overall, it appeared that the daughters who were told of their exposure during puberty were more likely to receive appropriate screening procedures at each examination, as well as to have an examination at least once a year. A speculation into the reason for this occurence is that DES daughters between the ages of 19 and 24 have been reported as having an increased occurrence of adenocarcinoma of the cervix, and therefore are being monitored more closely during this time. Reinforcement of the importance of the DES screening examination and familiarity with the screening procedure are occurring at an earlier age. Therefore, this DES daughter may be more likely to continue to receive examinations at least once a year, and be more likely to receive appropriate screening procedures at each examination due to her previous health care behaviors and expectations, and her knowledge of DES. Repetition of the behavior will reinforce and strenghten her beliefs in the benefits to be gained.

More frequent examinations are being done for women with extensive atypical epithelial changes in both groups of women (i.e., those who found out about their DES exposure during puberty and those who found out about their DES exposure after puberty) who have both an abnormal Pap smear and changes in the vaginal lining/tissue. The researcher feels that the health care provider may not stress the importance of more frequent examinations (i.e., more than once a year) for women who have an abnormal Pap smear as this is a common finding

in DES daughters. It is not until changes in the vaginal lining/tissue occurs with an abnormal Pap smear that credence is given to following the DES daughter more closely. Also, the DES daughter may be re-assured by her health care provider that abnormal Pap smears occur frequently in DES daughters and "not to worry about it". Therefore, the importance of more frequent examinations may not be advocated by her health care provider or the importance of follow-up is not reinforced.

The use of colposcopy and biopsy was utilized in a low percentage of the women who reported an abnormal Pap smear. However, the colposcopy and biopsy were utilized in a higher percentage of DES daughters who experienced both an abnormal Pap smear and had evidence of other epithelial changes, and who found out about their exposure after puberty. Again, the researcher feels this may be due to the frequency of abnormal Pap smears in the DES-exposed female and lack of concern of the health care provider for further follow-up. Also, lack of equipment (i.e., colposcope) in the health care provider's office may contribute to the lack of this procedure when indicated.

The colposcopy was utilized in 70.8% to 81.8% of the DES daughters in this sample. The high utilization of the colposcopy may have been due to high media recognition of the use of the colposcope in the initial screening of DES daughters. The cost of this procedure may contribute to the colposcopy not being used routinely in subsequent visits when indicated by abnormal Pap smears or epithelial changes.

Thus, the lack of recommended health care in the above-stated areas (i.e., Subquestions 1 - 6) may be attributed to the health care

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providers', as well as the DES daughters', lack of knowledge regarding the DES Task Force recommended health care; cost of procedures; lack of necessary equipment (i.e., colposcopy); lack of skills to perform further examination; or lack of referral to a health care provider knowledgeable regarding DES examinations. The extent to which breast examinations (Subquestion 7) were performed according to NCI guidelines will now be discussed.

Across all the groups, the extent to which breast examinations were performed according to the current NCI guidelines regarding the frequency of screening examinations was low, ranging from 0.0% to 23.7%. Possible explanations why a low percentage of DES daughters met the criteria for breast examinations include: the psychological stress/anxiety associated with the possibility of discovering an abnormal lump through BSE; lack of knowledge regarding BSE techniques; lack of confidence in ones examination abilities; lack of instruction for when and how to perform BSE; lack of reinforcement by health care provider; health care provider's concentration on the other aspects of the DES examination; amount of time required by a health care provider for a complete DES examination; health care provider's use of ACS versus NCI guidelines regarding mammography use; and the DES daughter's lack of knowledge of the use of mammography as advocated by the DES Task Force.

The frequency of BSE and health care provider breast examinations was used in assessing frequency of breast examinations in accordance with NCI guidelines. Also, whether or not a mammography had been performed for screening versus diagnostic reasons was ascertained.

NCI guidelines for use of mammography were used by the DES Task Force to establish recommended health care for the DES daughter.

The NCI does not recommend a mammography to be used routinely as a screening method for women under age 50. Since the benefit of screening women under 50 years of age is not yet clear, the NCI does not recommend mammography as a part of an annual examination for women under age 50 who are not in a high-risk group. According to the NCI, the three high-risk categories are: women age 50 or more, women age 40 or more with a family history of breast cancer, and women age 35 or more with a personal history of breast cancer (U.S. Department of Health and Human Services, August 1986, p. 5).

In this study, for the DES daughter to be considered as meeting the criteria for appropriate health care in regards to breast examinations, the woman must: perform monthly BSE; her provider must perform breast examinations at every DES screening examination; and a mammography was to be performed for screening only when the woman is in a high-risk group or the mammography was used as a diagnostic procedure for women who have symptoms or findings associated with the presence of breast cancer. Thus in this study, if a mammography had been performed for screening and the woman did not classify as high risk according to the NCI guidelines, the woman was considered not meeting the criteria for appropriate health care in regards to breast examinations as the use of mammography for screening was not in accordance with the NCI standards. However, if a mammography had been performed for a diagnostic reason, and the BSE and health care provider breast examination were in accordance with NCI guidelines, the woman was considered as meeting the criteria for appropriate

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health care even though she was not classified as high risk for screening according to NCI guidelines.

Although the 1985 DES Task Force has recommended the NCI guidelines for breast examinations for DES daughters, health care providers may use other standards in their practices, especially regarding use of mammographies. Some health care providers may recommend routine examination with mammography for women who are not in the three NCI high-risk groups because they feel it is effective in finding early breast cancers.

Medical associations advocate a variation in guidelines regarding the frequency and use of mammography. The following are examples of policies established by various medical organizations:

> The American Cancer Society recommends: "a baseline mammogram between ages 35 and 40. Between 40 and 49, mammography at one- to two-year intervals. Women over age 50 should have a mammogram every year."
>
> The American College of Obstetricians and Gynecologists mammography statement says that women: "over the age of 50 should receive regular breast examinations including mammography at intervals to be determined by the physician. For women between the ages of 35 and 50, it is recommended that a 'baseline' mammogram be done in connection with a clinical physical examination. From the results of this baseline evaluation and other examinations, the physician should determine the frequency of mammography."
>
> The American College of Radiology mammography policy states: "For asymptomatic women the first, or baseline,

mammograms should be obtained by age 40. An earlier age is preferable when there is a personal history of breast cancer or a history of premenopausal breast cancer in the patient's mother and/or sisters. Subsequent mammographic examinations should be performed at one- to two-year intervals determined by the combined analysis of physical and mammographic findings and other risk factors, unless medically indicated sooner. Annual mammography and physical examination are recommended for all women over age 50."

Each of these policy statements is intended to guide the physician. The policies can be expected to be modified as new information is obtained from research. The final decision regarding screening, of course, should be made on an individual basis. (U.S. Department of Health and Human Services, August 1986, pp. 6-8)

Thus the use of mammography, as an aspect in the criteria dealing with breast examinations of DES daughters, could have affected the extent to which breast examinations of DES daughters were being performed according to the NCI guidelines regarding the frequency of screening examinations. The health care provider's beliefs guide his/her standards of practice regarding breast examinations.

In the near future, the DES daughters may be identified as a high-risk group and thus require mammographies at an earlier age. Health care providers, as well as the self-care agents, should keep abreast on the most current NCI guidelines that direct DES care.

In summary, there is a deficit in the extent of health care received by DES daughters in accordance with the Federal Government's

DES Task Force recommendations. A severe deficit may be present in the DES population if it is believed that this sample represents a group biased toward seeking care and are considered most representative of daughters highly interested in their condition and typify self-care agents. If this sample is representative of well-informed, highly activated women and they are not receiving the standards of DES care, are the remainder of DES daughters receiving the DES care as advocated by the DES Task Force?

Additional Findings

A cross tabulation, of the frequency to which a health care provider answers questions a DES daughter has regarding her DES exposure by whether or not the DES daughter was satisfied with the health care provider who administers her DES health care, was performed. The cross tabulation indicated that when the health care provider "always" answered questions, 66.6% of DES daughters were satisfied with their health care provider; when their health care provider "almost always" answered questions 25.7% were satisfied; when their health care provider "sometimes" answered questions 6.3% were satisfied; when their health care provider "rarely" answered questions 1.4% of DES daughters were satisfied; and no DES daughters indicated they were satisfied when the health care provider "never" answered questions. In the study sample, 87.2% (n = 659) reported that they were satisfied with their health care provider. Therefore, a factor that contributes to client satisfaction is the ability to communicate with the health care provider.

A cross tabulation, between whether or not a screening examination was done at least once a year and whether or not the DES

daughter was satisifed with the health care provider who administers her DES health care, was made. The cross tabulation indicated that a screening examination was done at least once a year to 86.6% of the DES daughters who were satisfied with their health care provider, and a screening examination was done at least once a year to 62.7% of the DES daughters who were not satisifed with their health care provider. Thus, client satisfaction may be a significant determinant of compliance.

The DES daughter, who is satisfied with her health care provider, is more likely to receive a screening examination at least once a year than the DES daughter who is not satisfied with her health care provider. A determinant of client satisfaction is related to the ability and consistency to which the health care provider answers the DES daughter's questions.

In this study, 93.7% received a screening procedure at least once a year regardless of whether or not they were satisfied with their health care provider, and less than 25.0% of DES daughters were receiving 50.0% or more of the DES Task Force recommended health care. The client satisfied with her health care provider is more likely to go for examinations at least once a year, but it is not accurate to assume that this group of women, because they go for examinations at least once a year, will receive the care recommended by the DES Task Force at these DES screening examinations. Lack of knowledge of DES recommended care by the health care provider and/or DES daughter, and lack of provider's skills and/or equipment to perform a screening examination will affect the extent to which the DES daughter receives the health care recommended by the Federal Government's DES Task Force.

Limitations of the Study

In addition to the limitations cited in Chapter I, the following limitations have been identified which may have affected the results of this study:

1. The formation of the subquestions used to answer the overall research question and create the questionnaire, as well as the criteria used for scoring, was based upon the researcher's understanding and interpretation of the 1985 DES Task Force guidelines in regards to screening procedures for the DES daughter.
2. The DES-exposed Daughter Health Care Questionnaire did not address the aspect of screening procedures in regards to "Exposed daughters and their families should have adequate explanation and consideration of the physical and emotional aspects of this examination" (U.S. Department of Health and Human Services, 1985, p. 22). This area could encompass a questionnaire or interview in and of itself.
3. Another aspect of screening procedures not dealt with in the questionnaire referred to the BSE technique used by the DES daughter in the present study. The breast examination of DES daughters should conform with current NCI guidelines. The frequency of screening examinations was determined, but the BSE technique used was not examined. This analysis may have been helpful in determining if the DES daughter is conforming to the overall NCI guidelines in regards to breast examinations.
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4. Some study participants did not answer questions that applied to them. By not answering key questions that were used in scoring,

some of the participants were eliminated when calculating the overall extent to which DES daughters received the health care recommended by the Federal Government's DES Task Force.

5. The answers to open-ended questions resulted in a variety of responses which in turn had to be categorized by the researcher into manageable groups. The category into which the response was placed was the interpretation of the researcher without validation of this from the respondent.
6. A disadvantage of the mailed questionnaire used in this study was the inability to provide clarification of questions when needed.
7. Questions dealing with specific examination schedules in the questionnaire may have been difficult for the respondent to answer due to the frequency and variation of examination schedules over multiple years. Therefore, responses may need to be divided into specific time frames.
8. A nonprobability sample was utilized for its convenience and economical advantages. Probability sampling would have been more representative of the population. The DES population was difficult to access due to patients' rights, lawsuits, and lack of knowledge that they were DES-exposed.
9. The sample for this study was made up of predominantly white, middle to upper class females, whose educational level and total family income were above the general population. It must also be reiterated that the sample in this study may represent a group biased toward seeking care. These women knew of their DES exposure, were most representative of daughters highly interested in their condition, and typify self-care agents. Thus, the study

sample may differ in the extent to which it can be said to represent the DES female population.

