Voices of teenage Transplant Survivors

Miracle-Like

Susan J. Sample

VOICES OF TEENAGE TRANSPLANT SURVIVORS

Dr Sample documents her work at a transplant survivors' summer camp, coaxing poetry from teens who don't read it, but who have plenty to say about their "miracle-like" experiences post-transplant. She describes brave young people whose aching drive toward supervivere, (above + to live) bursts forth in striking poetic images and metaphors that blend the surreal with the mundane. The chapter "Our Scars, Our Selves" unpacks an atypical adolescent identity formation in simple terms. JD writes of dying and returning to life three times, concluding that "My time is now, and I am here." We can learn much about resilience from these teenaged poets.

–Johanna Rian, PhD, Program Director, Dolores Jean Lavins
Center for Humanities in Medicine, Mayo Clinic

The subtitle, "Miracle-Like," well captures the spirit and achievement of Susan Sample's Voices of Teenage Transplant Survivors. Sample presents poems written by adolescents participating in poetry workshops at the summer Youth Transplant Camp program near Salt Lake City. In a series of short chapters, she carries the reader into the workshop process, introducing many of the young poets and placing their work in context. One young man writes of his anger, "It makes me want to hit / something. That's better / than someone." A young woman with a liver transplant proudly affirms, "My scar is my scar. / It has personality. / It bubbles and dances when I laugh." These poems clearly illustrate the power of poetry to heal and the indominable spirit of youth. Poems of insight, honesty, and wit you won't forget.

–Jack Coulehan, MD, Emeritus Professor of Family, Population,
and Preventive Medicine and Senior Fellow of the Center
for Medical Humanities, Compassionate Care,
and Bioethics at Stony Brook University, USA

This book is essential reading for adolescents and young adults with chronic or terminal illness—and for their parents. The poems of young transplant survivors enable us to glimpse how it feels to live as though perpetually suspended, as if on borrowed time. Through her stories of these remarkable young people, Dr. Sample weaves a tapestry that illuminates distinctive, intimate concerns about identity, body image, belonging, hope, survival and mortality. In the words of one chapter title, "Mark This Beautiful."

–Kimberly R. Myers, MA, PhD, Professor of Humanities
and Medicine, Penn State College of Medicine, USA

It is increasingly recognized internationally that poetry can play a major supportive role both for patients of all ages as well as for their responsible health professionals. This inspirational book curated by Professor Susan Sample adds to this important message, with its insights through poetry by teenagers into their lives before and after heart, kidney, and liver transplants. This book should interest communities around the world concerned with organ replacement, whether young or older patients or their families, or responsible health professional staff and students.

–Donald RJ Singer MD, FRCP, Hippocrates Initiative
for Poetry and Medicine [hippocrates-poetry.org]

VOICES OF TEENAGE TRANSPLANT SURVIVORS

Miracle-Like

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INVESTOR IN PEOPLE

To all of the YTK campers, past and present,
who have enriched my life beyond measure
and
to Pam whose support and friendship
made this project possible

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ACKNOWLEDGMENTS

The making of this book is nearly as old as the Youth Transplant Kamp (YTK), which celebrated its 20th anniversary in 2020. I began offering poetry workshops to teenage campers in 2002 and continued through 2014, so my thanks extend back many years and encompass many individuals and organizations.

First and foremost, my deepest appreciation goes to all of the teenagers who participated in the writing sessions at YTK. Although I have included poetry written only during the first 6 years of the project, everyone whom I cajoled into writing deserves my thanks and admiration. I continue to learn from and be inspired by these courageous individuals. I also extend my heartfelt appreciation to parents who generously gave me permission to include writing by teens who have since died. I tried over the past year to contact as many former campers, parents, and/or copyright holders of the poetry as possible. I invite those whom I was not able to reach by mail, email, or telephone to contact me.

The poetry project was made possible initially with the support of the Utah Arts Council. The board of directors and arts education manager Jean Tokuda Irwin were strong proponents of the project. Special thanks go to Guy Lebeda, former literature coordinator, who offered me the opportunity to participate in the Utah Challenge America Project and encouraged my work with the teens long after the grant from the National Endowment for the Arts ended.

