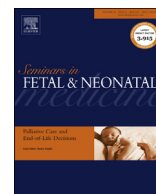




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## Review

# Counseling women and men regarding exposures to reproductive and developmental toxicants before conception or women during pregnancy



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## S U M M A R Y

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It should be apparent that determining the reproductive risks of an exposure during pregnancy or the cause of a child's congenital malformations is not a simple process. It involves a careful analysis of the medical and scientific literature pertaining to the reproductive toxic effects of exogenous agents in humans and animals, as well as an evaluation of the exposure and the biological plausibility of the concern of an increased risk or a causal connection between the exposure and a child's congenital malformations. It also involves having available a detailed physical examination of the malformed infant or child and a review of the scientific literature pertaining to genetic and environmental causes of the malformations in question. Abridged counseling on the basis of superficial and incomplete analyses is a disservice to the family. Experienced counselors understand that their primary task is to educate the pregnant women or family members concerning the risk of an environmental exposure. The counselor should advise them on the options available, but not on which option to select.

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## 1. Introduction

In 1944, during World War II, I received my draft notice for induction into the armed forces, which would occur in mid 1945. At the age of 15 years, I applied to the University of Rochester, since I had passed all the high school senior courses which included advanced physics, biology and chemistry. In June 1944, I was a freshman at the University and obtained a part-time position at the Manhattan Project Research facility in Rochester in the genetics and embryology divisions. Whereas all the employees at the University of Rochester were investigating the biological effects of ionizing radiation and the entire research staff had the highest level of security clearance, none of the staff were aware that researchers in Los Alamos were attempting to develop an atomic bomb. After the war ended in 1945, the Manhattan Project became one of the Atomic Energy Commission (AEC) facilities at the University. In 1949, I entered medical school but continued my embryology radiation research. The head of the division, Dr James Wilson, offered me the opportunity to be his graduate student in the summer of 1950 and Wilson spent the summer intensively training me in all

the experimental techniques used in that division. At the end of the summer, Dr Wilson announced that he had accepted a position at the University of Cincinnati. Rather than close the division, the Administration appointed me the Head of the Division. I had a budget, a technician and secretarial support and I taught the University of Rochester medical students embryology during the next four years while I was in Rochester completing my medical and graduate degrees. During these four years my national and international counseling effort began at the University of Rochester.

The only other major AEC facility in the country interested in radiation effects on reproduction was at Liane Russell's excellent laboratory in Oak Ridge, Tennessee. However, she was extensively involved in pursuing her research. So the calls and letters all came to Rochester, and then to the Massachusetts General Hospital where I was a resident physician and the Walter Reed Army Institute of Research where I was the head of the Radiation Biology Section for my two years of Army service from 1955 until 1957. I arrived at The Jefferson Medical College in 1957 and have been there for 56 years. In the 1950s there were practically no educational programs in medical school or graduate school that pertained to the evaluation of the risks of reproductive and developmental toxicants or counseling families with regard to the presence or absence of risks from these exposures. The concept of professional counseling was still in its infancy.

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## 2. The stages of medical and graduate school education in the USA: When did counseling with regard to reproductive and developmental toxicant exposure become a recognized and necessary skill?

Medical education in the USA received a major impetus following the publication of Abraham Flexner's (1910) monograph that was commissioned by the Carnegie Foundation for the Advancement of Teaching [1]. Prior to being contacted by the Carnegie Foundation, Flexner graduated from Johns Hopkins in 1885 at the age of 19 and crystallized in his mind the components of quality higher educational programs: small classes, personal attention and hands-on teaching. He returned to Louisville and founded a medical school using these principles. The graduates proved to be emissaries of what quality education can accomplish. It was these early successes that convinced the Carnegie Foundation that Flexner was the scholar who could improve medical education. Following the implementation of the Flexner Report many rural medical schools closed. Many physicians are unaware that Flexner was not a physician nor did he have an advanced degree. However, he was a brilliant teacher and scholar.

Over the next 50 years the Flexner model of medical education evolved into the bioscience model of medical education and medical practice. High quality basic science education and research 'could provide all the answers', so that physicians could diagnose, ameliorate, treat or cure medical problems with which they encountered.