In summary, the limitations discussed in this section encompass those factors that need to be considered when developing a methodology for future research and also may influence how results can be interpreted. Additional limitations regarding the instrument are discussed in the replication of study section.

Implications for Nursing

In this section, the implications of the study for nursing practice, education, and future research will be presented. These ramifications will be discussed within the conceptual framework designed for this study (see Figure 1, p. 17).

Implications for Nursing Practice

In this study, the DES daughter is viewed as a holistic, interacting, and interdependent being with bio-psycho-socio-spiritual dimensions possessing inherent worth and dignity. The DES daughter is a dynamic being who is continually in the process of growth and change. The DES daughter exchanges information with her environment as she receives input and responds with behavioral outputs. The DES daughter chooses to engage in given behaviors from a range of options based on her perceptions of the behaviors and of the options available to her.

Health of the DES daughter is described as her state of wholeness or integrity. The DES daughter's physical, psychological, interpersonal, and social aspects of health are inseparable. When the DES daughter experiences an interruption in her state of health, she calls upon the health care system to intervene in assisting her to

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restore equilibrium and achieve her own health potential. The health care system must in part assume responsibility for promoting, protecting, restoring, and maintaining the health of society's members. The DES daughter is an integral member and the focus of the health care system. The DES daughter has the right to participate in the determination of the level of health that she will attain or maintain.

The nurse, as a member of the health care team, intervenes when the DES daughter's ability to adapt is impaired or at risk of impairment (i.e., potential self-care deficit). The nurse is concerned with health promotion, prevention of, or care during diminished or depleted health states and assistance toward achievement of optimal health. Thus, the goal of nursing is to facilitate adaptation of the DES daughter toward her optimal health, and increase her self-care competencies.

The nurse must assess the client's knowledge of DES recommended health care, as well as her problem-solving skills and degree of self-care motivation. The nurse must also evaluate the DES daughter's degree of self-direction and control of her learning experiences that will have an impact on her achieving the recommended health care. Her degree of self-care competencies influence her self-care abilities and behaviors. It is her inability to initiate self-care that requires the intervention of health care professionals.

The nurse assists the DES daughter in evaluating her previous health care behaviors and expectations and how these behavior and expectations are affecting her current health care practices. Also, the nurse assists the DES daughter to develop problem-solving skills

and coping strategies to deal with the effects of her exposure. The nurse assists the DES daughter in becoming educated on the physiological effects and risks of prenatal exposure to DES; also, the nurse informs the DES daughter of the DES Task Force recommended health care for the DES-exposed daughter. The knowledge gained by the DES daughter will increase her self-care competencies. The nurse to achieve this goal interacts interdependently with the client and other members of the health care team.

In practice, the nurse is to facilitate primary health care to the DES population using the nursing process. The nurse will, if appropriate, have the initial contact of the DES daughter with the health care system. The nurse should assume responsibility and accountability for the coordination, integration, and continuing management of the DES daughter's total health care and services. Longitudinal care and follow-up of the DES daughter need to be provided.

The nurse gathers data regarding the functioning of the DES daughter. The nurse then identifies problems or needs of the DES daughter in terms of whether she lacks knowledge, capacity, or will to adapt. Positive health care related to DES exposure includes adherence to the DES Task Force recommended health care criteria: in knowledge of understanding of DES exposure, management, and treatment options.

The nurse plans strategies with the DES daughter to assist her in achieving the recommended health care and maintaining her optimal level of health. Strategies may include: developing an outline of the DES Task Force recommended health care in a format that allows the

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The nurse plans strategies with the DES daughter to assist her in achieving the recommended health care and maintaining her optimal level of health. Strategies may include: developing an outline of the DES Task Force recommended health care in a format that allows the

DES daughter to keep a record of the health care received and results of the screening examination. This log will be kept current, thus enabling the DES daughter to monitor the care she is receiving and facilitate adherence to recommended health care. Additional strategies include: educating the DES daughter on the resources available in the community (i.e., DES-support group); reviewing and reinforcing BSE techniques with a breast model; and providing a visit for the DES daughter and/or her family for questions and concerns dealing with her DES exposure.

The nurse evaluates with the DES daughter the degree of adaptation achieved, and whether further application of the process needs to be employed. Throughout the nursing process, the nurse validates and plans with the DES daughter the nature and direction of intervention taken for her behalf.

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management of care regarding a DES daughter. The CNS knowledgeable about recommended screening examinations regarding the DES-exposed female may present literature/findings (i.e., 1985 DES Task Force Recommendations) to the individual with a differing philosophy.

In order for the CNS to function effectively, the client, as well as other members of the health care team, must be familiar with the role of the CNS. The CNS needs to define as well as to defend this role. How a CNS defines his/her limits and organizes his/her practice determine the degree of freedom and success of a given CNS.

The CNS with his/her clinical expertise could assume responsibility in performing the entire DES screening examination if additional training and certification to perform this examination were acquired. The researcher feels additional assessment courses and certification are needed if the CNS is to perform screening examinations, and that abnormalities should be immediately referred to a physician knowledgeable in DES care. The CNS should continue to coordinate the DES daughter's care and collaborate with the referred physician. The above-stated conditions are also relevant to the nurse midwife.

The CNS may be called upon to counsel DES daughters regarding infertility and/or pregnancy problems. The CNS must be familiar with infertility and the options and resources available for infertile couples. Today's reproductive technology provide the possibility of artificial insemination and in vitro fertilization. The CNS must be comfortable with the complex medical, ethical, social, and legal implications of artificial insemination and in vitro fertilization. The CNS should be aware of community resources to which these couples

can be referred for further assistance. Also, the CNS should be aware of the possibility that the DES daughter may experience grieving due to her inability to bear a genetic child.

> Anxiety may result from documentation of DES exposure without sufficient information about its significance or sequelae. Many exposed women are worried about their sexual self-image and reproductive capabilities and fear the development of cancer. Any genital tract changes, e.g. adenosis, may cause undue concern unless the benign natures of the changes are explained. Therefore, it is important that sufficient time be allocated to provide information and to answer questions, responses to which must be appropriate to the age of the person and expressed in terms she can understand. Written materials, such as descriptions of the examination or drawings of changes associated with exposure, can be given to the patient when she arrives for her appointment, thereby allowing her time to prepare questions. (U. S. Department of Health and Human Services, November 1983, p. 9)

It is imperative that the CNS understands how his/her practice either hinders or helps health-related behaviors of the DES daughter. The DES daughter must be given the opportunity and responsibility for making decisions regarding the management of her health care. Increased compliance may be seen when the health care provider has invested time and energy into the care of the DES daughter and her family in a way that has developed trust, rapport, and a sense of continuity to the plan of care. The clinician must engage in teaching centered around the health maintenance aspect related to this study

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(i.e., DES Task Force recommended health care and BSE techniques). Such anticipatory guidance with each client encountered should begin with the initial contact and be reinforced with subsequent visits. Thus, time for exchange of information and exploration of the DES daughter's concerns are made available.

The CNS when providing care to the DES daughter must incorporate BSE instructions as well as a thorough breast examination. In this study, breast examinations were performed in 21.9% according to current NCI guidelines regarding the frequency of screening examinations. The DES daughter should be instructed regarding BSE techniques, as well as when to perform BSE. The importance of BSE and reinforcement of proper BSE techniques by the health care provider should be incorporated into each DES screening examination. The DES daughter should be aware of the most current NCI guidelines regarding frequency and technique of breast examinations and use of mammography.

The DES daughter's increased knowledge of the DES Task Force recommended health care and BSE techniques will result in the DES daughter gaining confidence in managing her health care and in practicing monthly BSE. Thus, the DES daughter's increased self-care competencies may result in increased compliance to the DES Task Force recommended health care.

A CNS must acquire personal and professional credibility. One way credibility can be established is by "word of mouth" of satisfied clients who have used the CNS's services in the past for non-related DES health problems, DES health care, or counseling. The CNS must be seen as an expert and trusted member of the health care team. Trust

is an inherent characteristic for effective team functioning. This takes time and effort; it will not be obtained overnight.

In advanced practice, marketing is a strategy professionals can utilize to become recognized and to develop clientele. Being able to sell oneself as a CNS is imperative to his/her success and ability to obtain personal and professional goals. Marketing skills must be added to the inherent characteristics of a CNS. A marketing plan and specific strategies should be developed. The CNS whose focus is in women's health can use his/her marketing skills to assist the DES-exposed female in the quest for positive health care. Public speaking has many outcomes: informational, needs assessments, public relations, increased community knowledge and awareness, and support for existing and/or new programs. Public speaking can be used by the CNS in marketing his/her skills. The DES issue could be incorporated into a health series for and about women. These programs could be sponsored by centers for women's health, hospitals, or community awareness groups with the CNS presenting: the health risks due to prenatal exposure; the DES Task Force recommended health care; and resources available in the community for these women. The CNS could also incorporate speaking engagements for nursing colleagues and other health care professions.

The leadership abilities of the CNS will contribute to the DES daughter acquiring the recommended health care as advocated by the DES Task Force. In this study, 84.0% received less than 50.0% of the health care recommended by the Federal Government's DES Task Force. Action to decrease this deficit of care must be taken in a planned, purposeful, and deliberate manner. The CNS needs to identify possible

reasons (i.e., lack of knowledge of health professionals and/or DES daughters, or lack of equipment and/or provider's skills in DES-related care) and implement problem-solving methods with the help of other health professionals.

The DES daughter is not receiving the recommended health care as advocated by the 1985 DES Task Force. The health care provider knowledgeable about DES needs to educate not only the client about the effects of DES exposure and recommended health care, but also needs to educate uninformed colleagues, and set up specific follow-up. Also, protocol for DES care in accordance with 1985 DES Task Force recommendations must be established for all health care settings.

The CNS should be familiar with resources and DES specialists in the community to whom referral for specialized health care can be made. Many health care providers are not familiar with the DES issue, and therefore are unable to provide the quality care the DES daughter requires. Of the insured DES daughters in the study, 27.1% had health insurance which did not cover DES examinations, thus making knowledge of resources for this group of daughters vital.

The CNS needs to be aware of the DES issue in order to provide comprehensive quality care to the female population. The CNS must keep current on new developments in DES research and changes in recommended health care. DES has affected not only the women who took it and the offspring exposed to DES in utero, but possibly the third generation as well. Therefore, careful screening by health professionals must be performed to identify women exposed to DES.

It should become a standard practice for nurses at all levels to ascertain from females within the age range of possible DES exposure

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whether there is a possibility that they have been exposed to DES in utero. Since many of the DES-exposed offspring are mostly asymptomatic, the first problem consists of finding these clients. This information can be obtained in a variety of health care settings (i.e., private physician's office, clinic, hospital, or health fair). Until the public becomes more fully aware of the DES issue, it is imperative that all possible avenues for dissemination of information and screening of the general population are made.

A special questionnaire should be created and included in the medical chart to screen for DES exposure. If at all possible, the DES-exposed client and her mother should be questioned. A careful history should be taken that includes documentation of medicine taken; if possible, this information should include the type, dosage, and duration of treatment. The health care provider, when taking a history and is informed that the female's mother had a history of miscarriages, troubled pregnancies, or spotting, should be alerted to the fact that the client may have been exposed to DES. Since many females do not know of their exposure, the health care provider must be alert to such clues.

