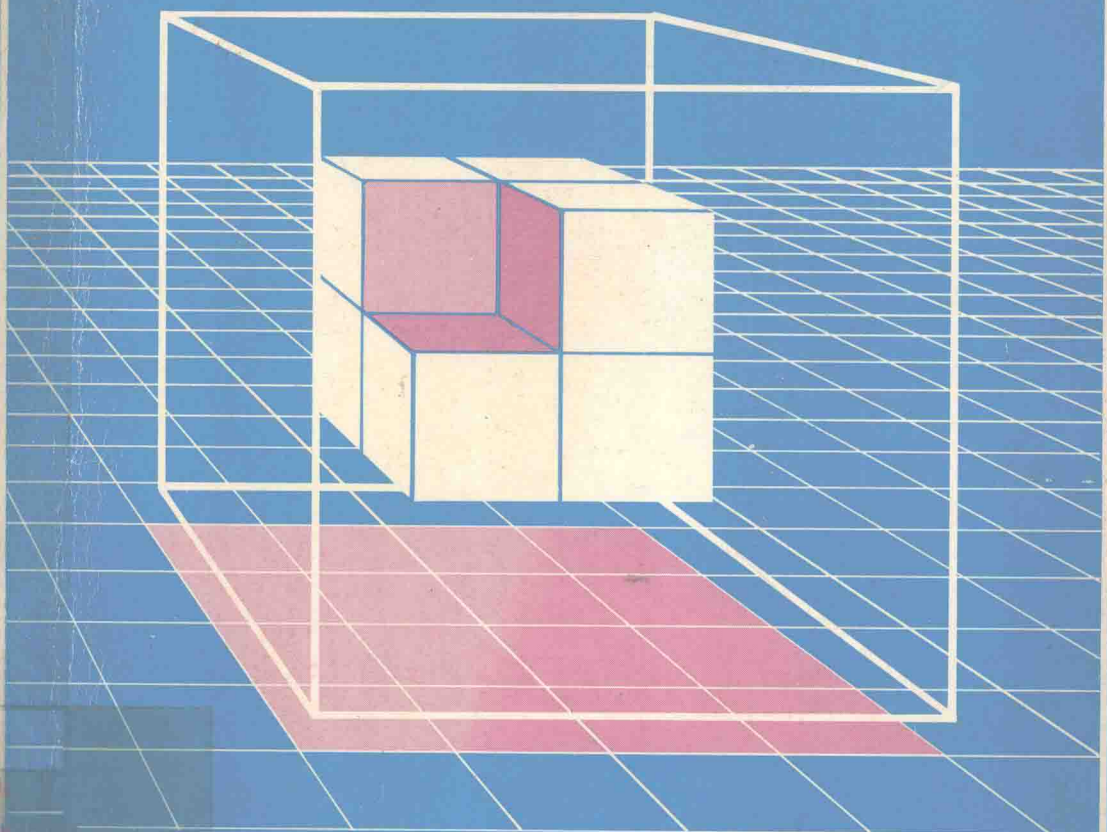
ADVOCACY

Risk and Reality



Mary F. Kohnke

ADVOCACY
RISK AND REALITY

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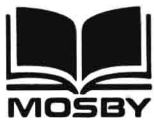

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To
MARY

PREFACE

This book is written for those who by inclination or position find themselves functioning in the role of advocate. In particular it focuses on nurses, since they have either chosen or been placed in the role, but the principles discussed in this book will serve anyone who is involved in advocacy. Another reason why this book focuses on nursing is that I am a nurse; nursing is what I know the most about. I discuss the risks and hazards of advocacy from the point of view of nurses, but these risks and hazards are common to all advocates. The risks faced by an advocate in one setting are only variations of those faced by an advocate in another setting. Therefore the types of knowledge needed to cope with risk are similar for all advocates.

I use the term "cope" advisedly, because cope you will. Nurse advocates in a sense set themselves up to be criticized by all who disagree with the decisions a client makes. It is much easier for an advocate's fellow professionals to make a scapegoat of the advocate, for supporting those decisions, than to attack the decisions of the client directly, especially if the client is sick, poor, or not knowledgeable enough to act for himself.