I also am indebted to the National Kidney Foundation of Utah and Idaho that established YTK and made it possible for children with different types of transplants to attend the expense-free camp where everyone is celebrated for what they can do. In addition to the board of directors, I want to thank Deen Vetterli, founder and CEO, and Richard Taylor, former development director, not only for granting me permission to work with teenage campers but for their belief in the importance of writing. My gratitude also goes to Ann Madsen, patient and community services director, for her administrative help every summer and again this past year. Mircea Divricean, president and CEO of Camp Kostopulos where YTK is held, insured that I always had time and space for the poetry workshops for which I am grateful.

Staff and faculty in Transplant Services at University of Utah Health also have been strong supporters of the project since its inception. Special thanks go to program manager Kim Phillips for helping educate me on organ transplantation and validating the significance of the teens' poetry. This past year, Kim helped me reconnect with patients, as did Cindy Terrell, Jacke Corbett, and Catarina Cosby at Utah Health, and Cecile Aguayo at Primary Children's Hospital (PCH). Former University child-life specialists Shannon Pay and Jill McFarland, and former PCH pediatric social worker Valerie Stevens each contributed to my understanding of posttransplant life and its unique challenges.

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Among the many faculty and staff at the U School of Medicine who helped contribute to the growth of my project were Jay Jacobson, MD, professor emeritus of medical ethics and infectious diseases, and Neal Whitman, EdD, professor emeritus of family and preventive medicine. Both offered me teaching opportunities that became the first bridges between patients, physicians, trainees, and medical students, which led me to research and scholarship in narrative and medicine. I especially thank Jay for his mentorship in my education and professional development.

I am grateful to the many professional organizations that sponsored presentations about the YTK poetry project, including: Utah Humanities, Society for Transplant Workers, National Association for Poetry Therapy, and the Saratoga (CA) Foothill Club. Thanks also to Jeannene Barham, executive director of The Quest for the Gift of Life Foundation, for inviting teens to share their poetry at several public events.

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In addition to the YTK teens, this book is dedicated to Pam Grant who was not only receptive to my initial idea of working with kidney transplant patients but also helped make the project possible through her work with the National Kidney Foundation of Utah and Idaho, and U of U Transplant Services. I am grateful for Pam's professional support in our many presentations on the YTK poetry project, but even more so for the personal friendship that has grown and deepened.

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INTRODUCTION

Poetry enables persons who have been redefined as "patients" to regain control of their lives through language. They can revise, redefine, and replace the biomedical terms used to name them in their own medical histories. It may even be requisite for healing. Rafael Campo in *The Healing Art: A Doctor's Black Bag of Poetry* says patients write illness narratives because of "the power of language – and of poetry in particular, with its signature capacity for speaking the unspeakable – to promote healing" (2003, p. 2). For physicians, health-care providers, and students, narrative is increasingly used as a clinical tool to learn how to listen with empathy and understanding, so they may better help patients heal. Poetry written by persons living with illness and disability, however, is unique in the canon of illness narratives. It "opens a very different window from narrative, emphasizing in its singular way discontinuity, surprise, and the uneasy relationship between words and the life of the body," says Marilyn Chandler McEntyre in *Patient Voices*: *Illness from Inside Out* (2012, p. 1).

The view into the lives of patients that poetry opens extends even wider with the publication of this book. The authors in *Voices of Teenage Transplant Survivors: Miracle-Like* are not well-known adult poets like most in Campo and McEntyre's books. Rather, they are members of a patient population, Adolescents and Young Adults (AYA), whose psychosocial needs are being increasingly identified as distinct from adult and pediatric patients.[1] They are "developing their own social and financial responsibilities; autonomy from