The CNS may also become involved in establishing and/or supporting public media campaigns. This could be accomplished by the CNS who is knowledgeable about DES appearing on radio or television talk shows; screening and educating at health fairs; actively participating and supporting "DES Awareness Week"; publishing of DES-related articles and research findings in medical and nursing journals, as well as women's magazines; speaking at hospital and clinic inservices; and participating in nursing seminars. The

researcher of this study would report the large deficit in recommended health care of the DES daughter, and emphasize the 1985 DES Task Force recommended guidelines. Women's lay literature (i.e., women's magazines, newspaper articles, and women's newletters) could be used to disseminate information on the DES issue to women of all age, ethnic, and socioeconomic groups. Information in women's lay literature would be distributed throughout the country. For the CNS, the challenge is providing information on the DES issue to health care colleagues, as well as to the public in a way that is both realistic yet nonthreatening.

The CNS should be aware of policies which might be instigated in support of organizational, economic, and environmental factors having the potential to modify health behavior. The CNS should actively support and inform clients of political efforts directed at the DES population. An example of a political effort directed at the DES population was a 1986 bill, H. R. 164 in the House of Representatives, and known as S. 169 in the Senate. It was a bill to provide matching Federal grants to states for public and professional DES education programs. It would also allow states to establish screening centers, a DES registry, and increase public outreach.

In summary, implications for nursing practice in the context of Orem's self-care theory were presented. The nurse in advanced practice, who possesses a comprehensive knowledge of the effects of DES exposure, can optimally provide or coordinate the specialized health care needed by the DES population. The CNS must be assertive in taking on this role. The CNS must educate her uninformed colleagues of the DES issue. The CNS must initiate the establishment

of protocols in health care settings that outline the 1985 DES Task Force recommended health care. The CNS must be aware of community resources available to DES daughters for health care, as well as financial assistance to acquire the needed health care. Also, the CNS must be aware of Government legislation of the DES issue.

Nurses at all levels of education are responsible for screening the general population for DES exposure. The nurse needs to develop and incorporate strategies to further develop self-care abilities and behaviors in a motivated group of females (e.g., increased frequency of BSE and knowledge of recommended health care). The nurse can influence the health-care acquired by the DES population.

Implications for Nursing Education

Nursing instructors, who are responsible for the education of undergraduate and graduate nursing students, or for continuing education programs for nurses, must include in the curricula the skills needed for nurses to meet new demands as a result of modern technology and changes in the focus of health care. Thus, nursing educators must prepare nurses to meet the new demands imposed on the nursing profession.

The curricula in nursing education at all levels should include the discussion of the history of DES exposure, the most current research findings, the required health care for this population, and resources available to the DES female. The nurse must be knowledgeable about the DES issue if information is to be dispersed among the general population as well as to other members of the health care team. The curricula in nursing education of the baccalaureate and graduate degree nurse should include courses of how to conduct

nursing research. Nurses should be committed to life-long learning and keep current their knowledge and skills.

The educational preparation of licensed nurses varies. These nurses not only have varied educational preparation, but varied motivation and skills for the care they give. Thus, the CNS should take this into consideration when planning strategies to inform nursing colleagues of the DES issue.

The curricula should also be designed to assist the student to understand how they may influence the client's decisions by the influence of the student's own set of perceptions, attitudes, beliefs, and behavior. The student's belief regarding the role of the DES daughter in obtaining health care could influence the degree of decision making the client is given. The student's perception and degree of importance given the DES issue will also influence the amount of information and reinforcement given to the DES daughter.

Emphasis should be placed on effectively using nursing diagnoses. For example when caring for the DES daughter, the identified lack of knowledge may be the etiology of the nursing diagnosis. An illustration of this would be in the following nursing diagnosis: noncompliance to BSE secondary to lack of knowledge of technique resulting in a deficit in self-care. Nursing diagnoses are valuable in planning strategies and generating outcomes.

Interdisciplinary education is a highly desirable and essential building-block for interdisciplinary practice. The quality of care received by the DES daughter is affected by the functioning of the interdisciplinary team. The role of the CNS needs to be clearly defined to the client and other members of the health team. It is not

the intention of the CNS to acquire the physician's responsibility for giving the comprehensive DES screening examination when medically indicated. Although the CNS can acquire assessment skills needed to perform DES screening examinations, any changes or abnormalities noted would be referred to a physician specializing in DES care for further evaluation.

In summary, nursing education has been discussed in relation to this study. Nurses in advanced practice need to continue to contribute to research, and thus increase the scientific knowledge base from which nursing education and practice are built.

Recommendations for Future Research

Replication of Study

The questionnaire used in this study serves a pioneering role for developing a more refined tool for future replication of this study. The following suggestions for revision of this instrument for future use will now be expounded upon. Refer to Appendix D when reference is made to specific questions in the questionnaire.

The term "DES-screening examination" appeared not to be a term familiar to all DES daughters. Therefore, instead of defining this term beyond the definition stated in the questionnaire, that is, "gynecologic examination" in the fear that it may skew the answers to related questions, it is suggested instead to reword questions in a manner such that the participant can tell what the examination she had done after her learning of DES exposure entailed. This could be accomplished by checking all the procedures that were done at this time.

In reference to the questions where qualitative answers such as, "other (please specify)", were used, it is strongly suggested that quantitative choices be provided. It has been the experience of this researcher that although the information attained through this process has an invaluable amount of knowledge gained, it is extremely difficult to analyze due to the participant's inability to provide a focused answer to the stated question and the number of varied responses. Also, it appeared that the participants at times did not understand the base question, and therefore provided an answer that did not address the stated question.

A 24-year span exists between the first and last DES daughter exposed in utero. For daughters who learned of their exposure at 14 years of age or earlier, the 1985 DES Task Force recommends: periodic screening examinations should begin at age 14 or at the onset of menses, whichever is earlier, unless there is vaginal bleeding or discharge; bleeding or discharge should be evaluated without delay (U.S. Department of Health & Human Services, 1985, p. 22).

A question inquiring about the examination of females, known or suspected of being DES-exposed who were examined at a younger age than 14 years and whose menarche had not occurred, should only have been examined if vaginal bleeding, spotting, or abnormal discharge occurred. An examination at a younger age is then considered mandatory. A question directly related to the occurrence of vaginal bleeding, spotting, or abnormal discharge should be addressed in regards to periodic screening examinations of females known or suspected of being DES exposed who knew of their exposure at age 14 or earlier.

To address this criteria more effectively, it is recommended that a small section of the questionnaire be referenced for these DES daughters. Questions should include: age at which they had their first DES screening examination; age of onset of menses; and had they ever experienced bleeding other than menstrual periods or a change in vaginal discharge and if so, did this occur before the first DES examination and if so, was this the reason for the initial DES examination.

Thus, the need to elicit information regarding menstrual periods and vaginal bleeding/discharge from the entire study sample would not be warranted unless the researcher wanted additional information from which to draw conclusions or to formulate hypotheses for further studies. If these areas were not of interest to the researcher, additional space gained from removing these questions could be used to address other areas of interest.

A richer understanding of the DES daughter's satisfaction with her health care provider who administers her DES health care may be elicited if a Likert-type scale for Question #6 is used in future questionnaires. A correlation between satisfaction with health care provider, frequency with which the health care provider answers questions regarding DES exposure, and adherence to the DES screening examination schedule could provide a hypothesis regarding adherence to DES Task Force recommended health care.

Overall, the study participants did not have difficulty filling out Questions #17 and #18. It is suggested that the category "other" be eliminated or specific choices be provided if the researcher is interested in a predetermined area (refer to earlier discussion

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regarding "other"). The "other" answers provided dealt mainly with laboratory tests and/or surgical interventions.

The criteria stating that breast examinations of DES daughters should conform with current NCI guidelines is hard to assess in a questionnaire. The method of BSE used by the participants was not ascertained in this questionnaire. It is difficult to obtain if participants are conforming to the BSE techniques in a questionnaire. This could be incorporated in future research per a personal interview.

Additional questions which should be included in the questionnaire are: allergy to iodine (could explain why a DES daughter is not receiving iodine staining); prior sexually transmitted diseases (esp., herpes and/or human papilloma viruses), age at first intercourse, number of sexual partners (could increase risk of cervical cancer); family history of breast cancer; history of hysterectomy; and use of birth control pills and/or other uses of estrogens.

Future DES researchers may wish to incorporate the personal interview initially to help them develop their instrument, since much of the needed research has not previously been conducted. Once the instrument has been developed, it may be advantageous to mail questionnaires thus enabling the researcher to obtain a sampling from a wider range of geographical locations. If funding is possible, a toll-free phone number could be furnished for the use by respondents where clarification of any questions on the questionnaire was needed.

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Future DES researchers may wish to incorporate Pender's Health-Promotion Model to guide their study. Although the DES

daughter fits well into Orem's self-care theory, the researcher feels Pender's Health-Promotion Model may provide more of a basis for directing the interpretation of the research findings.

The health-promotion model is useful in explaining and predicting health-promoting behaviors. The health-promoting behaviors are categorized into individualized perceptions, modifying factors, and variables affecting likelihood of action. The perceptions of the DES daughter that may affect her decision-making phase of health-promoting behavior (i.e., use of data) includes her important of health, perceived control, self-awareness, definition of health, perceived health data, and perceived benefits. These factors will influence the DES daughter's readiness to engage in health-promotion behaviors. sociodemographic characteristics serve as modifying factors for health behavior. Previous experience with health-promoting action increases feelings of competence in following through with appropriate behavior. The DES daughter who obtains a feeling of comfort with knowledge and skills needed to manage her DES exposure will more likely facilitate the implementation of health-promoting behaviors.

Interactions with health professionals can serve as an important factor in the decision to engage in specific health behavior. Cues can trigger health-promoting behavior (e.g., mass media focusing on DES concerns). The intensity of the cue needed to trigger health-promoting actions will depend on the level of readiness of the DES daughter to engage in health promoting behaviors. The above overview describes the applicability of the health-promotion model to this study.

Future Research Areas

This study serves as a stepping stone for future research activities. The outcome of the study lays the foundation that is needed to proceed to a higher level of inquiry. There is a deficit in the recommended health care received by the study sample. Further research could be undertaken to explain underlying causes for this deficit. The study of health and of the human potential for health promotion and maintenance is an important aspect of nursing research.

Recommendations for future studies that will increase knowledge of the effects of DES exposure are:

— Replication and or future research should be undertaken to reach a more varied study sample in regards to income and educational levels.

— A study to ascertain from health care providers what examination procedures they perform routinely for their DES-exposed clients

— A study to ascertain in the DES issue is addressed in the curricula of medical students.

— A study to ascertain in the DES issue is addressed in the curricula of nursing students.

— A research study investigating whether care differs from one area of the country to another.

— A research study investigating if DES daughters are activated individuals in other areas of their health.

— A research study addressing the DES daughter's psychological areas of concern regarding alterations in sexuality and the fear of cancer.

— A research study investigating a possible link between the rate of endometrosis and DES exposure.

— A research study investigating a possible link between early menopause and DES.

— Future studies focusing on the health care received by DES sons and DES mothers.

— Abnormalities, other than reproductive, related to exposure to DES

— Relationship (i. e., DES-related abnormalities, compliance to and knowledge of recommended health care) between exposed siblings. and/or twins who are also products of pregnancies during which their mothers took DES.

— Rate of miscarriages, and ectopic and high-risk pregnancies among DES daughters versus the general population.