Advocacy is not a new idea. Lawyers have engaged in advocacy for years, but for pay. Certain organized groups, such as Common Cause, have set themselves up as consumer advocates. Cities have set up offices of consumer advocacy, hospitals

have hired ombudsmen, and even police departments have been forced to create civilian review boards.

However, it is when a lone individual gets involved in advocacy that the problems inherent in the activity become most obvious. The early years of the career of Ralph Nader offer some good examples of these types of problems. Nevertheless, the role of advocate has become more and more an individual role. This is especially true in the profession of nursing. In the literature the nurse is encouraged to be the patient's advocate, and many nurses (and other health care professionals) have found that the public, too, expects this to be part of the nurse's job.

Despite this social pressure to go out and "rescue the Holy Grail," we nurses rarely find anyone telling us how to do so and how to avoid the risks involved. As a result we see either very little advocacy or more reports of failures than reports of successes. It was with these thoughts in mind that I ventured onto the somewhat precarious course of writing a book on the practice of advocacy.

How one approaches the study of advocacy is presented in Chapter 1, along with my view of what advocacy basically entails. The rest of the chapters are devoted to some of the essential categories of knowledge one needs to consider in the enactment of the role of advocate. They are set up in an order that permits a reasonable learning style, but one can skip around. I may be accused of leaving out more than I have included and of being superficial, especially in the areas of ethics and legalities. However, so many excellent books and articles have been written in both these areas that to condense them here would be an injustice not only to the reader but also to the authors. But no one has written on advocacy itself. This omission has left many in the position of having to enact a role about which they have little or no knowledge. This book helps to fill that gap. Rather than call this a "how to do" book, however, I call it a "how to think, analyze, and survive" book.

What I would most like you to remember as a result of having read this book is that advocacy is the act of loving and caring. As such, it is not to be approached as something that we all do, because we don't. It is not something that we are born with, because we aren't. If we were, it would be more common. Advocacy, like caring, is something that we do because we either experienced it from others as we grew or learned it because it was valuable and right for us to do. Loving and caring are not automatic; they involve an act of free will, a choice of a way to behave and to see ourselves in relation to others. Some say that loving and caring require a self-imposed discipline; others say that they result from a natural gift. But as is true of all disciplines and gifts, one must learn how to use them, not only for the sake of others but also for one's own sake. Thus, this book is intended to show you how to perform your social duty and survive at the same time.

This is the point in a preface where an author generally admits, "I had help." But before I acknowledge the people who helped me and duly thank them, I would like to say a bit about the risk and reality of asking for help—from the points of view

of both the helper and the asker. When you ask for help or consultation—in other words, seek out an advocate—you are generally going to get what you asked for. However, you may not always like what you get. Writing a book is like producing a baby: like any mother, you believe your baby is perfect. God help anyone who points out that the baby has six toes, crossed eyes, or blemishes—that, in fact, your product may not be quite perfect.

Brave and diplomatic indeed must be the helper who swims in these waters. Seeking help, the most mild-mannered of authors can suddenly become a shark defending prized territory. One might assume that the more experienced an author is, the less sensitive he is. However, it is just as likely that the reverse will be true.

The people I asked for help gave it kindly and graciously. I, *of course*, accepted it in a like manner. I accept full responsibility for everything that appears in this book. My helpers tried to keep it clean, clear, and somewhat literate. If there are passages that are less than that, they probably resulted from my more sensitive, sharkish moments—when the helpers swam for the shore.

Let me briefly mention the five people who helped me the most with the manuscript—and a sixth, my brother John, who also assisted me. I wrote the book while on sabbatical leave in Florida. John appeared almost every day, late in the afternoon at cocktail time, with, I am sure, two purposes in mind. The first was to remind me that there was a real world with real people in it outside the glass walls of "The Refuge" and the narrow focus of my typewriter. The second was to maintain, or at least to check on, the sanity of his sister. He was usually successful on both counts, since his arrival generally stopped the writing process for that day.