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[1] The emergence of adolescent medicine as a subspecialty of pediatrics can be traced back to the mid-20th century (Alderman, Rieder, & Cohen, 2003). In 1967, the first academic program was established at Montefiore Medical Center/Albert Einstein College of Medicine; the following year, the Society for Adolescent Medicine was organized. It was not until 1994, however, that the American Board of Pediatrics offered subboard certification in adolescent medicine. Adolescent and Young Adult (AYA) medicine is a more recent development particularly in oncology (Steinbeck, Towns, & Bennett, 2014) due to the need for transition care. According to a 2014 Institute of Medicine report, AYA individuals (ages 12–26) represent nearly 20% of the total population in the United States, yet account for 25–35% of people with chronic conditions that require transitional care (McManus et al., 2020).

parents; a personal set of values and identity; strong peer relationships, including intimate and sexual relationships; and obtaining adequate preparation to join the workforce" (D'Agostino, Penney, & Zebrack, 2011, p. 2329). The teenagers represented in this book are living with a chronic illness relatively unknown to many in the medical world, much less the lay public: transplant disease. The youths survived transplant surgeries for solid organs – kidney, heart, liver, pancreas, and various combinations – but must cope with the unpredictability of posttransplant life, including a lifetime of immunosuppressants and side effects, some unknown. Their medical histories have compelled them to confront existential issues many people elect not to consider until later in life: the fundamental vulnerability of the human body, the fragile uncertainty of life, and dependence upon others. The teens are survivors because, as with most solid organ transplantation, someone else died. That fact further marginalizes transplant survivors. "They think it's gross," one camper told me about friends' responses to his kidney transplant. "Barbaric" is how medical professionals, as well as the society-at-large, in the future will likely view organ transplantation from cadavers, a pulmonologist and medical director of the lung transplant program at an academic medical center told me.

First and foremost, though, the authors whose voices we hear in this book are just teens. Many would not even fain to like writing, much less poetry. Yet, they participated in poetry workshops I offered each summer from 2002 through 2014 at the Youth Transplant Kamp (YTK) near Salt Lake City, Utah. Campers in the workshops ranged from 12 through 17 years old. They came from Utah, Idaho, Nevada, Wyoming, Montana, and other surrounding states for one week packed with horseback riding, canoeing, hiking, swimming, games, singing, crafts, and socializing. For 2 years, poetry was offered as part of the Utah Arts Council's Challenge America Project, which funded workshops for marginalized and underserved adolescents outside of traditional school settings. I continued to teach the workshops in response to their popularity with the camp staff, National Kidney Foundation, and most importantly, the teens. Summer after summer, they chose to return, clipboards and pens in hand, to write poems on the hottest days in July. Writing became integral to YTK; it offered the teens a safe space to articulate their experiences with life and the very real possibility of death, to express how it feels – emotionally, socially, and physically – to be a survivor.

The first audience for their poetry was fellow campers. We began each workshop with everyone reading what they had written during the previous day's session. I soon realized the importance of a larger audience for their poems, which was validated by Pamela Grant, pediatric renal disease social worker at University of Utah Hospital now retired, who helped me organize the project and assisted every summer. Grant and I presented the teens' poetry at conferences to physicians, medical students, social workers, and poetry therapists. In addition, the teens read their writing at the Intermountain Donor Services's Family Recognition Ceremony, Utah Humanities's Great Salt Lake Book Festival, and groundbreaking ceremonies for the Celebration of Life Donor Monument in Salt Lake City. Whether medical practitioners or clinicians, undergraduate students or postgraduate medical trainees, humanities scholars or members of the organ transplant community, everyone who listened to the teens' poetry found it insightful and inspiring, poignant and courageous, and healing.

2020 marked the 20th anniversary of the Youth Transplant Kamp, one of the few, if not the only, camps in the United States established for children and teenagers who have had different types of solid organ transplants. This book is intended to celebrate the camp, founded after a Salt Lake City mother of a heart transplant survivor, Susan Krantz, realized how essential it would have been to her late daughter's emotional health to have been part of a community of teenagers who could understand her experiences and help navigate life post-transplant. Ultimately, this book is intended to honor the teens who were courageous enough to write about their experiences and now, as young adults, grant permission to share their work, so all of us can learn about the challenges of living after transplantation surgery alongside the vicissitudes of life itself. Their voices remind us that while medicine's technological advances can prolong human life, the additional years are not free of anxiety or anguish. Posttransplant life is, as then 12-year-old BreaAnna says in Chapter 3, *miracle-like*: full of wonder, amazement, and deep gratitude for a new life that is simultaneously strange and extraordinary.