The structural anomalies of the vagina, cervix, and uterus in women exposed to DES have caused concern about their reproductive potential. In this study, 337 (50.3%) of the DES daughters reported the ability to conceive and of these, 249 (73.9%) had at least one viable pregnancy. Of these 249, 155 (62.3%) gave birth to one child; 72 (28.9%) gave birth to two children; 15 (6.0%) gave birth to three children; 5 (2.0%) gave birth to four children and 2 (0.8%) gave birth to twins.

A miscarriage was reported in 167 (49.6%) of the DES daughters who conceived (n = 337). A total of 293 known miscarriages was reported: 94 reported having 1 miscarriage; 42 reported having 2 miscarriages; 17 reported having 3 miscarriages; 9 reported having 4 miscarriages; 4 reported having 5 miscarriages; and 1 reported having 8 miscarriages.

Although a question was not included that asked about the occurrence of ectopic pregnancies, 57 DES daughters wrote in as an additional comment that they had experienced an ectopic pregnancy. A total of 83 ectopic pregnancies was reported: 37 reported having at least 1 ectopic pregnancy; 16 reported having 2 ectopic pregnancies, 2 reported having 3 ectopic pregnancies; and 2 reported having 4 ectopic pregnancies. Therefore, this researcher feels additional research in the areas of miscarriage and ectopic pregnancy should be pursued.

Additional comments were included in 266 (39.7%) of the 670 questionnaires. (Refer to Appendix H for examples.) Of these, 115 (43.2%) dealt with reproductive problems experienced by the DES daughter (i.e., trouble conceiving, infertility, incompetent cervix, preterm labor, miscarriages, ectopic pregnancies, and high-risk pregnancies).

Also, of the 266 daughters who wrote additional comments, 32 (12.0%) reported having a T-shaped uterus and 3 (01.1%) reported having a didelphic uterus. DES daughters reported having experienced endometriosis in 12 (4.5%) of the additional comments. Urinary tract and kidney anomalies were reported by 6 (2.3%) in the additional comments. Included in this count was one daughter who had three kidneys and another who had only one kidney; their health care providers stated it may be attributed to DES exposure. Thus, additional comments stated by the DES daughters also indicate future areas of needed research on DES issues.

In summary, the professional nurse at the graduate educational level needs to acquire and develop his/her research skills, and

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develop their role as a researcher/inquirer. Nursing-based research dealing with DES exposure needs to be conducted.

Summary

In Chapter VI, a summary and intrepretation of findings were presented. Limitations of the study were cited and implications of the study for nursing practice, education, and future research work presented. Orem's model of self-care was used as the conceptual framework for this study and was included in the discussion for nursing practice. The findings in this study indicate that there is a deficit in the extent to which DES daughters received the health care recommended by the Federal Government's DES Task Force. Further research needs to be undertaken to explain underlying causes for this deficit so that attention can be focused in these areas.

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APPENDICES

A P P E N D I X A

1985 DES Task Force Recommendations

Screening

DES Daughters

APPENDIX A

1985 DES Task Force Recommendations

Screening

DES Daughters

Periodic screening examinations should begin at age 14 or at the onset of menses, whichever is earlier, unless there is vaginal bleeding or discharge; bleeding or discharge should be evaluated without delay. Exposed daughters and their families should have adequate explanation and consideration of the physical and emotional aspects of this examination.

The screening procedure should include a thorough pelvic examination using careful palpation (feeling), cytology test (the Pap or Papanicolaou smear), and tissue inspection including the use of one-half strength aqueous Lugol's (iodine) solution for cervical and vaginal staining (Nonstained areas of the vagina may indicate adenosis).

Minimally, DES daughters should be examined at least once a year, with more frequent examinations done for women with extensive of atypical epithelial changes (e.g., widespread adenosis or associated epithelial change).

Use of a colposcope (an instrument for examination of vaginal and cervical tissues by means of magnifying lenses) is not required at every examination of DES daughters. Colposcopy should be utilized

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(a) in all cases where abnormal cytology (Pap smear) is observed, (b) in cases of extensive or widespread epithelial changes (such as squamous metaplasis), and (c) where feasible as part of the initial examination. It must be recognized that colposcopy may be a relatively expensive procedure, and most physicians do not have colposcopes or the special training needed for their use. Many of the changes which can be observed with the colposcope and can also be detected by use of the most simpler and less traumatic technique of iodine staining.

Biopsies should not be done routinely, but should be reserved for special indications such as abnormal Pap tests or other evidence of significant epithelial abnormalities.

In addition, breast examinations of DES daughters should conform with current National Cancer Institute guidelines. (U. S. Department of Health and Human Services, 1985, pp. 22-23)

APPENDIX B

DESAD Project Protocol

Examination and Counseling of Daughters

APPENDIX B

DESAD Project Protocol

EXAMINATION AND COUNSELING OF DAUGHTERS

Examination

The gynecologic examination of a DES-exposed female is similar but more detailed than a routine pelvic examination. The examination used in the DESAD Project is outlined below. When changes characteristic of the DES-exposed population are present, the physician may wish to consult a gynecologist familiar with the details of evaluation and followup of DES-exposed individuals.

Order of Gynecologic Examination for Women Exposed to DES <u>in Utero</u>

—Vulvar Inspection

—Vaginal and Cervical Palpation (Digital)

—Vaginal and Cervical Inspection (Speculum)

—Cytology (Separate Slides of Vaginal Fornices and Cervix)

—Colposcopy (Optional)

—Iodine Staining of Cervix and Vagina

—Biopsy of Atypical Findings

—Bimanual (Recto-vaginal) Examination

Inspection of the Vulva No changes of the vulva have been associated with DES exposure. If the patient is extremely young and the hymen unusually tight, topical application of an anesthetic jelly or spray may reduce discomfort during initial dilatation. If the hymen permits passage of the index finger, the examination may usually proceed if pediatric instruments are used. Patients should be encouraged to use tampons during menstrual periods as this facilitates subsequent examination.

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Palpation of the Vagina Palpation of the vagina is a crucial part of the DES examination and occasionally provides the only evidence that a clear cell adenocarcinoma is present, especially when the tumor is located beneath an intact mucosa. The finger used for palpation should be moistened with water rather than lubricant jelly in order not to ruin the cytologic specimens obtained subsequently. The entire length of the vagina including the fornices should be carefully assessed. During palpation, vaginal ridges and other structural changes of the cervix may be noted. Areas of thickening or induration should arouse suspicion and be sampled by biopsy.

Speculum Examination After palpation, a bivalve speculum of appropriate size is inserted into the vagina. The Graves speculum is most commonly used. In virginal females, a pediatric Graves or a Pederson speculum may be effective when the standard speculum is too short to permit examination of the entire vagina including the fornices. Warm water, not jelly, should be used for lubrication during insertion of the speculum. Excess mucus, which is sometimes present in the DES-exposed women, should be gently removed with a saline moistened cotton swab.

The epithelial surface of the vagina must be carefully inspected. On naked eye examinations adenosis, which is the presence of glandular epithelium or its secretory products in the vagina, may appear red and granular or be invisible; and areas of squamous metaplasia, which is newly formed squamous epithelium and usually characterized by a low content of glycogen, may be indistinguishable in color from areas of normal squamous epithelium. During inspection,

the speculum should be gently rotated as it is being withdrawn in order to assess the entire surface of the vagina.

Cytology The secretions and epithelium in the upper third of the vagina should be thoroughly sampled with a wood or plastic spatula; the middle or lower third of the vagina should be similarly sampled if grossly visible mucosal changes are evident. The spatula should be rotated around the entire circumference of the vaginal fornices and the material transferred promptly to a slide and placed immediately in fixative. A second sample should be obtained from the endocervical canal and ectocervix. Aspiration of the external os is one method of sampling the endocervical canal. This procedure should be followed by a scrape of the ectocervix.

Colposcopy Colposcopy, if performed, should always be done before iodine staining. The chief benefits of colposcopy are accurate assessment of the extent of the epithelial changes on the cervix and vagina and the detection of areas likely to disclose the most abnormal changes on biopsy. Colposcopy has not proved essential in the detection of clear cell adenocarcinoma, both because the tumor does not have a specific vascular pattern and also, because on rare occasion, a tumor is entirely intramural and does not involve the mucosa. In general, colposcopy is considered at present to be optional in the routine screening and followup of DES-exposed daughters, but of importance if an abnormal cytologic smear is encountered.

Iodine Staining Iodine staining of the vagina and cervix confirms the boundaries of the epithelial changes observed by colposcopy, or indicates those boundaries when colposcopy has not been done. If

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colposcopy has been performed, the iodine stain of choice is half-strength Lugol's solution (half-strength is 2.5 percent iodine with 5 percent potassium iodide in water). Otherwise, Schiller's iodine solution is preferable (1 gram iodine and 2 grams potassium iodide in 300 ml. water). Because the iodine stains only the normal (highly glycogenated) squamous epithelium that lines the vagina and the cervix, lesions within the wall cannot be detected. To evaluate the tissues after staining, the speculum is withdrawn again, after which it is reinserted for biopsy, if indicated. Reinsertion may be facilitated by lubrication with jelly to compensate for the dehydrating effect of the iodine.

Indications for Biopsy Biopsy is performed when the vagina or cervix is indurated or granular, contains a palpable nodule, has discrete areas of a different color or texture than the surrounding tissue, or discloses highly atypical colposcopic findings. Random biopsies of nonstaining areas are not recommended since they rarely disclose neoplastic or preneoplastic lesions. Use of ferrous subsulfate (Monsel's solution), silver nitrate, or gelfoam with tampons after biopsy may facilitate hemostasis.

Bimanual Examination Bimanual examination should include examination of the vagina and rectum and is performed in the usual manner.

Examination Schedule Examination of females known or suspected of being DES-exposed should begin following menarche or by the age of 14 years if the menarche has not occurred. Examination at a younger age is not advised, unless vaginal bleeding, spotting, or abnormal discharge occurs; then it is considered mandatory. Examination under anesthesia is rarely necessary.

The interval between examination is determined on an individual basis. For most patients yearly examinations are adequate. Women with vaginal adenosis were initially seen more frequently at the DESAD Project centers, although most now are seen annually.

Subsequent examinations are performed as outlined above and include palpation, inspection, cytology, and iodine staining. Attention should be focused on the changes observed since the previous evaluation. While cervical cytology is recommended on an annual basis, smears from the vagina can be omitted if there are no epithelial changes in the vagina. Women should be questioned about interval bleeding or abnormal discharge.

Education and Counseling Anxiety may result from documentation of DES exposure without sufficient information about its significance or sequelae. Many exposed women are worried about their sexual self-image and reproductive capabilities and fear the development of cancer. Any genital tract changes, e.g. adenosis, may cause undue concern unless the benign natures of the changes are explained. Therefore, it is important that sufficient time be allocated to provide information and to answer questions, responses to which must be appropriate to the age of the person and expressed in terms she can understand. Written materials, such as descriptions of the examination or drawings of changes associated with exposure, can be given to the patient when she arrives for her appointment, thereby allowing her time to prepare questions. (U. S. Department of Health and Human Services, 1983, pp. 7-9.)