At The C.V. Mosby Co. there were three people who suffered me patiently. My editor Alison Miller and her assistant Susan Epstein were always available to me, but they may have wished that they had been on vacation certain days when I called. Also, there was Steve Hetager, who edited my manuscript. I don't know what I would have done without him. How seldom we authors acknowledge the debt we owe people like these.

At the very start of this project, before my sabbatical leave, I had a research assistant, Peggy Garbin (soon to be Dr. Peggy Garbin). Peggy's assistance in helping me separate reference materials that were essential from those that were not was invaluable. A bright and scholarly young woman, she had the intellect, humor, and political expertise necessary to make justifiable criticisms of the literature and of some of my ideas as well.

Every author needs a devil's advocate. For a book like this and an author like me, an especially astute one was needed. I found just such a person in Dr. Mary Duffy. She was my primary reader of the first draft, and those of you who are familiar with my first drafts will know what a chore that must have been. I asked her to respond to the manuscript in two ways: Was it clear? Was I ever in error? You will notice that I did not ask her, "Am I right?" or "Do you agree?" Like the fine

consultant and diplomat she is known to be, Dr. Duffy limited herself to the former two questions in her written critiques. In our conversations, however, she did volunteer some answers to the two questions I did not ask her, and although I took these comments into consideration, I did not always act on them. So in no way is she to be held responsible for my sins of commission or omission. But I do hold her responsible for having provided me with thoughtful and scholarly comments and support. It is that kind of no-nonsense support that anyone who embarks on the writing of a book needs. As an advocate, I would like to advise you to go out and find a Dr. Mary Duffy, a Peggy Garbin, and people like those I found at Mosby. They make the publishing process survivable.

I must add that I had a friend who was with me all the time. I do not hold this friend responsible for any of the content of this book; the responsibility for that is all mine. But this friend's inspiration, quieting influence in times of desperation, and patience with me were always present. For these things I am eternally grateful and say simply, "Thank you, Lord."

One final word before you embark on this journey into the role of advocate: I have attempted to keep footnotes and supporting documentation to a minimum. I have occasionally included footnotes to clarify particular points or to provide bibliographic information. At the ends of chapters, I have often included lists of supplemental readings as well as comments about their value to the subjects under discussion.

Mary F. Kohnke

CONTENTS

Chapter 1

ADVOCACY: WHAT IT IS

EVERY FEW YEARS A PARTICULAR TERM OR CONCEPT becomes very popular. Presently "advocacy" is one of these popular buzzwords. Everybody talks about advocacy and seems to be doing it. The term involves such connotations as "protect" and "rights" and conveys the idea that it is something that "good guys" do. Advocacy also seems rather simple, that it is something anyone can do. In nursing education we tell our students to be the patient's advocate. We do not, however, tell them very much more about it, except that it is a "good thing." We seldom deal with questions such as "Is advocacy risky or troublesome?" or "Can advocacy be hazardous to your health?" The answer to these questions is yes; advocacy can be risky and even hazardous. But nonetheless, it is a good thing, and like most good things should be done.

In order to be an effective advocate, you need to know what advocacy is, how to do it, and how to do it well and safely. For just as you cannot venture into a minefield without a mine detector, you cannot venture into advocacy without knowledge and foresight. In the words of the New Testament, advocates should be "as wise as serpents and as gentle as doves."

DEFINITIONS

Let's start with definitions. The definition in most general dictionaries is that advocacy is "the act of defending or pleading the case of another." This definition is applicable to a courtroom situation, and it describes the situation that exists when the other person is very young or unconscious, when he is not present to defend himself, or when he is not able to act in his own behalf. This definition does not apply to advocacy in general or to most of the situations that the practicing nurse encounters. Nurses do not always deal with the very young patient or the unconscious patient. Most of their clients are conscious and able to speak or act. Therefore, what is the role of the advocate in this vast majority of cases? Briefly, the role of the advocate is to *inform* the client and then to *support* him in whatever decision he makes. This type of support differs from the support provided by a lawyer. In the practice of law, the lawyer advocate actually presents the client's case and either pleads for justice or defends the client from accusation. In the nurse advocate role, however, support means that when the client makes a decision, the nurse abides by it and defends his right to make it. The role of advocate comprises only two functions: to inform and to support.

