

Contents

<i>Series Foreword</i>	ix
<i>Preface: A Note to the Reader</i>	xi
<i>Acknowledgments</i>	xv
Introduction: Why We Need a Psychological Science of PCOS and What This Book Does	3
1. Breaking the Psychological Silence: An Overview of PCOS	9
2. PCOS Stigma: One Diagnosis but Multiple Stigmas	25
3. Gendered Embodiment of PCOS	43
4. Social Support and Close Relationships in the PCOS Context	67
5. Psychological Risk and Growth in PCOS	91
6. Health Risks and Inadequate PCOS Health Care Resources	109
7. A PCOS Call to Action: Interventions, Advocacy, and Psychological Science	131
<i>Appendix A: Methodology</i>	<i>149</i>
<i>Appendix B: Suggested Reading List</i>	<i>159</i>
<i>References</i>	<i>163</i>
<i>Index</i>	<i>189</i>
<i>About the Author</i>	<i>193</i>

INTRODUCTION

Why We Need a Psychological Science of PCOS and What This Book Does

The purpose of this book is to build a psychological science of polycystic ovary syndrome (PCOS). Why should psychology as a discipline care about PCOS? As you will read in this book, the reality is that individuals living with PCOS can have poor mental and physical health and experience a host of other negative psychosocial outcomes (negative self-beliefs, unfair treatment from others, close relationship difficulties, poor health care experiences). These are topics that psychologists care deeply about, and yet PCOS remains severely understudied in psychology. Moreover, because of this inattention, the lives of many cisgender women, nonbinary, and transgender individuals of various ages and racial/ethnic identities who are encountering this condition remain understudied and therefore invisible. Psychologists are working with these individuals in clinical and health care settings where PCOS may go unaddressed. Individuals living with PCOS are our research participants, students, colleagues, family members, and friends, and yet we do not fully understand how PCOS impacts their lives.

As the purpose of this book is to build a psychological science of PCOS, primary audiences for the book are scholars, researchers, and practitioners. Indeed, this book is part of the American Psychological Association (APA)

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The Psychology of PCOS: Building the Science and Breaking the Silence, by S. L. Williams
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Division 35 (Society for the Psychology of Women) book series and likely will draw professionals who are division members and those who are social, health, and clinical psychologists. However, scholars from other disciplines (e.g., public health, nursing) and other areas of study (e.g., women's health, gender, and LGBTQ studies) would also see the relevance of this text for their own scholarship. A secondary and yet equally important audience for this book is individuals living with PCOS and their advocates. One of the realities that struck me when looking for books that could help me understand my own PCOS experience is that all the books focused on controlling or reversing symptoms of PCOS through exercise and changing eating habits. None of the books shared personal stories of how PCOS affected everyday life. I wanted to connect with others struggling with as well as flourishing in spite of PCOS. I wanted to make sense of my experience of PCOS and know that I was not the only one going through it. Despite being written with a more academic tone, I hope that individuals dealing daily with PCOS will find validation in the PCOS themes and stories shared within this book's pages.

WHAT THIS BOOK DOES

This book lays the groundwork for a psychological science of PCOS by breaking what I see as the silence surrounding PCOS in the discipline of psychology. It spotlights a wide range of psychosocial experiences that individuals diagnosed with PCOS may encounter, all of which are topics relevant to psychological research. I chose to focus on psychosocial experiences because the current published literature from a mostly biomedical perspective does not tell the complete story of PCOS. I based the chapters on the results of one-on-one phone interviews I conducted with 50 individuals who told me that at some point a physician had told them they had PCOS. In the book, I use research and theory from psychology and other social sciences to explain PCOS experiences described by my interviewees and integrate existing research and other information on PCOS (scientific papers, chapters, entire books, websites, and online articles) whenever possible. I use these multiple ways of knowing to ultimately highlight potential priority areas for future research; because this type of qualitative analysis does not focus on frequencies of reported experiences or representativeness, future quantitative and mixed methods studies are needed.

By no means is the range of topics covered in the book exhaustive. This text is not intended to be a comprehensive review of PCOS. You will note that the sample of individuals I interviewed is not representative but

rather purposefully diverse to delve into the areas understudied within PCOS research. Also noteworthy, I conducted the interviews with individuals living with PCOS from February 2020 through May 2021. I recognize that the pandemic was salient in the United States and across the globe at the time of data collection and analysis (see Appendix A for additional discussion). Thus, I acknowledge that findings of interview data discussed within this book were both collected and reported in this context. Additionally, this context may have influenced whether individuals volunteered for this study—for instance, individuals with the most COVID-related stress may not have seen the study ad or had enough time to complete it. Context is an important element within qualitative research, emphasizing that there is not one universal truth. Consequently, much more than in quantitative research, results of qualitative research may change depending on the specific sample and context. As is further supported by the content of this book, I would expect PCOS experiences to vary across person and context.

