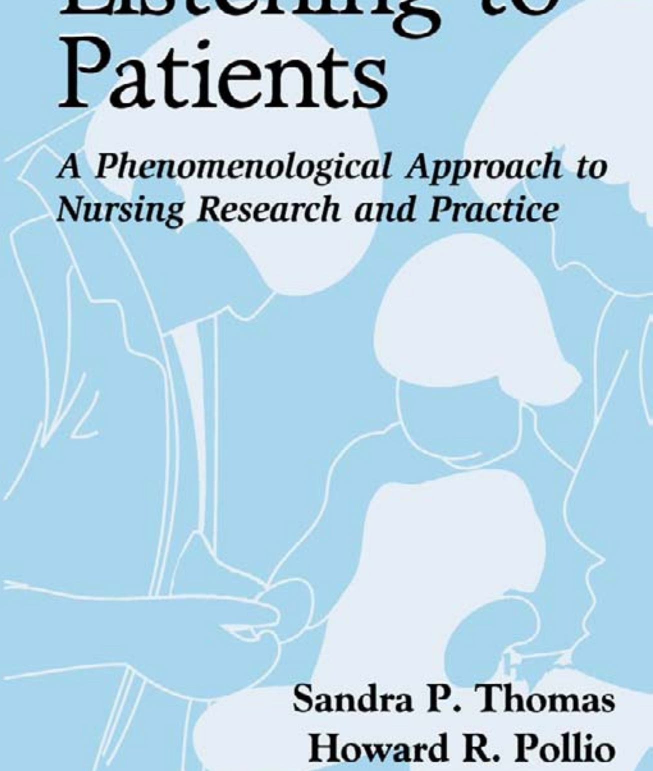

Listening to Patients

A Phenomenological Approach to Nursing Research and Practice

Sandra P. Thomas
Howard R. Pollio

Springer Publishing Company

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This book is dedicated to the patients who shared their experiences with us. We are hopeful that nurses everywhere will hear their voices.

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Preface

This book began with a casual remark, a jaunty little exchange between an experimental psychologist-turned-phenomenologist (Howard) and a psychiatric nurse-turned-researcher (Sandra) who had studied phenomenology with Howard in 1981 and later developed a fuller appreciation of its relevance for the discipline of nursing. For nearly a decade, the two of us have collaborated in leading an interdisciplinary phenomenology research group on Tuesday afternoons. Sparked by discussion among the group, this book was conceived on one of those Tuesdays. Our brief exchange that afternoon went something like this: "Why don't we write a book for nurses?" "Great idea! I'll draft a prospectus." After Ursula Springer concluded that the prospectus had merit and invited us to proceed with the book, a great deal of new learning and hard thinking was required before we could complete it. The process of writing this book has deepened not only our knowledge and appreciation of existential phenomenology but also our mutual respect for each other as scholars and as people.

At times we knew what we wanted to say to nurses but struggled to find ways to say it. Writing is always a humbling experience. The philosopher Maurice Merleau-Ponty, on whom we rely heavily for inspiration, understood how writers must grope for the right words to communicate with their readers. How true we found his observation that "writers experience the excess of what is to be said beyond their ordinary capacities" (*The Prose of the World*, 1973, p. 57). At other times, we really did not know what we thought about a topic until we wrote about it. Putting words on paper, and then repeatedly revising them, eventually clarified our thoughts. Again, Merleau-Ponty was prescient: "Many writers . . . begin a book without knowing exactly what they are going to put in it" (*The Phenomenology of Perception*, 1962, p. 177). Eventually, all the words were on paper. It is our hope that readers will sense our passion for existential phenomenology and understand our conviction that it provides a basis for a new dimension of nursing science and practice.

Who are the potential readers of this book? As we wrote, we thought of graduate students and faculty, certainly, but we also meant to speak directly to clinicians, in all specialty areas of nursing, who might be interested in hearing about a humanistic philosophy and research methodology that has the potential to illuminate the deeper meanings of health crises and universal human experiences such as pain and spiritual distress.

We would be greatly pleased if teachers of undergraduates selected this book as a text. With this possibility in mind, we deliberately presented our material in a clear, jargon-free style accessible to anyone enrolled in college courses.

Every nurse hears patient stories, but not every nurse learns to *listen* to them in a way that permits *hearing* their richness and power. What this book hopes to promote is a method of hearing those stories and making meaning of the narratives within the context of nursing practice. The book is organized into five major sections. Part One introduces nurses to phenomenological thinkers, such as Merleau-Ponty, and applies insights from philosophy to the processes of engaging in dialogue with patients and interpreting what they tell us. In this introductory section, we begin the task of acquainting readers with the major contexts within which human existence is experienced (body, other people, time, and world). Thereafter, a specific section of the book is devoted to each of these contextual grounds of human life. In Part Two, for example, we examine philosophy, theory, and research about the body. In Part Three, we explore the human experience of other people. In Parts Four and Five, we address the topics of time and world, respectively. Compelling original research, conducted in a variety of health care settings by members of the research team at the University of Tennessee, is presented throughout the book. We anticipate that you will find the words of patients and their families riveting as you read these research reports.