These two functions seem on the surface to be relatively simple. Perhaps this is why most nurses do not study advocacy further. Most educators of nurses do not teach advocacy per se. They teach ethics, ethical codes of behavior, and the intricacies involved in ethical dilemmas. The literature is filled with articles and books on various aspects of ethics and the ethical dilemmas facing a professional. I am not

saying that ethics is unimportant, but rather that ethical codes change from profession to profession, culture to culture, and time to time. Professionals must practice within the ethical codes of their professions. But these codes are only one aspect of the larger knowledge base of advocacy and the role of the advocate. Advocates must act ethically, but ethics does not teach one the role of advocate.

The same applies to the legalities of professional practice. Professionals must practice within the legal restraints of their license and the law. They must be aware of the laws governing their practice—not only for the client's safety but also for their own. But again, these laws change from state to state and from time to time. They are even more fluid than ethical codes. Though the advocate works within the confines of the law, the law does not teach a person how to be an advocate. Laws are written to act as protective devices. It is indeed wise to keep abreast of the laws that affect one's practice, for they are a valuable part of one's knowledge base as an advocate—but only a part.

Thus it is a mistake to think that all an advocate needs to know is some ethics or some law. The advocate role is action filled. It has many complexities and needs to be treated as a totality in and of itself.

There are many risks and hidden hazards in advocacy for both the client and the advocate. The most important attributes for the advocate to possess, for the safety of both, are a state of open-mindedness and a broad knowledge base about people, society, and the social order. Open-mindedness allows the advocate to listen to, and hear, what the client is saying. This attribute demands that the advocate have a knowledge of self, which includes an understanding of one's own attitudes, values, and beliefs. Such self-knowledge allows the advocate to hear and understand the attitudes, values, and beliefs of others without identifying with them. The advocate allows others to have different values and beliefs. Open-mindedness is extremely important, for the advocate must be able to present information as objectively as possible and to allow clients to make their own decisions, even when those decisions differ from the advocate's personal judgment.

VIEWED AS A GESTALT

Proficiency in many areas of knowledge is needed to create this open-mindedness, an essential ingredient for learning the advocate role. For purposes of discussion in this book, I have divided these areas of knowledge into ten major categories: (1) informing and supporting, (2) systems analysis, (3) social ethic, (4) ethics, (5) issues, (6) medical-industrial complex, (7) social laws, (8) politics, (9) professional education, and (10) professional practice.

As you can see, advocacy entails many areas of knowledge. Rather than view advocacy according to its parts, however, it is better to view it as a gestalt or picture.