In the remainder of this introduction, I will explain how I taught the workshops and one way of understanding the poetry in the context of illness narratives.

My approach to teaching poetry at YTK was influenced by two groups supporting the project. The Utah Arts Council, with funding from a two-year grant from the National Endowment for the Arts, targeted marginalized teens at a youth correctional facility, detention center, homeless resource center, and alternative high school in its Challenge America Project. The focus of the writing workshops was creative self-expression and exploration of teens' individuality and voices, best discovered, the facilitators and I soon found, in informal, often unstructured sessions. Chronically ill teens suffered some of the same hardships as their at-risk peers – missing school and lagging behind academically and socially, their bodies looking different from "normal" teens – but for very different reasons. Their lives were interrupted by frequent doctors' visits, extended hospitalizations, learning or developmental disabilities resulting from diseases that required organ transplantation, and later, side effects of medications and comorbidities such as cancer. Another difference was the attitude of YTK teens toward authority figures. They depended upon, rather than rebelled against, parents, physicians, and an array of health-care professionals whom they needed not just for rides to school but for surgeries to save their lives. These teens were accustomed to structure and might have participated in more formal poetry writing. However, the board of directors of the National Kidney Foundation of Utah and Idaho agreed to the workshops as long as they did not resemble classroom activities. YTK is, after all, a summer camp. It is held at Camp Kostopolus, the nation's longest running summer camp designed for people with disabilities and special medical needs. Away from hospitals and homes where their lives were restricted to protect and prolong their health, campers could explore and experience normal activities. The camp's philosophy is to encourage, but never force, youth to participate. Accordingly, the directors assured me they would ask teens to attend the first poetry workshop; the teens could then decide for themselves whether to return.

I did plan every workshop, drawing mostly upon my experiences as a writer-in-the-schools but also my experience teaching college composition and reflective writing to medical students. I learned I had to engage students in the *process* of writing, so they could discover the pleasure and exhilaration of creativity. I also had to convince them of the value of the *product* they created: a text through which they could glimpse a new, perhaps surprising perspective on their selves; words artfully inviting them to reenvision their capabilities, ignite their curiosity, and acknowledge their individual power. At camp, I likened writing poetry to the ropes course: "You've got to be willing to take risks. You've got to let yourself leap into the unknown to discover what you're really feeling and thinking." Language would be their rope – and mine. Together, we strove to fulfill the definition of poetry I offered the first day – "intense language" – from Jack Collom and Sheryl Noethe in *Poetry Everywhere* (1994, p. xiv), based on their years as poets-in-the-schools. Poetry, Collom says, is "what people may write (say) when their sense of discovery is working well" (p. xiv).

The best way I have found to nurture that sense of discovery in inexperienced creative writers is through a renewed emphasis on the five senses – sight, touch, hearing, taste, and smell – which are particularly well suited to writers in medical settings. Although medicine has as its focal point the body, there is a curious absence of awareness of the personal body. Physicians are enculturated to recognize the materiality of patients' bodies and to pathologize body parts, but they are not encouraged to be aware of their own bodies, especially as representations of mortality. Patients who accept medicine's promise of restitution –

a narrative Arthur Frank defines in *The Wounded Storyteller: Body, Illness, and Ethics* (1995) in which physicians, like mechanics, restore the body to its previous state – are distanced from their ill bodies, thus dislocated from their changed selves. So, during the first workshop each summer, I read poems in which the five senses figure prominently as means of discovery and followed up with writing prompts that would not only appeal to their senses but also increase the teens' awareness of and appreciation for the unique information their bodies could yield about the world and their selves. By emphasizing the central and necessary role of their bodies in meaning making, I differentiated the process of creative writing from expository writing the teens associated with school. Although I believe all writing fundamentally functions as an episteme, a means to knowledge and understanding, I found emphasizing the body's role in creative writing particularly appropriate at the transplant camp where all levels of ability are recognized and respected. Like the campers themselves, all types of bodies are celebrated; we emphasized what the youth have survived and can do.