When reporting the PCOS experiences of individuals I interviewed for this book, I describe them as *individuals living with PCOS*. Most published books and articles on PCOS describe those impacted by PCOS as *women*. I chose to use more inclusive language because, of the 50 individuals with PCOS whom I interviewed and discuss in this book, 50% indicated that their gender fit a label other than “woman.” Of course, this number is not a direct representation of the population of those with PCOS but rather reflects my intentional inclusion of diverse voices with PCOS.

Because those with PCOS whom I interviewed were a diverse group of individuals who identified their gender as woman, transgender, transmasculine, genderfluid, or nonbinary, I differentiate cisgender women from gender-diverse individuals in the book. I chose the label of *gender diverse* as opposed to other common terms, such as gender nonconforming, because it is more expansive and does not imply a comparison with an assumed normative way of being (APA, 2015). Additionally, whereas *cisgender* individuals are those whose gender identity corresponds with their sex assigned at birth, the umbrella term of *transgender* (trans) refers to the various ways that gender identity might not map to sex assigned at birth. Although trans individuals can fit within a binary system of gender, such as when individuals assigned male at birth self-identify as women or individuals assigned female at birth self-identify as men, not all gender-diverse individuals fit this binary. An entire group of people identify their gender as outside of the binary system and may self-identify with labels such as nonbinary, genderfluid, or genderqueer. Thus, I believe the label *gender diverse* captures these varying identities. Admittedly, the gender-specific language used in this book may quickly become inaccurate

or outdated. I ask in advance for forgiveness when my labels and descriptions fall short of the best identifications and experiences of those impacted by PCOS.

Throughout the text, I provide illustrative excerpts taken directly from interview transcripts. These quotes are verbatim, except where I have replaced conversational elements (e.g., “um,” “like”) that are awkward to read and detract from understanding the content with ellipses (“. . .”). Alongside the excerpts, I also include pseudonyms instead of real names and use age ranges (e.g., late 20s) instead of specific ages. I made these choices to protect the identities and confidentiality of the individuals living with PCOS I interviewed. Although I also include self-reported gender identity with each excerpt, I do not include racial/ethnic identity to further protect confidentiality. Instead, racial/ethnic and other demographic representation are reported in aggregate in a table in Appendix A. Importantly, although I asked specific questions during the interviews, I coded responses across questions. Therefore, most of the themes are not attached to particular interview questions. Additionally, the themes that I drew from the interviews were present across racial/ethnic identity. I have noted exceptions in the text when cultural aspects of PCOS experience were discussed by interviewees. Finally, whenever available, I used pronouns self-identified by individuals I interviewed. In a limited number of instances when these were not specified, I used a neutral “they” pronoun for individuals who identified as gender diverse (e.g., transgender, nonbinary).

WHAT THIS BOOK COVERS

Because this book focuses on the psychosocial aspects of PCOS, I limit discussion of biological and more technical medical research, including it only to explain the condition itself. In the remaining seven chapters, I introduce PCOS and its symptoms and provide a critical analysis of the silence surrounding PCOS, including the silence of diverse experiences based on gender (Chapter 1), illustrate how PCOS symptoms are stigmatizing (Chapter 2), investigate diverse experiences based on gendered embodiment of PCOS (Chapter 3), describe social support and close relationships in the context of PCOS (Chapter 4), explore psychological risks of PCOS and evidence of psychological growth despite these risks (Chapter 5), examine the health risks of PCOS combined with the inadequate PCOS-related health care resources (Chapter 6), and call for interventions, advocacy, and psychological science to improve the lives of individuals living with PCOS (Chapter 7). I also include

two appendixes at the end of the book to provide further details on my methodology, as well as to offer suggestions on further reading for those interested in additional review or more medically oriented information.

In sum, in the formation of this book, I relied heavily on an academic approach that integrated my own qualitative research study with what is known from published academic literature to provide a road map to begin building a psychological science of PCOS. However, the spirit of the book goes beyond the academic, verging on manifesto. As described by Breanne Fahs (2020) in *Burn It Down: Feminist Manifestos for the Revolution*, manifestos express rage and seek revolution; they are demanding, radical, impolite, and unapologetic. Manifestos express power and authority in a nontraditional sense, as a way for the voiceless to express their cry for change. As such, the spirit of this book is manifesto, a PCOS Manifesto that demands the silence be broken. I—no, *we*—demand to be heard.