A P P E N D I X C

Pilot Study Questionnaire

APPENDIX C
DES-EXPOSED DAUGHTER
HEALTH CARE QUESTIONNAIRE

A vast number of American women received Diethylstilbestrol (DES) during pregnancy in the belief that it would prevent miscarriages, thus resulting in exposure of a large number of sons and daughters. The health care of these individuals needs to be carefully monitored. This study will compile information on the health care of daughters who know, or who think, they are DES-exposed. The following questionnaire is an important first step in monitoring the health care being received by the DES-exposed daughter. Your responses, as DES daughters, will provide a crucial "first look" and can help to alert the scientific community of possible areas of needed research or deficits in health care. We hope you will help with this project. Participation is freely voluntary. If you consent to participate, please fill out and return the questionnaire. This questionnaire should take approximately 20 minutes to complete. If you need extra room, use the comment section or additional sheets. DO NOT put your name on the questionnaire or identify yourself in any way. Results of this study will appear in an upcoming issue of DES Action Voice. Thank you!

PLEASE RETURN NO LATER THAN NOVEMBER 29th, 1986

QUESTIONNAIRE

1. Race (Check one):
   ( ) White
   ( ) Black
   ( ) American Indian
   ( ) Hispanic
   ( ) Other (please specify) _____

2. Age (Write in): _____

3. Education (Circle highest level completed):

   1 2 3 4 5 6 7 8 (Grammar School) 9 10 11 12 (High School) 13 14 15 16 (College) 17 18 19 20 (Graduate School)

4. Total Family Income (Check one):
   ( ) Less than $9,999
   ( ) $10,000 to $14,999
   ( ) $15,000 to $19,999
   ( ) $20,000 to $24,999
   ( ) $25,000 to $49,999
   ( ) $50,000 or more

5. Have you given birth to any children? (Check one)
   ( ) Yes If yes, number of children _____
   ( ) No

6. Have you had any miscarriages? (Check one)
   ( ) Yes If yes, how many? _____
   ( ) No

7. Do you have health insurance? (Check one)
   ( ) Yes
   ( ) No

If yes, does your health insurance cover your DES examinations? (Check one)
   ( ) Yes
   ( ) No

8. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol (DES) while pregnant with you? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

9. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's physician
   ( ) Informed by mother
   ( ) Diagnosis by physician through physical examination
   ( ) Other (please specify) _____

10. Have you tried to obtain medical records to verify DES exposure? (Check one)
    ( ) Yes
    ( ) No

11. Does your physician answer questions you have regarding DES exposure? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

12. At what age did you learn that you were a DES daughter? (Write in) _____

13. Do you have menstrual periods?
    ( ) Yes
    ( ) No

    If yes, at what age did you start your menstrual period? (Write in) _____

14. Have you ever had a DES-screening examination?
    ( ) Yes
    ( ) No

    If yes, at what age did you have your first DES-screening examination? (Write in)_____

IF YOU ANSWERED "NO" TO QUESTION 14, SKIP TO QUESTION 25.

15. Was a colposcopy (an examination using a magnifying instrument) done on your first DES examination?
    ( ) Yes
    ( ) No

16. Once you had your first DES-screening examination, was a screening examination done once a year?
    ( ) Yes
    ( ) No

PLEASE ANSWER THE FOLLOWING QUESTIONS AS RELATED TO THE HEALTH CARE YOU HAVE RECEIVED SINCE 1978.

17. How often does your physician recommend you to return for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)

18. How often do you see a physician for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)

19. If you are currently seeing a physician more than once a year, please specify reason for this? (Check as many as appropriate)
    ( ) Abnormal Pap smear
    ( ) Indicated by results of iodine staining
    ( ) Indicated by results of colposcopy
    ( ) Indicated by results of biopsy
    ( ) Physician did not specify reason
    ( ) Other (Specify: _____)

20. At your DES examinations, which of the following procedures are routinely being done? (Please check all that are appropriate)

ALWAYS	SOMETIMES	NEVER	
			Pelvic examination: manual examination.
			Pap smear: a test in which cells are gently scraped from the cervix and put onto a slide to be examined under a microscope.
			Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix
			Colposcopy: an examination using a colposcope (magnifying device) to look at cervical and vaginal cells. The colposcope does not touch the patient during the exam.
			Biopsy: removal of a small piece of tissue with a surgical instrument for examination in order to help establish a diagnosis.
			Other procedure(s) (please specify: _____)

21. During your routine DES examination, does your physician ask you if you have experienced vaginal bleeding other than menstrual periods? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

22. During your routine DES examination, does your physician ask you if there has been a change in your vaginal discharge (i.e., increase in amount, change in color, or change in odor)? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

23. If you have experienced vaginal bleeding other than menstrual periods or a change in vaginal discharge, what action did your physician take?: (Specify)_____

24. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to question 25)

If yes, please complete the following table: (List the most recent abnormal Pap smear first and then move across the columns and complete yes or no for each of the categories)

Abnormal Pap Smear (Date)	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes _____ ( ) No
2.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes _____ ( ) No
3.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes _____ ( ) No

25. Do you perform self-breast examinations monthly? (Check one)
( ) Yes
( ) No
( ) Not routinely, but do check on occasion

26. Does your physician examine your breasts at least once a year?
( ) Yes
( ) No
( ) Not routinely

27. Have you ever had a mammography (breast X-ray)? (Check one)
( ) Yes
( ) No

If yes, please state at what age and why: _____

ADDITONAL COMMENTS:

PLEASE RETURN QUESTIONNAIRE TO:
Louise Pointkowski RN
---- - --st Street
Wyandotte, Michigan 48192

APPENDIX D

Instrument

APPENDIX D

DES-EXPOSED DAUGHTER HEALTH CARE QUESTIONNAIRE

The objective of the following questionnaire is to seek information important for monitoring the health care received by DES-exposed daughters. Your responses, as DES daughters, will provide a crucial "first look" and can help to alert health care researchers to possible areas of needed research or deficits in health care. We hope you will help with this project. Participation is voluntary. If you consent to participate, please fill out and return the questionnaire. Results of this study will appear in an upcoming issue of DES Action Voice.

INSTRUCTIONS

This questionnaire should take approximately 20 minutes to complete. Place a check mark in the appropriate boxes. If you need extra room, please use the comment section or additional sheets. DO NOT put your name on the questionnaire or identify yourself in any way. Thank you!

PLEASE RETURN NO LATER THAN FEBRUARY 21st, 1987

QUESTIONNAIRE

1. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol [DES] while pregnant with you)? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

2. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's health care provider
   ( ) Informed by mother
   ( ) Diagnosis by health care provider through physical examination
   ( ) Other (please specify) _____

3. Have you tried to obtain medical records to verify DES exposure?
   ( ) Yes ( ) No

4. At what age did you learn that you were a DES daughter? (Write in age) ___

5. Does your health care provider answer questions you have regarding DES exposure? (Check one)

   ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

6. Are you satisfied with your health care provider who administers your DES health care? ( ) Yes ( ) No

7. Have you ever had a DES-screening examination (i.e., gynecologic examination)? ( ) Yes ( ) No

If yes, state age you had your first DES-screening examination? (Write in age) ___

IF YOU ANSWERED "NO" TO QUESTION 7, SKIP TO QUESTION 17

8. Was a colposcopy (an examination using a magnifying instrument) done on your first or second DES examination? ( ) Yes ( ) No

9. Once you had your first DES-screening examination, was a screening examination done at least once a year? ( ) Yes ( ) No

(OVER)

PLEASE ANSWER THE FOLLOWING QUESTIONS AS RELATED TO THE HEALTH CARE YOU HAVE RECEIVED SINCE 1978.

10. How often does your health care provider recommend you to return for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

11. How often do you see a health care provider for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

12. If you are currently seeing a health care provider more than once a year, please specify reason for this? (Check as many as appropriate)
    ( ) Abnormal Pap smear
    ( ) Results of iodine staining
    ( ) Results of colposcopy
    ( ) Results of biopsy
    ( ) Health care provider did not specify reason
    ( ) Other (Please specify: _____)

13. At your DES examinations, which of the following procedures are routinely being done? (Please check the appropriate box for each procedure)

ALWAYS	SOMETIMES	NEVER	DON'T KNOW	PROCEDURES
				Pelvic examination: bimanual examination.
				Pap smear: a test in which cells are gently scraped from the cervix and put onto a slide to be examined under microscope.
				Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix
				Colposcopy: an examination using a colposcope (magnifying device) to look at cervical and vaginal cells. The colposcope does not touch the patient during the exam.
				Biopsy: removal of a small piece of tissue with a surgical instrument for examination in order to help establish a diagnosis.
				Other procedure(s) (please specify): _____

14. During your routine DES examination, does your health care provider ask you if you have experienced vaginal bleeding other than menstrual periods? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

15. During your routine DES examination, does your health care provider ask you if there has been a change in your vaginal discharge (i.e., increase in amount, change in color, or change in odor)? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

16. If you have experienced vaginal bleeding other than menstrual periods or a change in vaginal discharge, what action did your health care provider take?: (Please specify): _____

17. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to Question 18)
( ) Don't Know (If don't know, skip to Question 18)

If yes, please complete the following table: (List the most recent abnormal Pap smear, giving your approximate age or the year of occurrence; and then move across the columns and complete "yes", "no", or "don't know" for each of the categories)

Abnormal Pap Smear Age/Year	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know

18. Have you ever been told by your health care provider that you have had changes in the vaginal lining/tissue (i.e., epithelial changes, dysplasia, adenosis)? (Check one)
( ) Yes
( ) No (If no, skip to Question 19)
( ) Don't Know (if don't know, skip to Question 19)

If yes, please complete the following table: (List the most recent vaginal tissue changes, giving your approximate age or the year of occurrence; and then move across the columns and complete "yes", "no", or "don't know" for each of the categories)

Tissue Changes Age/Year	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know

19. Have you given birth to any children? (Check one)
( ) Yes If yes, number of children ____
( ) No

(OVER)

The interval between examination is determined on an individual basis. For most patients yearly examinations are adequate. Women with vaginal adenosis were initially seen more frequently at the DESAD Project centers, although most now are seen annually.

Subsequent examinations are performed as outlined above and include palpation, inspection, cytology, and iodine staining. Attention should be focused on the changes observed since the previous evaluation. While cervical cytology is recommended on an annual basis, smears from the vagina can be omitted if there are no epithelial changes in the vagina. Women should be questioned about interval bleeding or abnormal discharge.

Education and Counseling Anxiety may result from documentation of DES exposure without sufficient information about its significance or sequelae. Many exposed women are worried about their sexual self-image and reproductive capabilities and fear the development of cancer. Any genital tract changes, e.g. adenosis, may cause undue concern unless the benign natures of the changes are explained. Therefore, it is important that sufficient time be allocated to provide information and to answer questions, responses to which must be appropriate to the age of the person and expressed in terms she can understand. Written materials, such as descriptions of the examination or drawings of changes associated with exposure, can be given to the patient when she arrives for her appointment, thereby allowing her time to prepare questions. (U. S. Department of Health and Human Services, 1983, pp. 7-9.)

APPENDIX C

Pilot Study Questionnaire

APPENDIX C
DES-EXPOSED DAUGHTER
HEALTH CARE QUESTIONNAIRE

A vast number of American women received Diethylstilbestrol (DES) during pregnancy in the belief that it would prevent miscarriages, thus resulting in exposure of a large number of sons and daughters. The health care of these individuals needs to be carefully monitored. This study will compile information on the health care of daughters who know, or who think, they are DES-exposed. The following questionnaire is an important first step in monitoring the health care being received by the DES-exposed daughter. Your responses, as DES daughters, will provide a crucial "first look" and can help to alert the scientific community of possible areas of needed research or deficits in health care. We hope you will help with this project. Participation is freely voluntary. If you consent to participate, please fill out and return the questionnaire. This questionnaire should take approximately 20 minutes to complete. If you need extra room, use the comment section or additional sheets. DO NOT put your name on the questionnaire or identify yourself in any way. Results of this study will appear in an upcoming issue of DES Action Voice. Thank you!

