

# Chapter 1

## Introduction to Brain Tumor Survivorship and Historical Perspective

Stewart Goldman and Christopher D. Turner

### Introduction

“Death precludes late effects.” This attitude was our (and many others’) first introduction to the issues of survivorship, and reflected the Oncologist’s viewpoint of the late 1980s and early 1990s. Today, though neuro-oncologists are focused on increasing cure rates, we are increasingly aware that “the costs of the cure have a lifetime to be repaid” and, thus, our focus on late effects have taken on increased interest.

### Background

The field of cancer survivorship is relatively new. Interest in cancer survivors and the late effects they experience has grown as the number of cancer survivors in the United States has tripled in the last 30 years to more than 11 million in 2005.<sup>1</sup> One should, therefore, not be surprised to learn that there has been a rapid increase in the number of publications on cancer late effects and survivorship issues within the last decade. A simple search of PubMed for the term “cancer survivorship” in the title or abstract reveals only 38 publications before the year 2000 and 186 publications since then [<http://www.ncbi.nlm.nih.gov/pubmed/> accessed November 30, 2008] Many of the early publications on cancer survivors before 1990 dealt exclusively with a single type of cancer or a single late effect. In 1974, Meadows was one of the first to describe and advocate for a comprehensive approach to evaluate cancer survivors for treatment related late effects,<sup>2</sup> but the concept took time to catch on. Through the rest of the 1970s and 1980s there were relatively few broad publications of cancer

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S. Goldman (✉)

Gus Foundation Chair Neuro-Oncology, Medical Director Neuro-Oncology,  
Associate Professor of Pediatrics, Children’s Memorial Hospital, Northwestern  
University, Fienberg School of Medicine, Chicago, IL 60614-3394, USA  
e-mail: [sgoldman@childrensmemorial.org](mailto:sgoldman@childrensmemorial.org)

survivorship issues across many disciplines that were published through the medical literature.<sup>3-6</sup> While the number of cancer survivors was growing during this period, their numbers were still relatively small when compared to the total number of patients diagnosed with cancer. The focus of oncologists and others that cared for cancer patients was justifiably focused on improving survival first, but by the end of the 1990s the five-year relative survival rate for all malignancies combined had increased to 64%.<sup>7</sup> It is notable to point out that beginning in the 1980s researchers began to focus attention on the central nervous system late effects associated with the treatment of childhood leukemia and brain tumors, and there were several important early studies reported.<sup>8-16</sup>

A second converging phenomenon was also occurring in the oncology community in the late 1980s and into the 1990s. Cancer survivors began to organize in greater numbers and the cancer survivorship advocacy community began to strengthen and grow. The National Coalition for Cancer Survivorship (NCCS), a broad reaching cancer advocacy coalition, was founded in 1986 and a more unified voice was being heard from survivors.<sup>17</sup> Instead of just being “happy to be alive” these groups brought increasing attention to the plethora of late effects experienced by the increasing number of cancer survivors.

The growing importance of these two trends, the increased number of survivors and a stronger, more unified cancer survivorship advocacy network, converged in 1996 when the National Cancer Institute (NCI) established an Office of Cancer Survivorship to focus research efforts on the short- and long-term consequences of cancer and its treatment.<sup>18</sup> Since then, there has been a rapid increase in grant support and publications on the late effects of cancer treatments.

Much of the early work in this field has focused on childhood cancer survivors, but in the last few years increased focus is being paid to survivors of adult malignancies. Unfortunately, survivors of CNS malignancies have been either excluded or underrepresented in many of the earlier late effect studies.

In the case of pediatric CNS tumor survivors, the concern was that their neurocognitive deficits would adversely affect the results and, in the case of adult CNS tumor survivors, the number of long-term survivors of malignant tumors was often not large enough to study. Recently, more attention has focused on CNS tumor survivors. The neurocognitive late effects of pediatric CNS tumor survivors due to the tumor or its treatment have been better described in recent publications.<sup>19-21</sup> There is also an ongoing effort to enrich a new cohort of the much-publicized Childhood Cancer Survivorship Study with survivors of CNS tumors, recognizing that this population was not adequately represented in the original cohort.

Research on survivors of adult CNS tumors has benefited from broader acceptance of the widening of the definition of cancer survivorship research to include patients from the time of diagnosis forward in examining the effects of treatment on an individual. Unfortunately, the percentage of adult CNS tumor survivors has not meaningfully changed, due in large part to limited advancement in the survival of those with high-grade gliomas.

As one proceeds through this book, it is important to recognize that cancer survivorship is a journey encompassing many phases, from recovery of the acute toxicities of therapy to the psychological adjustments of the survivor, their families, friends, teachers, coworkers and society. Survivors of brain tumors face the long-term late effects described in the subsequent chapters of this book, as well as challenges by a world not adequately prepared to adapt and accept this growing population.

## Scope of this Book

The goal of this book is to present the current knowledge of late effects experienced by survivors of CNS malignancies for both children and adults in one comprehensive text.

The intended audience is physicians, nurses, psychologists and other health care professionals who care for CNS tumor survivors. We hope this book, together with our patients and their families, will be an aid for the future.

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