Although we realize that some readers may be drawn by clinical interests or personal curiosity to particular chapters and not proceed in the sequence we chose for organizing our material, we urge a bit of caution. Chapters 1 and 2 provide essential information about our philosophy and approach to phenomenological research; to avoid redundancy, specific procedural details are not repeated in subsequent chapters. Thus, we strongly suggest a careful reading of these chapters before proceeding. The introductory chapters in each of the main sections of the book (Chapters 3, 6, 10, and 14) are also important in setting the stage for those chapters that immediately follow them. In anticipation of various questions that may arise, we have used the term "patient" rather than client, customer, or consumer, although no implication should be drawn that we consider the recipients of nursing services as passively dependent and unable to enter into a relationship of mutuality with caregivers. With regard to protection of the rights of human subjects, all projects were approved by the Institutional Review Boards of the university and the institutions where interviews were conducted. To preserve patient rights to confidentiality, transcriptionists and members of the phenomenology research group were asked to sign confidentiality pledges for every project. Real names of interviewees never appear on the typed interview transcripts used by the research group in our weekly thematizing sessions. While we do include verbatim quotes from patient interviews in this book, all names of institutions are removed and all names of persons appearing in the text are pseudonyms.

This is not the first book in nursing about phenomenology, but we hope it will prove to be a useful addition to the extant body of literature on this topic. This book is unique in its philosophical basis (Merleau-Ponty), its approach to clinical practice and research, and its thorough coverage of the major existential grounds described by existential-phenomenological thought. We have sought feedback about its content and readability from more than a dozen colleagues, and we are now ready for you, our readers, to enter into dialogue with us, scanning the pages we have written and critically reflecting on our ideas. We invite, and eagerly await, your response. Our hope is that we will succeed in stirring both your thoughts and your emotions. In this time of distress and turmoil produced by the corporatization of health care delivery systems, nurses are burning out and patients are feeling abandoned. It is a time for us to engage in a deepening reflection about the fundamental meanings of a practice so intimately linked to the most joyous and tragic experiences of human life. When nurses reflect deeply upon their practice, our patients will surely be the ultimate beneficiaries.

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I

Phenomenology and Nursing

What is phenomenology? It may seem strange that this question has still to be asked half a century after the first works of Husserl. The fact remains that it has by no means been answered. Phenomenology is the study of essences; and according to it, all problems amount to finding definitions of essences: the essence of perception, or the essence of consciousness, for example. But phenomenology is also a philosophy which puts essences back into existence, and does not expect to arrive at an understanding of man and the world from any starting point other than that of their 'facticity.' It is a transcendental philosophy which places in abeyance the assertions arising out of the natural attitude, the better to understand them; but it is also a philosophy for which the world is 'already there' before reflection begins—as an inalienable presence; and all its efforts are concentrated upon re-achieving a direct and primitive contact with the world, and endowing that contact with a philosophical status.

—Maurice Merleau-Ponty, *Phenomenology of Perception* (1945/1962), p. vii

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The Patient, the Nurse, and the Philosopher: Seeing Rose through the Eyes of Merleau-Ponty

Two people are talking. One is a phenomenological nurse researcher; the other is a woman who recently suffered a stroke. The researcher, Janet, speaks first: "Can you describe for me some specific experiences you've had since your stroke that stood out for you?" Rose, the patient, replies: "Well first of all, I was just devastated that everything I had was taken away from me, you know—my jewelry, my money, everything. . . . Yeah, one day you're working and the next day you're an invalid, so you know, you think you're through."

"You think you're through?"

"You think you'll just never be a whole person again, when you realize you're paralyzed. When you can't move a finger or anything, you know."

"You didn't feel like a whole person?"

"Well, you know, I'm a person that tries to do the right thing for everyone, take care of everybody. And I just couldn't understand . . . and . . . I said if I can't get better I want to die. And if I can get better I will. . . . And like I said before, you have to want to do things. If you want to sit in a wheelchair okay. So my husband pushed me down to therapy the first day. And this big man approached me and said 'I'm here to help you. I'll teach you to walk.' He said, 'You'll stand up and I will hold you and we'll go around with the walker.' And I said, 'I can't do that.' He said, 'Well, you have the right to choice. If you don't want to, that's your right. But I've never let a person fall, and I want to help you. But you have to be willing to do it or you can sit in that wheelchair the rest of your life.' So immediately, I said [to myself] 'Well look, you know, you got to try.' And in three days I was walking . . . very slowly and very carefully, but I was walking."