PLEASE RETURN NO LATER THAN NOVEMBER 29th, 1986

QUESTIONNAIRE

1. Race (Check one):
   ( ) White
   ( ) Black
   ( ) American Indian
   ( ) Hispanic
   ( ) Other (please specify) _____

2. Age (Write in): _____

3. Education (Circle highest level completed):

   1 2 3 4 5 6 7 8 (Grammar School) 9 10 11 12 (High School) 13 14 15 16 (College) 17 18 19 20 (Graduate School)

4. Total Family Income (Check one):
   ( ) Less than $9,999
   ( ) $10,000 to $14,999
   ( ) $15,000 to $19,999
   ( ) $20,000 to $24,999
   ( ) $25,000 to $49,999
   ( ) $50,000 or more

5. Have you given birth to any children? (Check one)
   ( ) Yes If yes, number of children _____
   ( ) No

6. Have you had any miscarriages? (Check one)
   ( ) Yes If yes, how many? _____
   ( ) No

7. Do you have health insurance? (Check one)
   ( ) Yes
   ( ) No

   If yes, does your health insurance cover your DES examinations? (Check one)
   ( ) Yes
   ( ) No

8. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol (DES) while pregnant with you? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

9. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's physician
   ( ) Informed by mother
   ( ) Diagnosis by physician through physical examination
   ( ) Other (please specify) _____

10. Have you tried to obtain medical records to verify DES exposure? (Check one)
    ( ) Yes
    ( ) No

11. Does your physician answer questions you have regarding DES exposure? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

12. At what age did you learn that you were a DES daughter? (Write in) _____

13. Do you have menstrual periods?
    ( ) Yes
    ( ) No

    If yes, at what age did you start your menstrual period? (Write in) _____

14. Have you ever had a DES-screening examination?
    ( ) Yes
    ( ) No

    If yes, at what age did you have your first DES-screening examination? (Write in)_____

IF YOU ANSWERED "NO" TO QUESTION 14, SKIP TO QUESTION 25.

15. Was a colposcopy (an examination using a magnifying instrument) done on your first DES examination?
    ( ) Yes
    ( ) No

16. Once you had your first DES-screening examination, was a screening examination done once a year?
    ( ) Yes
    ( ) No

7. Do you have health insurance? (Check one)
   ( ) Yes
   ( ) No

If yes, does your health insurance cover your DES examinations? (Check one)
   ( ) Yes
   ( ) No

8. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol (DES) while pregnant with you? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

9. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's physician
   ( ) Informed by mother
   ( ) Diagnosis by physician through physical examination
   ( ) Other (please specify) _____

10. Have you tried to obtain medical records to verify DES exposure? (Check one)
   ( ) Yes
   ( ) No

11. Does your physician answer questions you have regarding DES exposure? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

12. At what age did you learn that you were a DES daughter? (Write in) _____

13. Do you have menstrual periods?
   ( ) Yes
   ( ) No

   If yes, at what age did you start your menstrual period? (Write in) _____

14. Have you ever had a DES-screening examination?
   ( ) Yes
   ( ) No

   If yes, at what age did you have your first DES-screening examination? (Write in)____

IF YOU ANSWERED "NO" TO QUESTION 14, SKIP TO QUESTION 25.

15. Was a colposcopy (an examination using a magnifying instrument) done on your first DES examination?
   ( ) Yes
   ( ) No

16. Once you had your first DES-screening examination, was a screening examination done once a year?
   ( ) Yes
   ( ) No

PLEASE ANSWER THE FOLLOWING QUESTIONS AS RELATED TO THE HEALTH CARE YOU HAVE RECEIVED SINCE 1978.

17. How often does your physician recommend you to return for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)

18. How often do you see a physician for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)

19. If you are currently seeing a physician more than once a year, please specify reason for this? (Check as many as appropriate)
    ( ) Abnormal Pap smear
    ( ) Indicated by results of iodine staining
    ( ) Indicated by results of colposcopy
    ( ) Indicated by results of biopsy
    ( ) Physician did not specify reason
    ( ) Other (Specify: _____)

20. At your DES examinations, which of the following procedures are routinely being done? (Please check all that are appropriate)

ALWAYS	SOMETIMES	NEVER	
			Pelvic examination: manual examination.
			Pap smear: a test in which cells are gently scraped from the cervix and put onto a slide to be examined under a microscope.
			Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix
			Colposcopy: an examination using a colposcope (magnifying device) to look at cervical and vaginal cells. The colposcope does not touch the patient during the exam.
			Biopsy: removal of a small piece of tissue with a surgical instrument for examination in order to help establish a diagnosis.
			Other procedure(s) (please specify: _____

21. During your routine DES examination, does your physician ask you if you have experienced vaginal bleeding other than menstrual periods? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

22. During your routine DES examination, does your physician ask you if there has been a change in your vaginal discharge (i.e., increase in amount, change in color, or change in odor)? (Place a check in the appropriate space on the scale)

5	4	3	2	1
Always	Almost always	Sometimes	Rarely	Never

23. If you have experienced vaginal bleeding other than menstrual periods or a change in vaginal discharge, what action did your physician take?: (Specify)_____

24. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to question 25)

If yes, please complete the following table: (List the most recent abnormal Pap smear first and then move across the columns and complete yes or no for each of the categories)

Abnormal Pap Smear (Date)	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No _____
2.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No _____
3.	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No	( ) Yes ( ) No _____

25. Do you perform self-breast examinations monthly? (Check one)
( ) Yes
( ) No
( ) Not routinely, but do check on occasion

26. Does your physician examine your breasts at least once a year?
( ) Yes
( ) No
( ) Not routinely

27. Have you ever had a mammography (breast X-ray)? (Check one)
( ) Yes
( ) No

If yes, please state at what age and why: _____

ADDITONAL COMMENTS:

PLEASE RETURN QUESTIONNAIRE TO:
Louise Pointkowski RN
---- - --st Street
Wyandotte, Michigan 48192

APPENDIX D

Instrument

APPENDIX D

DES-EXPOSED DAUGHTER HEALTH CARE QUESTIONNAIRE

The objective of the following questionnaire is to seek information important for monitoring the health care received by DES-exposed daughters. Your responses, as DES daughters, will provide a crucial "first look" and can help to alert health care researchers to possible areas of needed research or deficits in health care. We hope you will help with this project. Participation is voluntary. If you consent to participate, please fill out and return the questionnaire. Results of this study will appear in an upcoming issue of DES Action Voice.

INSTRUCTIONS

This questionnaire should take approximately 20 minutes to complete. Place a check mark in the appropriate boxes. If you need extra room, please use the comment section or additional sheets. DO NOT put your name on the questionnaire or identify yourself in any way. Thank you!

PLEASE RETURN NO LATER THAN FEBRUARY 21st, 1987

QUESTIONNAIRE

1. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol [DES] while pregnant with you)? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

2. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's health care provider
   ( ) Informed by mother
   ( ) Diagnosis by health care provider through physical examination
   ( ) Other (please specify) _____

3. Have you tried to obtain medical records to verify DES exposure?
   ( ) Yes ( ) No

4. At what age did you learn that you were a DES daughter? (Write in age) ___

5. Does your health care provider answer questions you have regarding DES exposure? (Check one)

   ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

6. Are you satisfied with your health care provider who administers your DES health care? ( ) Yes ( ) No

7. Have you ever had a DES-screening examination (i.e., gynecologic examination)? ( ) Yes ( ) No

If yes, state age you had your first DES-screening examination? (Write in age) ___

IF YOU ANSWERED "NO" TO QUESTION 7, SKIP TO QUESTION 17

8. Was a colposcopy (an examination using a magnifying instrument) done on your first or second DES examination? ( ) Yes ( ) No

9. Once you had your first DES-screening examination, was a screening examination done at least once a year? ( ) Yes ( ) No

(OVER)

PLEASE ANSWER THE FOLLOWING QUESTIONS AS RELATED TO THE HEALTH CARE YOU HAVE RECEIVED SINCE 1978.

10. How often does your health care provider recommend you to return for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

11. How often do you see a health care provider for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

12. If you are currently seeing a health care provider more than once a year, please specify reason for this? (Check as many as appropriate)
    ( ) Abnormal Pap smear
    ( ) Results of iodine staining
    ( ) Results of colposcopy
    ( ) Results of biopsy
    ( ) Health care provider did not specify reason
    ( ) Other (Please specify: _____)

13. At your DES examinations, which of the following procedures are routinely being done? (Please check the appropriate box for each procedure)

ALWAYS	SOMETIMES	NEVER	DON'T KNOW	PROCEDURES
				Pelvic examination: bimanual examination.
				Pap smear: a test in which cells are gently scraped from the cervix and put onto a slide to be examined under microscope.
				Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix
				Colposcopy: an examination using a colposcope (magnifying device) to look at cervical and vaginal cells. The colposcope does not touch the patient during the exam.
				Biopsy: removal of a small piece of tissue with a surgical instrument for examination in order to help establish a diagnosis.
				Other procedure(s) (please specify): _____

14. During your routine DES examination, does your health care provider ask you if you have experienced vaginal bleeding other than menstrual periods? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

15. During your routine DES examination, does your health care provider ask you if there has been a change in your vaginal discharge (i.e., increase in amount, change in color, or change in odor)? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

PLEASE ANSWER THE FOLLOWING QUESTIONS AS RELATED TO THE HEALTH CARE YOU HAVE RECEIVED SINCE 1978.

10. How often does your health care provider recommend you to return for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

11. How often do you see a health care provider for DES examinations? (Check one)
    ( ) Every six months
    ( ) Once a year
    ( ) More than one year apart (Specify frequency: _____)
    ( ) Other (please specify) _____

12. If you are currently seeing a health care provider more than once a year, please specify reason for this? (Check as many as appropriate)
    ( ) Abnormal Pap smear
    ( ) Results of iodine staining
    ( ) Results of colposcopy
    ( ) Results of biopsy
    ( ) Health care provider did not specify reason
    ( ) Other (Please specify: _____)

13. At your DES examinations, which of the following procedures are routinely being done? (Please check the appropriate box for each procedure)

ALWAYS	SOMETIMES	NEVER	DON'T KNOW	PROCEDURES
				Pelvic examination: bimanual examination.
				Pap smear: a test in which cells are gently scraped from the cervix and put onto a slide to be examined under microscope.
				Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix
				Colposcopy: an examination using a colposcope (magnifying device) to look at cervical and vaginal cells. The colposcope does not touch the patient during the exam.
				Biopsy: removal of a small piece of tissue with a surgical instrument for examination in order to help establish a diagnosis.
				Other procedure(s) (please specify): _____

14. During your routine DES examination, does your health care provider ask you if you have experienced vaginal bleeding other than menstrual periods? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

15. During your routine DES examination, does your health care provider ask you if there has been a change in your vaginal discharge (i.e., increase in amount, change in color, or change in odor)? (Check one)

    ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

16. If you have experienced vaginal bleeding other than menstrual periods or a change in vaginal discharge, what action did your health care provider take?: (Please specify): _____

17. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to Question 18)
( ) Don't Know (If don't know, skip to Question 18)

If yes, please complete the following table: (List the most recent abnormal Pap smear, giving your approximate age or the year of occurrence; and then move across the columns and complete "yes", "no", or "don't know" for each of the categories)

Abnormal Pap Smear Age/Year	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know

18. Have you ever been told by your health care provider that you have had changes in the vaginal lining/tissue (i.e., epithelial changes, dysplasia, adenosis)? (Check one)
( ) Yes
( ) No (If no, skip to Question 19)
( ) Don't Know (If don't know, skip to Question 19)

If yes, please complete the following table: (List the most recent vaginal tissue changes, giving your approximate age or the year of occurrence; and then move across the columns and complete "yes", "no", or "don't know" for each of the categories)

Tissue Changes Age/Year	Was Iodine Staining done?	Was a Colposcopy done?	Was a Biopsy done?	Other procedure(s) (specify)
1.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes ( ) No ( ) Don't Know	( ) Yes _____ ( ) No ( ) Don't Know

19. Have you given birth to any children? (Check one)
( ) Yes If yes, number of children ____
( ) No

(OVER)

20. Have you had any miscarriages? (Check one)
( ) Yes If yes, how many ____
( ) No

21. Do you have (or ever had) menstrual periods? ( ) Yes ( ) No

If yes, at what age did you start your menstrual period? (Write in) _____

22. Do you perform breast self-examinations monthly? (Check one)
( ) Yes ( ) No ( ) Not routinely, but do check on occasion

23. Does your health care provider examine your breasts at least once a year? (Check one)
( ) Yes ( ) No ( ) Not routinely

24. Have you ever had a mammography (breast X-ray)? ( ) Yes ( ) No

If yes, please state at what age and why: _____

The next set of questions is background information that will contribute to understanding the results of this study.