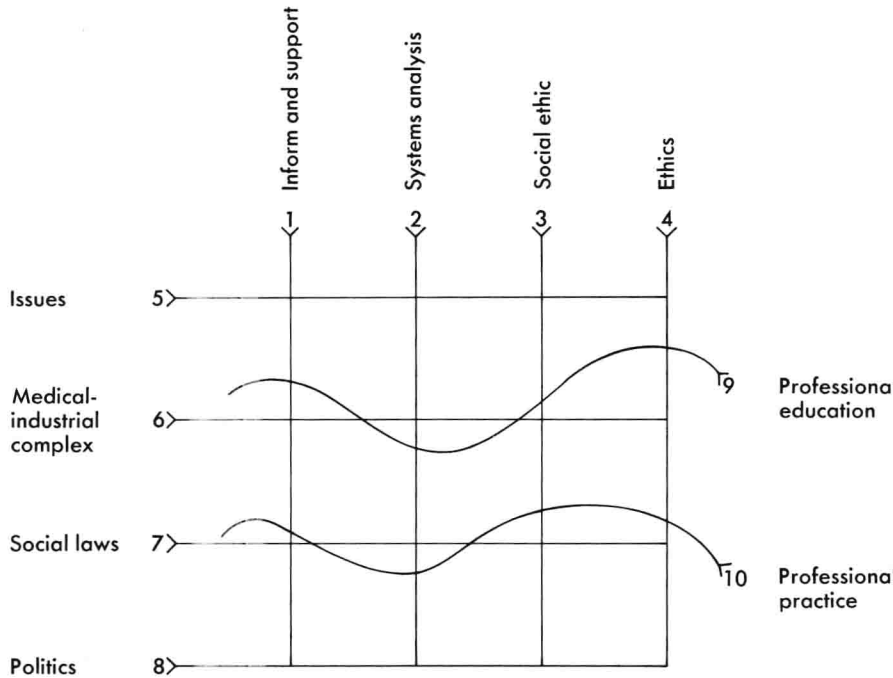

FIGURE 1

Since each part intertwines with every other part, the study of one does not give you a picture of the whole. You must look at each part, but then you must put them together. No one logical sequence fits for everyone. The sequence you follow depends on your learning style and what you bring to the study. It may help if I pictorially present what I am about to verbally describe. But keep in mind that this diagram (Fig. 1) is only one approach to the study.

The vertical lines (1, 2, 3, and 4) represent the first four categories of knowledge: informing and supporting, systems analysis, social ethic, and ethics. The horizontal lines (5, 6, 7, and 8) represent the next four categories: issues, medical-industrial complex, social laws, and the politics of society viewed on a broad basis. The wavy lines (9 and 10) represent the last two categories, professional education and professional practice. At this point a little imagination is in order, for you, the reader, must take this two-dimensional diagram and view it in a four-dimensional way so that movement and pattern are depicted. You will then be able to visualize all the lines intersecting each other and interrelating at any one point along this time-space continuum.

EXAMINED IN DETAIL

Now that you have an overall picture of how the categories intertwine, let's look at each category in greater depth. Although all ten categories of knowledge are needed, the first four categories are what I call fundamentals or basics, for these are the areas of advocacy that do not change over time, but remain essentially the same. The first category deals with the types of knowledge that are involved in the informing and supporting functions themselves. Providing others with information has many facets. One must either have the information or know where to get it. The advocate must want the client to have the information (we don't always want people to know too much). The client must agree to knowing the information (he has a right not to know). The knowledge must be presented in a way that is meaningful to the client. Finally, the advocate must cope with the fact that there may be many persons who do not want the client to have the information. For example, hospital administrators, other professionals (physicians, nurses, and so on), even families and friends, may view informing in a somewhat negative way, as if the client were "the enemy." The act of informing, which on the surface seems simple, can have some complex ramifications.

The same is true of the act of supporting. An advocate must know how to support without falling into a defending and rescuing position, in which responsibility for decision making belongs to the advocate and not to the client. The advocate must understand that supporting a client's right to make a decision does not mean giving approval for the decision. Even clients may demand more of the advocate than support. They may want the advocate to fight their battles for them. Finally, as in the act of informing, there will be people who do not approve of the advocate's supporting the client. They may view such support as the height of disloyalty—to the hospital, to fellow professionals, and to the client's family members, who, after all, say they have the client's best interests at heart. Therefore, what starts out as a simple act turns into a rather complex undertaking.

The second category of knowledge deals with how one examines or analyzes a system. The better an advocate knows the people with whom he or she deals and the systems within which they work, the better the advocate can lessen the risks and hazards involved in advocacy. Therefore, the advocate must have some knowledge of self, clients, families, the health care professions, and health care institutions. In short, the advocate must look at the stated and the unstated goals of self and others. The unstated goals, which are often disguised, are the ones that play the biggest role. The advocate must learn to listen with an educated ear in order to determine what the unstated goals are in a particular situation. Knowing these goals assists the advocate in developing strategies to deal with the risks inherent in informing and supporting. This knowledge also helps to effect needed changes in systems without

causing total disruption and failure in the achievement of goals. Essentially, systems analysis involves following a logical sequence of steps and arriving at alternatives. The advocate then examines each alternative with a fair degree of knowledge of its potential success or failure. Put simply, systems analysis can be called process of gaining understanding.