To articulate their unique experiences, I limited my presentation of poetic forms to free verse, specifically, the personal lyric. In *Poetry as Survival* (2002), Gregory Orr defines the personal lyric as "a poem that usually features an 'I' and that focuses on autobiographical experience or a personal crisis of some sort" (p. 22). He further distinguishes "the transformative lyric" as a "kind of poem [that] has a crucial role to play in our psychological, imaginative, and spiritual lives" (p. 3). Orr suffered through many personal traumas as a youth and recalls his discovery as an adolescent that "the language in poetry was 'magical'…it could create or transform reality" (p. 8). In writing his first poem, he was "simultaneously revealed to myself and freed of my self by the images and actions of the poem" (p. 8).

Although the personal lyric does not necessarily use formal meter or rhyme, it does use imagery and other poetic elements. In the workshops with teens, I discussed rhythm and sound, alliteration and assonance, images and metaphors, memory, imagination, irony and humor, line breaks and stanzas. However, I embedded these "teaching moments" in the performance of poems, readings of either exemplars I had chosen or those the teens wrote. As I explain in Chapter 3, I told camp staff that the only teaching equipment I needed was a whiteboard, which would enable me to visually explain concepts as well as model the writing process. The teens, however, pointedly reminded me that I had promised our workshops would be totally different than school: no textbooks, no grades – and no whiteboard. This limitation actually transformed into a strength of the workshops. The teens listened closely when I read aloud poetry that exemplified the various elements. They listened even more intently when the poems read were theirs. Every afternoon, they wrote in yellow notebooks I handed out the first day of the workshop.

At the close of each session, I collected the notebooks, transcribed the day's poems onto my computer, and printed out copies, which I distributed at the beginning of our next session. They took turns reading their poems aloud to the group as everyone followed along. Thus, the teens were introduced to poetry first through sound. Poems written in free verse, which do not "announce a relationship to order at the outset" like metrical poems, "commit themselves to the idea of…possibility and emergence," says poet Robert Hass (1984, p. 123). Like the welter of experiences they wrote about, the teens' free verse has "an assumption of openness or chaos in which an order must be discovered" through hearing and developing rhythm.

Scrawled on, over, and above the lines on their yellow notebooks, their words were not always easy to decipher. Nor were they always written with line and stanza breaks. As part of my teaching, I shaped their poems as I typed them, recalling the sounds of their voices as I decided where to break lines or begin new stanzas. However, except for misspellings, I did not correct or revise their language. When I shared their transcribed poems, I explained my choices and asked for their approval. No one ever objected – although I acknowledge that in my role as the teacher, the teens might not have felt comfortable questioning me. It seemed then, as it does now in my role as writer-in-residence at a cancer hospital helping patients write about their experiences, that the teens were amazed by the power of seeing their own voices in print. As poet and translator Rosanna Warren explains, "The poet's job…is to find the artistic 'shapeliness' in all this wounding experience, the music. From that comes meaning, comes beauty – and discovery" (Gibson, 2019, p. 29).

Even with my shaping, the teens' poems are "raw": they have not been revised or polished. That was not the purpose of the original project. On a more practical level, there simply was not enough time for revision; each workshop took place for four of the five days YTK was in session. Many of the campers did return for several summers, so they could draw upon what they had learned during previous workshops. After a day or two of seeing their poems typed, many teens would shape their writing themselves.