25. Ethnic Group (Check one):
( ) White ( ) American Indian
( ) Black ( ) Hispanic ( ) Other (please specify) _____

26. Age (Write in) _____

27. Education (Circle highest level completed):

1 2 3 4 5 6 7 8	9 10 11 12	13 14 15 16	17 18 19 20
(Grammar School)	(High School)	(College)	(Graduate School)

28. Marital Status (Check one)
( ) Single ( ) Married ( ) Separated ( ) Divorced ( ) Widowed

29. Total Family Income (Check one):
( ) Less than $9,999 ( ) $20,000 to $24,999
( ) $10,000 to $14,999 ( ) $25,000 to $49,999
( ) $15,000 to $19,999 ( ) $50,000 or more

30. In what state do you currently reside? (Write in) _____

31. Do you have health insurance? ( ) Yes ( ) No

If yes, does your health insurance cover your DES examinations? ( ) Yes ( ) No

ADDITIONAL COMMENTS:

PLEASE RETURN QUESTIONNAIRE TO:
Louise Pointkowski RN
P. O. Box 375
Wyandotte, Michigan 48192

This research study is a partial requirement for the completion of a Master of Science in Nursing degree from the College of Nursing, Michigan State University.

APPENDIX E

Operational Definitions of Recommended Health Care

APPENDIX E

Operational Definitions of Recommended Health Care
I. Initiation of Periodic Screening Examinations

Subquestion: 1. For those DES daughters who were told of their exposure during puberty, are periodic screening examinations being done beginning at age 14 or at the onset of menses (whichever is earlier)?

4. At what age did you learn that you were a DES daughter? (Write in age) _____

7. Have you ever had a DES-screening examination (i.e., gynecologic examination)? ( ) Yes ( ) No

   If yes, state age you had your first DES-screening examination? (Write in age) _____

9. Once you had your first DES-screening examination, was a screening examination done at least once a year? ( ) Yes ( ) No

21. Do you have (or ever had) menstrual periods? ( ) Yes ( ) No

    If yes, at what age did you start your menstrual period? (Write in) ____

II. Screening Procedures

Subquestion: 2. Are Des daughters receiving the appropriate screening procedure at each examination which minimally includes a thorough pelvic examination using careful palpation, cytology test, and tissue inspection including the use of one-half strength Aqueous Lugol's solution for cervical and vaginal staining?

13. At your DES examinations, which of the following procedures are routinely being done? (Please check the appropriate box for each procedure)

ALWAYS	SOMETIMES	NEVER	DON'T KNOW	PROCEDURES
				Pelvic examination: bimanual exam
				Pap smear: a test in which cells gently scraped from the cervix and put onto a slide to be examined under microscope.
				Iodine staining: a test which uses a dilute iodine solution which is applied to the vagina and cervix.

III. Examination Schedule

Subquestion: 3. Are DES daughters being examined at least once a year?

9. Once you had your first DES-screening examination, was a screening examination done at least once a year? ( ) Yes ( ) No

11. How often do you see a health care provider for DES examinations? (Check one)
( ) Every six months
( ) Once a year
( ) More than one year apart (Specify frequency: _____)
( ) Other (please specify) _____

IV. Indications for More Frequent Examinations

Subquestion: 4. Are more frequent examinations being done for women with extensive atypical epithelial changes?

11. How often do you see a health care provider for DES examinations? (Check one)
( ) Every six months
( ) Once a year
( ) More than one year apart (Specify frequency: _____)
( ) Other (please specify) _____

12. If you are currently seeing a health care provider more than once a year, please specify reason for this. (Check as many as appropriate)
( ) Abnormal Pap smear
( ) Results of iodine staining
( ) Results of colposcopy
( ) Results of biopsy
( ) Health care provider did not specify reason
( ) Other (Please specify: _____)

V. Use of Colposcopy

Subquestion: 5.a. Is colposcopy being utilized in all cases where abnormal cytology (Pap smear) is observed?

17. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to Question 18)
( ) Don't Know (If don't know, skip to Question 18)

Abnormal Pap Smear Age/Year	Was a Colposcopy done?
1.	( ) Yes ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know

Subquestion: 5.b. Is colposcopy being utilized in cases of extensive or widespread epithelial changes (such as squamous metaplasia)?

18. Have you ever been told by your health care provider that you have had changes in the vaginal lining/tissue (i.e., epithelial changes, dysplasia, adenosis)? (Check one)
( ) Yes
( ) No (If no, skip to Question 19)
( ) Don't Know (If don't know, skip to Question 19)

Tissue Changes Age/Year	Was a Colposcopy done?
1.	( ) Yes ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know

Subquestion: 5.c. Is colposcopy being utilized in the initial examination (for baseline data)?

8. Was a colposcopy (an examination using a magnifying instrument) done on your first or second DES examination? ( ) Yes ( ) No

VI. Use of Biopsies

Subquestion: 6.a. Are biopsies being performed when indicated by abnormal Pap tests?

17. Have you ever had an abnormal Pap smear? (Check one)
( ) Yes
( ) No (If no, skip to Question 18)
( ) Don't Know (If don't know, skip to Question 18)

Abnormal Pap Smear Age/Year	Was a Biopsy done?
1.	( ) Yes ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know

Subquestion: 6.b. Are biopsies being performed when there is other evidence of significant epithelial abnormalities?

18. Have you ever been told by your health care provider that you have had changes in the vaginal lining/tissue (i.e., epithelial changes, dysplasia, adenosis)? (Check one)
( ) Yes
( ) No (If no, skip to Question 19)
( ) Don't Know (If don't know, skip to Question 19)

Tissue Changes Age/Year	Was a Biopsy done?
1.	( ) Yes ( ) No ( ) Don't Know
2.	( ) Yes ( ) No ( ) Don't Know
3.	( ) Yes ( ) No ( ) Don't Know

VII. Breast Examinations

Subquestion: 7. Are breast examinations of DES daughters being performed according to the current National Cancer Institute guidelines regarding the frequency of screening examinations?

22. Do you perform breast self-examinations monthly? (Check one)
( ) Yes ( ) No ( ) Not routinely, but do check on occasion

23. Does your health care provider examine your breasts at least once a year? (Check one)
( ) Yes ( ) No ( ) Not routinely

24. Have you ever had a mammography (breast X-ray)?
( ) Yes ( ) No

If yes, please state at what age and why: _____

BACKGROUND DATA

1. Are you a DES-exposed daughter (i.e., did your mother take Diethylstilbestrol [DES] while pregnant with you)? (Check one)
   ( ) Know for sure
   ( ) Think I am - - not verified by medical records
   ( ) Don't know

2. How were you informed that you were exposed to DES? (Check one)
   ( ) Letter or phone call from mother's health care provider
   ( ) Informed by mother
   ( ) Diagnosis by health care provider through physical exam
   ( ) Other (please specify) _____

3. Have you tried to obtain medical records to verify DES exposure?
   ( ) Yes ( ) No

5. Does your health care provider answer questions you have regarding DES exposure? (Check one)

   ( ) Always ( ) Almost always ( ) Sometimes ( ) Rarely ( ) Never

6. Are you satisfied with your health care provider who administers your DES health care? ( ) Yes ( ) No

19. Have you given birth to any children? (Check one)
   ( ) Yes If yes, number of children ____
   ( ) No

20. Have you had any miscarriages? (Check one)
   ( ) Yes If yes, how many ____
   ( ) No

25. Race (Check one):
   ( ) White ( ) American Indian
   ( ) Black ( ) Hispanic ( ) Other (please specify)____

26. Age (Write in) _____

27. Education (Circle highest level completed):

   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
   (Grammar School) (High School) (College) (Graduate School)

28. Marital Status (Check one)
   ( ) Single ( ) Married ( ) Separated ( ) Divorced ( ) Widowed

29. Total Family Income (Check one):
   ( ) Less than $9,999 ( ) $20,000 to $24,999
   ( ) $10,000 to $14,999 ( ) $25,000 to $49,999
   ( ) $15,000 to $19,999 ( ) $50,000 or more

30. In what <u>state</u> do you currently reside? (Write in) _____

31. Do you have health insurance? ( ) Yes ( ) No

If yes, does your health insurance cover your DES exams? ( ) Yes ( ) No

A P P E N D I X F

Approval Letter from UCRIHS

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MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

November 19, 1986

Ms. Louise A. Pointkowski
2811 - 21st Street
Wyandotte, Michigan 48192

Dear Ms. Pointkowski:

Subject: Proposal Entitled, "Extent to Which Female Offspring Exposed to Diethylstilbestrol (DES) in Utero Receive DES Task Force Recommended Health Care"

I am pleased to advise that I concur with your evaluation that this project is exempt from full UCRIHS review, and approval is herewith granted for conduct of the project.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to November 19, 1987.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to my attention. If I can be of any future help, please do not hesitate to let me know.

Sincerely,

Henry E. Bredeck, Ph.D.
Chairman, UCRIHS

HEB/jms

cc: Dr. Barbara Given

APPENDIX G

Relevant Subquestions by Group

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To answer the overall research question:
TO WHAT EXTENT DO DES DAUGHTERS RECEIVE THE HEALTH CARE RECOMMENDED BY THE FEDERAL GOVERNMENT'S DES TASK FORCE?

	Relevant Subquestions
Learned of exposure during puberty:	1
Abnormal Pap Smear:	4, 5a, 6a
Epithelial changes:	4, 5b, 6b
Received care (for all DES daughters):	2, 3, 5c, 7

Relevant Subquestions	Group
1 2 3 5c 7	1. Women who learned of exposure during puberty who did not have abnormal Pap Smear or epithelial changes.
1 2 3 4 5a 5c 6a 7	2. Women who learned of exposure during puberty who had an abnormal Pap Smear but not epithelial changes.
1 2 3 4 5b 5c 6b 7	3. Women who learned of exposure during puberty who did not have an abnormal Pap Smear but did have epithelial changes.
1 2 3 4 5a 5b 5c 6a 6b 7	4. Women who learned of exposure during puberty who had an abnormal Pap Smear and epithelial changes.