From this conversation, Janet Secrest (1997) came to the conclusion that the world of the stroke survivor is one in which loss and effort are uniquely significant (see Chapter 11). In addition, each of the survivors whom she interviewed described a sense of *discontinuity* in the self: The stroke seemed to break the survivor's experience into a pre- and post-stroke person. The anxiety evoked by such an experience is clearly evident in Rose's statement, "I'll never be a whole person again." But Rose did not talk directly about who she is or was. Instead she began by describing how devastated she felt when her personal possessions—her things—were taken away. The issue of time came up next, with a clear contrast between a *before* ("One day you're working") and an *after* ("The next day you're an invalid"). There also was an ominous concern for the future: "And you think you're through." It is only at this point, however, that Rose described a bodily component of what it meant to be through ("You're paralyzed . . . can't move a finger or anything") and the personal significance of the paralysis ("[I won't be able] to do the right thing for everyone" or "take care of everybody"). This new way of being with people presents a problem for her. The narrative then comes full circle when Rose is told in physical therapy that she has the "right to choice," but if she's willing to cooperate with the therapist she won't have to sit in the wheelchair for the rest of her life. Rose's recovery requires other people, perhaps making her aware for the first time that she doesn't always have to be the one who "takes care of other people;" she can let them take care of her for a change.

This conversation is about Rose's concern over who she is both before and after a stroke. She does not talk about her "self" as a collection of habits, memories, traits, and skills encased inside her skin and separate from the world. What Rose does talk about are her absent possessions, her changed relationships to other people, her personal past and possible future, and her limited ability to negotiate space in the physical world. We might say that Rose experiences her life in terms of other people, personal objects, time, and her body's relationship to the world. *Others, time, body*, and *world*, including personal objects, comprise the *four major existential grounds of human existence*, the contexts against which human life and experience always emerge. Because nursing is interested not only in how life progresses biologically but also in how people experience their lives from their own, unique, first-person perspective, it makes sense that we should be interested in the one contemporary philosophy—existential phenomenology—explicitly concerned with these issues.

Although existential phenomenology has found its way into many nursing research textbooks, it usually receives relatively brief mention, perhaps a few pages, or at most, a single chapter. More often than not, it is presented to readers along with other inductive, qualitative research approaches that are also given a cursory overview by the authors of these texts. In conjunction with several other qualitative methods, phenomenology shares an emphasis on: (1) respect for people, (whether patients or study participants), considering them as co-researchers and not as "subjects"; (2) the use of in-depth interviewing to discover perceptions and feelings; and (3) rigorous interpretation of texts that result from such interviews. Its philosophical underpinnings, however, are unique and deserve careful examination—a task that may seem intimidating to nurses who lack a strong background in philosophy. Perhaps because of its European origins and esoteric terminology, phenomenology sounds especially mysterious to readers encountering it for the first time. Many contemporary authors continue to sprinkle their accounts of phenomenology with the German or French terms by which phenomenology was introduced, thereby creating additional difficulty for the reader who is not fluent in these languages.

Nursing needs a more comprehensive, and comprehensible, presentation of this philosophical tradition and research methodology. As a research method, it has great value for studying those aspects of our patients' experiences that are not measurable by blood pressure cuffs, rating scales, or questionnaires—such as the meaning of a stroke to a woman like Rose. Even when experiences—such as stress—have been deemed "measurable" by scientists, many questionnaires are not sensitive to cultural and/or gender differences and fail to capture what is most salient to the individuals responding to them. For example, no standard stress questionnaire measures *vicarious stress*, which proved to be the number one stressor for women in a study by our research team (Thomas & Donnellan, 1993). We had given the women a well-validated and reliable instrument, but we also asked them an open-ended question, permitting them to describe their greatest distress in their own words. By doing so, we discovered the shortcomings of the instrument and learned what was *really* causing them distress. What bothered the women most were events that were happening to their significant others, such as the impending divorce of a son, job problems of a husband, illness of a sister or friend. In these stressful circumstances the women suffered empathically along with their loved ones but had little or no control over what was happening. This type of stress has received little attention in the vast literature based on administration of standard stress questions about a person's own work, health, and finances (e.g., what is the amount of your mortgage? how many times have you been to the doctor?)

Experiences such as this to us led our research team to become dissatisfied with structured questionnaires and, eventually, drawn to phenomenological methodology for our continuing studies of anger, stress, and depression (cf. duMont, Droppleman, Droppleman, & Thomas, 1999; Fields et al., 1998; Thomas, McCoy, & Martin, 2000; Thomas, Smucker, & Droppleman, 1998; Wood, Meighan, Thomas, & Droppleman, 1997). We joined the growing number of scholars in other disciplines who had become disenchanted with the results of quantitative studies. Among the reasons for this disenchantment, Van Maanen (1982, p. 13) listed the following: (1) the relatively trivial amount of variance explained by the researcher's selection of variables; (2) the abstract nature of the key variables; (3) the lack of comparability across studies; (4) the failure to achieve much predictive validity; (5) the high level of technical sophistication, rendering many research publications incomprehensible to all but a few readers; and (6) the complexity of multivariate analysis, "which, even when understood, makes change-oriented actions difficult to contemplate."

While quantitative research is still of great value in discovering such things as precise changes in blood pressure, in millimeters of mercury, after a relaxation intervention, and we have no argument with the usefulness of many descriptive-correlational