The third category in the knowledge base is information about what I call the social ethic of the group of people with whom one is dealing. This category does not differ much from systems analysis except that it is more specific in its focus. The term "ethic" as used here is borrowed from John Gardner's book *Excellence*. Gardner believes that the ethic of a group or an institution can be viewed in terms of a continuum, with egalitarianism on one end and libertarianism on the other. Although people may not have a conscious awareness of where they fall on this continuum, they have all formed opinions about the rights of others and about what is owed them or not owed them by society. Some knowledge of the social ethic of a group of people will, as in systems analysis, help an advocate to identify the risks involved in his or her actions and the alternatives that must be considered. Assessing the social ethic is an integral part of the systems analysis process.

The fourth category of knowledge, ethics, flows from the third. There is in most societies a general code of ethics to which everyone at least gives lip service. Within each profession there is a more formal code that is supposed to govern professional behavior in general and specific acts in particular.

Ethics is the study of the nature of right and wrong; it is a vast and intricate field. In this book I will deal with the following aspects of ethics: how ethical positions can affect decision making, how ethical positions are related to developmental stages, and how ethical positions are changeable over time.

The next four categories of knowledge comprise the current broad problems that society has not completely resolved and that influence the individual as well as the group decision-making process. The fifth category is what I call issues: racism, sexism, ageism, and access to education and to health care. These issues have an important effect on the advocate and the risks inherent in the role of advocate. For example, an advocate may work with people who do not believe that persons of another race or color have the same rights that they have. They may believe that blacks, Puerto Ricans, or Chicanos, for example, should take and accept what they get from the system, which is likely to be controlled by whites who "know what is best." A female patient may face a similar situation, especially if her physician is a male who believes women are basically emotional, have no brains, and therefore cannot be expected to make decision for themselves, and if she is unlucky enough to have a husband or male family members who hold the same beliefs. The advocacy process then becomes very complicated. More and more frequently, this same situation is also becoming true for the elderly. If an elderly person disagrees with the professionals, he is labeled "senile"; and if he disagrees with his family, the same

result can occur, especially if he is seen as an inconvenience by both groups. The problem is compounded if the person is also a woman and black. The issue of access to education and health care is closely related to these three "isms." Prejudice influences a person's ability to acquire knowledge or adequate health care. The advocate faces risks in the informing and supporting role for an individual client; when an advocate moves to help certain groups of people acquire the knowledge needed to advance or gain access to health care, the risks may increase.

The sixth category of knowledge is the role of the medical-industrial complex, as some call it, in the health care of the population as a whole. What, if any, special interest groups affect the nature of health care? How do these groups influence the advocate's role? Pharmaceutical companies, for example, make money by selling drugs. If an advocate informs people of alternate methods of maintaining health—sleep without drugs, bowel regularity without laxatives, healthy diets without vitamin supplements, and so on—the advocate is not going to be the drug companies' favorite person. If hospitals need full occupancy to remain solvent, and an advocate helps people to maintain themselves at home, then while the advocate is saving money for the client, he or she is losing money for the institution. If an advocate helps a client improvise equipment at home rather than buy expensive supplies, the supply companies lose money. These groups are tied together to remain viable. If one suffers as a result of an increase in knowledge on the part of consumers, they all are threatened. These groups are joined by other, larger groups, who have special stakes or financial interests in them in the form of stock in a company or a job to maintain in an institution. One could say the bottom line is this: there is no money in health care, but lots of it in "illness care"; so don't rock the boat!

The seventh category consists of the social laws—in other words, laws dealing with social issues—that are passed to protect the population as a whole or segments of the population. How do these laws affect the groups for whom they are passed, and how do they affect others? What are the ramifications of laws enacted to correct past wrongs? Do they, in fact, affect in an adverse fashion the population as a whole or other segments of the population? For example, how do welfare laws affect people? Do the rules governing eligibility for welfare benefits keep people dependent for fear of losing them if they work but cannot make enough to support themselves? Do these rules dictate to people what they will do and, in reality, take away free choice? Does welfare instill an element of fear into a person's decision-making process? Does remaining docile become a requirement for receiving benefits? What if an advocate provides people with knowledge that allows them to question the system? Will the officials who give out the "goodies" like being questioned about their methods? Who will they retaliate against—the welfare recipient or the advocate who started the questioning? These kinds of questions can be raised about many types of laws; the advocate must be aware of the implications involved.

The eighth category of knowledge is the effect politics plays in resolving