Relevant Subquestions	Corresponding Criteria	Group
2 3 5c 7		5. Women who learned of exposure after puberty who did not have an abnormal Pap Smear or epithelial changes.
2 3 4 5a 5c 6a 7		6. Women who learned of exposure after puberty who did have an abnormal Pap Smear but did not have epithelial changes.
2 3 4 5b 5c 6b 7		7. Women who learned of exposure after puberty who did not have an abnormal Pap Smear but did have epithelial changes.
2 3 4 5a 5b 5c 6a 6b 7		8. Women who learned of exposure after puberty who had an abnormal Pap Smear and epithelial changes.

A P P E N D I X H

Comments of DES-Exposed Daughters on Questionnaire

APPENDIX H

Comments of DES-Exposed Daughters on Questionnaire

"Thank you for this study. This 'disease' and its symptoms will be with us forever. We will overcome this only by knowing what to look out for. And thanks to people like you for making us aware through research!"

"The Government should be made to subsidize these exams."

"Thanks for this. Any research will always help us. After seeing DES 'specialists' for 13 years, I've finally found one who is great. I have, in the past, been the one to bring current DES info to my so called specialists!"

I must admit that my appreciation for the value of gynecologic testing on a yearly basis was well instilled in me at a young age because of my DES exposure. However, so many of my non-exposed DES friends fail to see the importance of routine checkups unless they have a GYN problem or issue concerning birth control or infertility. We women need to wise up and get on top of our personal health!!"

"... My DES exposure has brought us 7 years of heartache, expense, surgeries, and grief."

"There are no questions here about the emotional impact of DES exposure. I probably will never be able to have children. I have the constant threat of cancer hanging over my head. My reproductive system has been tampered with and I have no way to deal with it other than talking about it with other DES victims.

I have had severe emotional problems throughout my life. I must deal with the fact that I will always have to take medication because of the altered chemistry in my brain. (I take Lithium and Sinequan). Did the DES exposure cause this?

I spend my life consumed by rage at the insensitive male M.D.'s and drug companies. I will carry this pain with me until the end of my days.

Please include this in your survey. Because after all the painful exams and laser surgeries and fears about biopsy results I am still left with my anger.

The only bright spot in all this is that my husband and I are on the waiting list for a baby girl from Korea. Knowing that I will become a mother in 2 months eases some of this pain. Good luck with your Master's thesis!"

"I have had to have a complete hysterectomy and oophorectomy due to severe adenosis. ... The problems I have encountered due to DES exposure have almost completely destroyed my health and well being. It is painful to even think of all the problems."

" --- 'Infantile' reproductive system

--- Difficulty getting pregnant

--- 3 miscarriages -- all 1st trimester

--- Cervical incompetence (current cerclage put on at 19 weeks for 1-1/2 cm dilation in 2nd child)

--- No spontaneous labor on 1st delivery (induced with cervical tearing & poor dilation)

--- Abnormal placental adhesions with hemorrhage & manual removal

--- Bleeding in 1st and 2nd trimester secondary to low placenta during current pregnancy

--- My daughter has no vaginal opening and will have surgery. (I did not take DES). Other implications unknown at this time."

"Due to my DES exposure, I underwent a total abdominal hysterectomy in 1981. My husband and I have no children and it hurts me very much knowing that I will never be able to conceive."

"... Mom took DES for my brother and sister too. Brother has a low sperm count but does have 2 children. Sister has had cone biopsy for carcinoma-in-situ. She appears to be O.K. for now. An unexposed sister also had a cone biopsy because of abnormal Pap smear (I am unsure of the specific problem).

... My concern is for my daughter. Hopefully there are no long term problems passed on to her.

Thank you for your study."

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Thank you for your study."

"... Also, it would be great to have a DES hotline for those times when you would love to talk to someone about your fears, concerns, anxieties, etc."

"Part of the reasoning for my not going for specialized DES exams anymore is that I felt like a research project, and with anywhere from 1 - 3 or 4 doctors gathered around, it really seemed ominous even though my exams are all benign (I have anatomical changes 'DES Hood'?). When I was younger I felt like I was making an important contribution, now that I'm in my child-bearing years, I find these exams extremely unnerving."

"The objection I have to my treatment is the extent to which my present Dr. goes to protect the rest of the medical community at the expense of pursuing the problem."

"My biggest problem is the fact that it has literally taken more than 7 years to find adequate (DES informed) medical attention. This began from when I first found out that I was DES exposed in 1976. Before that time I had 5 D&Cs and a cone that has left me with an incompetent cervix. To be honest, I have been butchered quite badly in this area. Even in a city as large as Atlanta, there are not an abundance of medical practitioners who are concerned or informed about DES patients."

"My health care during my unsuccessful pregnancies was less satisfactory than my current health care. They didn't link the

repeated miscarriages to DES until after the third one, even though my exposure was verified."

"... In the past I have had very un-informed providers. One told me I had cancer; took biopsies; had me return in one week to tell me I didn't have it after all. He had never examined a DES daughter before! Others were as bad..."

"... I've been through DES screening at a county health facility where I received poor info."

"I was told that since my colposcopy was fine (6 years ago) that all I need now is yearly Pap tests. But, honestly I'm not sure the MD's really know what proper protocol is! Or that a standard exists."

"I feel OB/GYN's should be provided with updated guidelines re: care of DES exposed women -- too many I have seen have not been sensitive to my concerns."

"I have been going for regular examinations every six months since 1978. I am satisfied with my health care provider in terms of cancer checks. In terms of the questions of other areas, such as fertility (I am single), general infections and how they relate to DES daughters, and other areas, I am not satisfied. I do not fault my health care provider, rather the lack of researh done. More studies need to be done in other areas."

"My mom always knew what drug she was taking while carrying me. In fact she stopped taking it because it was making her sick but her doctor scared her enough so she took it again."

"Several years ago, after a Class II+ Pap and subsequent biopsies, I was advised to have cryosurgery of the cervix. A second opinion at U. C. Medical Center -- a horrible, horrible experience as 'DES research material', by the way -- confirmed this recommendation. I refused and did not follow this recommendation. Two years later, it was found that DES daughters don't heal properly after cryosurgery -- that the procedure often causes more problems than it solves.

This was the last straw in my ongoing series of quite horrid experiences with the medical establishments. I still have a perpetual Class II+ or III Pap, but I have no intention of receiving 'treatments' to continue my role as a guinea pig."

"Because I've moved so often for jobs and school, and often to small towns, I have not had continuous care from one doctor. This causes overreactions by doctors unfamiliar with my history (despite photos) -- they tend to want to biopsy. Also, I've found it very difficult to find sympathetic doctors (as opposed to nurses) -- most aren't willing to discuss my concerns & fears (e.g., 'don't worry about miscarriages until you want to get pregnant')."

"... I would answer emotional questions too (fears about cancer, miscarriage); has DES made me fearful of having children? YES! Afraid of cancer? YES!"

"I feel that health care providers should be more alert to effects, other than cancer, of DES exposure & should let their patients know other potential risks. I only found out that I have a T-shaped uterus after my miscarriage, & was still unaware of higher risk of tubal pregnancies — until after I had one and began doing my own research/reading. I had felt safe because my doctor said the risk of my developing cancer was pretty much over. Maybe there needs to be more publicity in general..."

"I am glad this research information is being collected. I feel like the more background information that can be accumulated the better we can treat the complications."

"... Forgive my cynicism, but despite all the attention given to a fetus by 'pro-life' groups, and all the attention given to infertility and surrogates, etc., no one can tell me why I can't have a full-term successful pregnancy! I can't be the only one with this problem. Why is there no research to help pinpoint why I miscarry?!"

"In 1984 my mother had a radical mastectomy. She was taking DES during my pregnancy in 1953. She may have taken it in 1950 with my brother's also. He died in 1980 from Leukemia."

"Think it would be very interesting for someone to do a study on the emotional effects of DES exposure. Willing to bet the DES exposed have significantly higher levels of assertiveness, etc.

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Thanks to this experience. When you are injured in your 'femaleness' so to speak, it goes deep."

"... My OB/GYN did not monitor me as high risk and did not seem to be concerned about what the infertility doctor said. In October 1984, I delivered a 2 lb. 8 oz. infant with severe respiratory problems along with the other complications of prematurity and a five month hospital stay. He is also diagnosed as having severe cerebral palsy. I have since been very educated on DES. If I would have known then all the information I know now on DES daughters, I would have been monitored as a high risk patient. I have seen two other infertility specialists since then. They recommend getting pregnant and being treated high risk. I, of course, am real puzzled as to what route to take (no more children, pregnancy, adoption, or surrogate mother)..."

"Medical records purchased from hospital after many rare unexplained problems."

"I wanted to add some comments to your questionnaire perhaps to clarify my answers.

My mother was given the drug Stilbestrol in June of 1950. I was born in late March of 1951. I was exposed at a very early stage. About the third week, as far as we can tell. The drug was continued until I was born.

I was born with a urethral stricture and it was also misplaced. I had to have two dilations a week until I finally had surgery years

later. I have read where this is found in some exposed males. My mother developed breast tumors and died from breast cancer.

My periods never lasted over two days and were very light for the extent of my menstrual life. Finally at the age of 26 I went through premature menopause which has only now been diagnosed. I was told that it was probably anxiety for several years. I have not had a period since I was 26 years old. Almost ten years ago. My periods did stop for one year when I was 20 and again at 24, but they would return lightly until they did end.

My babies all had birth defects. My daughter who did survive, a miracle, is almost 14 years old. She had two major surgeries for her birth defects. She is now having menstrual problems too. Hers have stopped, as mine did. Genetic work-ups have been suggested to us to see if I became a carrier of birth defects because of DES and perhaps my daughter will be too. If she is able to have children. At this point we are only beginning the testing.

In my city and state, adequate health care for DES is extremely hard to find. Physicians are hesitant about having us for patients because of any possible legal proceedings as a result of DES. Information of any nature regarding DES is almost impossible to find. I had to search myself, the physicians offered me no advise whatsoever. I was really shocked. The Cancer Society in my city did not even have any information on DES or know what it was. And this is the capital of the State.

But, I have found out that I do have many DES problems. I have the extremely small uterus. I show signs of DES on the cervix. I am going to have a colposcopy and biopsy on February 20th. The HSP dye test is being considered. I am infertile and was most of my life

according to my GYN.. The babies were a mystery as far as they can tell. My reproductive tract functioned so very little most of the time. But DES screening is really impossible to find in this State. This has been a long and a very hard struggle. And the end is not here yet."

"Shortly after I lost my second daughter (born premature at 7 months), I heard about DES. I read that it could cause reproductive abnormalities, & I knew there had to be a reason I lost my babies so late in pregnancy. I also knew my mom had had lots of problems trying to get pregnant & that she'd bled off & on, early in her pregnancy with me. I knew they'd given her 'several things', but she couldn't remember what any of it was.

By this time, I was 24 years old. My mom's doctor had long since died & my medical records were destroyed. I wanted children, I needed answers. Every time I saw a new doctor I'd ask about DES, but got nowhere. Finally after 2 years, an Australian doctor on an exchange program with the military in Hawaii examined me & exclaimed, 'This is a DES daughter!' to my OB-GYN & began to explain to him about the physical changes he could see because of DES — cockscomb cervix, etc. I insisted they do further tests, because we were in an Army Medical Center. I fought the battle for answers for years. I couldn't accept their telling me that DES was nothing to worry about!

I no longer ask questions & accept answers. I find my own answers thru DES Action and medical journals.

Without DES Action, we victims would have nothing. As long as we're living with the pain & stress & uncertainties resultant of that drug, the story is not over.

I'm doing everything I can to educate others about DES, & warn of the possibility of another similar occurence in the future if we don't end indiscriminate sex hormone use.

Little by little, we'll eventually reach our goal.

Thank God for DES Action.

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