Unfortunately, the bioscience model is incomplete and can result in a significant portion of the patient population being dissatisfied with their care. This was evident to George Engle at the University of Rochester. He was trained in psychiatry and internal medicines and published many articles about the biopsychosocial model of health care delivery that reflected his interest in psychosomatic medicine [2]. At the University of Rochester Engle established the 'medical psychiatric liaison service' staffed by internists and psychiatrists. Engle indicated that he would prefer having physicians with behavioral training rounding on the other clinical services rather than on the psychiatry service. Engle was adamant that you cannot ignore the impact of the environment on the patient's disease or the behavioral defenses available to the patient. It was clear that Engle believed that compassion and empathy were important components of the biopsychosocial model of medical care.

Carl Rogers [3–5] is probably the most important contributor to the elements of proper counseling since he emphasized the humanistic approach to psychological counseling. If the patients or contacts do not sense that the counselor is compassionate or empathetic, their interaction will be less than satisfactory. Exhibiting genuine compassion and empathy results in a client-centered interaction with much greater success in properly communicating and educating the contact. The client, patient or contact has to believe that the counselor believes that the contact deserves respect, which is demonstrated by exhibiting compassion and regard for the contact (unconditional, positive regard) [4]. The fundamental precepts of Rogerian counseling include congruence (being genuine in one's concern), empathy, and unconditional positive regard [4]. A widely accepted component of genuine concern in medical counseling is the responsibility of the counselor to provide core knowledge of the evidence addressing the issue in question. To be genuinely concerned is to seek and provide reliable information. A further adaptation of these principles involves providing an unbiased discussion of the facts surrounding the problem being addressed. Empathy requires some knowledge of, and sensitivity to, the social and cultural position of the persons being counseled.

During the first 50 years of the twentieth century, the rules of professional counseling were rarely articulated or taught. It was only after the writings of Engle and Rogers that the essential features of professional counseling were legitimized, whether it pertained to psychotherapy, medical care and especially for counseling contacts concerning reproductive and developmental risks from environmental exposures.

## 3. The history of providing counseling to pregnant women exposed to reproductive and developmental toxicants (teratogenesis, congenital malformations), and men and women with preconception exposures (mutagenesis in the gametes and in the offspring in the next generation)

Individual counseling is part of the practice of clinical medicine. However, at the beginning of the twentieth century there were very few individuals prepared to counsel patients with regard to the risk of reproductive, developmental and mutagenic toxicants.

Our laboratory has provided consultations dealing with the risk of various environmental toxicant exposures during or before pregnancy since 1950. In 1960 a group of 60 scientists interested in birth defects met at the Slone Kettering Institute in New York City to discuss their common interests in the causes of birth defects and decided to create a Birth Defects Society. In 1961 many of those scientists met in Cincinnati where the charter of the Teratology Society was drafted. Within the Teratology Society a proportion of the membership was interested in providing counseling to the patient population. There were diverse opinions as to whether individuals who provided counseling should receive training and pass a certification examination. That issue was never resolved. However, the problem was partially solved in the 1990s when the Organization of Teratology Services was formed, which frequently meets with the Teratology Society at the latter's annual meeting. In 2005, the name of OTIS was changed to the Organization of Teratology Information Specialists. In Europe the European Teratology Society (founded in the 1970s) and European Network of Teratology Information Services (ENTIS) define the counseling organizations in Europe having active scientific and counseling programs, as also happens in Japan and Australia. But none of these organizations professionally certifies individuals to provide counseling, although some members may be certified genetic counselors.

In North America there are many OTIS members and branches. The Mother Risk program ([Motherrisk.org](http://Motherrisk.org)) headed by Dr Gideon Koren is located at the Hospital for Sick Children and the University of Toronto. In San Diego, Dr Kenneth Lyon Jones heads the largest program in California; and in Seattle, the TERIS program was initiated with a federal grant obtained by Dr Jan Friedman. With the advent of the Internet, consulting has become more rapid and efficient. In 2012 the Ask the Expert (ATE) website of the HPS (Health Physics Society) received about 2 400 000 hits. More than 700 000 prepared answers to questions were downloaded. More than 1800 contacts were still quite anxious after reading the website answers and requested a personal consultation. During 2012 our laboratory received its 25 000th consultation. We also receive consultations by letter, telephone and e-mail unrelated to the HPS website. From this extensive experience we have learned that many physicians and other health care counselors are not prepared to counsel patients concerning reproductive and developmental risks. Approximately 6–10% of the contacts concerned about various environmental toxicants had been provided inaccurate information that stimulated unwarranted anxiety that could have resulted in an unnecessary interruption of a wanted pregnancy.

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