Overall, though, the teens' poems remain raw, which, as some researchers suggest, may offer psychological benefit. At this early stage, writing is intuitive, like "dropping a bucket into the well of oneself, pulling it up dripping to see what is there," says Gillie Bolton (1999, p. 120), a champion of the therapeutic power of writing. However, the YTK poetry workshops were developed as an art project because I am a writer and poet. Although Grant, the pediatric social worker who joined me during the workshops, is a licensed clinical social worker, only once did she intervene when a camper wrote about her social distress. That said, the poetry the campers wrote, like the illness narratives created by most patients, is therapeutic.

"Creativity," says Louise DeSalvo in *Writing as a Way of Healing: How Telling Our Stories Transforms Our Lives,* "seems a basic human response to trauma and a natural 'emergency defense against depression'" (1999, p. 175). Quantifying the relationship between writing and health has been a focus of psychologist James Pennebaker for more than 30 years. His research has shown measurable physiological benefits of expressive writing about traumatic events, including enhanced immune function and lower blood pressure and heart rates. Months after writing, participants continued to report fewer depressive symptoms and less general anxiety. Once translated into language, traumatic events are ordered, leading to understanding and clarity, thereby empowering the writer: an argument physician-writer Campo makes specifically in terms of poetry. "I believe poetry may indeed exert a powerful therapeutic force for the afflicted, abetting and sustaining an assured and self-actualizing response to suffering" (2003, p. 92). In eight principles, Campo explains why patients write illness narratives. Patients "discover and…name for himself or herself what the affliction is," (p. 94) gaining authority in the world of medicine and control over their body and self. Through creating metaphors, patients "are propelled toward an entirely new conclusion" about their suffering. Furthermore, poetry, "places the patient in direct *communication* with others who have suffered with a disease, across centuries and across cultures" (p. 96).

This social connection, the sense of community that language creates, is not limited to fellow patients. When "suffering can be transmuted into art," says DeSalvo, writing becomes "a form of public testimony" (1999, p. 41). When audiences listen to illness narratives, they bear witness to the complexity of emotional, physical, and even existential suffering of patients. Our moral imagination is awakened through narrative, particularly the intense language of poetry. Words charged with emotion condense experiences into meaning that resonates in the bodies of audience members as the voice of the poem, the "I" of the personal lyric, becomes "we," and encompasses listeners and readers. We are transformed into empathic witnesses. For health-care professionals "committed to active, respectful confirming listening," says physician Rita Charon in *Narrative Medicine: Honoring the Stories of Illness* (2006, p. 180), bearing witness to illness narratives "enable[s] us to not just *feel* on a patient's behalf but to commit acts…that lead beyond empathy to the chance to restore power or control to those who have suffered." Such acts may seem beyond the ability of those of us who are not clinicians; narrative ethics, however, can instruct all of us how to become empathic witnesses. When we listen to patients' narratives, they "open up moral dimensions of the lives of ill persons when they are *not* being patients," writes Arthur Frank. The pressing ethical question they pose is: "*how* *to live a good life while being ill*" (1995, p. 156). To bear witness means also pay attention to how we change. Frank calls this "thinking *with* stories," a concept Charon and other scholars have expanded upon. "Ultimately," writes Frank, "narrative ethics is about recognizing how much we as fellow-humans have to do with each other" (p. 163).

A sense of shared humanity points to the significance of *Voices of Teenage Transplant Survivors*. They are keenly aware of mortality. Transplant disease intensifies this most basic fact of life. Through their guileless poems, the teens remind us that creating our individual identity occurs amid the call of social responsibility. We need relationships with others; the teens know this in the most fundamental way. When we "think with" their poems, our lives are enriched.

In the chapters that follow, I have framed their poetry with short narratives to contextualize their writing. These narratives are short, as are the chapters themselves, to reflect the compactness and intensity of the teens' poems. My voice is intended to accompany, not overwhelm or diminish, the authority of the teens. Brevity also enacts what Arthur Frank refers to as "unfinalized," a term he borrows from M. M. Bakhtin's theory of dialogical narration: "each character appears as more than what is being told," writes Frank, "and so what is told is acknowledged never to be the full story" (1995, p. 15).

I invite you to enter these poems that follow and allow the voices of teenage transplant survivors to enter your life where they might take hold in new and meaningful ways.