

1-1-2015

Unreliable Bodies: A Follow-up Twenty Years Later by a Mother and Daughter about the Impact of Illness and Disability on their Lives

Kaethe Weingarten

Miranda Worthen

San Jose State University, miranda.worthen@sjsu.edu

Follow this and additional works at: https://scholarworks.sjsu.edu/healthsci_rec_pub



Part of the [Family Medicine Commons](#)

Recommended Citation

Kaethe Weingarten and Miranda Worthen. "Unreliable Bodies: A Follow-up Twenty Years Later by a Mother and Daughter about the Impact of Illness and Disability on their Lives" *Family Process* (2015).
<https://doi.org/10.1111/famp.12197>

This Article is brought to you for free and open access by SJSU ScholarWorks. It has been accepted for inclusion in Faculty Publications by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

Unreliable Bodies: A Follow-up Twenty Years Later by a Mother and Daughter about the
Impact of Illness and Disability on their Lives

By Kaethe Weingarten and Miranda Worthen

Waking up in Maine, three thousand miles away from my daughter who is 35 weeks pregnant with her second child, I reach for my phone to see if there is a text. No longer listening for sounds from her bedroom, wondering if she has fainted or collapsed, I am still, nonetheless, tethered to her unreliable body. I can only hope that her tether to me is thinner than mine is to her; but I know that hers to her three-year old daughter is like mine was to her.

Twenty years ago, in 1995, my daughter, Miranda Worthen, and I sat down to write a talk for a Medical School Conference, subsequently published (Weingarten & Worthen, 1997), about the impact on each of us of the other's medical condition. At that point, I had been diagnosed and treated for breast cancer twice. Miranda was born with a rare genetic disorder that can affect -- and had -- many organ systems. The conceptual frame of the original article provided an analysis of the "impact of having a condition that is either poorly or well understood" (Weingarten & Worthen, 1997, p.41). We constructed our article around the narrative categories of narrative coherence, narrative closure and narrative interdependence (Chatman, 1987). However, these terms were shortly to prove inadequate to the task of describing, much less accounting for, our embodied experiences. A subsequent article (Weingarten, 2000), drawing on several narrative schemas, was more successful.

Each of us has had considerable feedback over the years about how helpful the original article was to readers. Comments affirmed our hope that our writing would be considered in the light of the long tradition of people using personal story to illuminate shared experience, such as Murray Bowen (1978). In 2011 we decided to write a follow-up article, but our efforts were undermined by medical events in both of our lives. Medical problems frequently disrupt both of our lives and the lives of our networks of support; it is part of the story we wish to document here. Medical crises require focused thought, planning and action. Stepping back and analyzing one's emotions are a "luxury" that few can manage when resources are required just to get one's body through time. We have set the time parameters of this article at 1995-2010. During these years, Kaethe was 47-63 years old and Miranda was 16-31 years old.

Writing the original article, sitting together at the computer, talking, composing, commenting on the writing itself, was one of the most emotionally difficult experiences either of us had ever had. Neither of us wanted to face the degree to which our own medical conditions had impacted the other. Having now lived for 25 years with multiple life-threatening diseases, I know for certain that the most painful aspect of illness for me is the impact – fear, worry, limitations, loss -- my illness causes others. This is more unbearable to me than any physical pain I have endured. Writing this article means I must immerse myself in this relational pain. Not knowing what will unfold, as the reader is similarly unsure right now, I hope that I – that we -- will feel more not less integrated by the end of this process.

To be transparent about our process, we wrote this article as follows. I, Kaethe Weingarten, took the lead on the introduction and literature review. The history and response sections were written individually and not shared with each other until they were complete. By contrast, the discussion and conclusion were jointly conceptualized and written. We did not want to influence each other's descriptions and thus our collaborative inquiry began after we had completed our own story-making. I, Kaethe Weingarten, narrate our jointly written sections.

We compare the process of writing the discussion and conclusion to the pedagogy of emergent design. We have tried to capture both the first blush of meaning-making as well as that honed by our respective professional disciplines, psychology and family therapy for me and psychology and public health for Miranda. The process of writing these sections required and illustrated the very intergenerational conversation that we highlight as a feature of our lives. What has been less present at times is richly present now, in 2015.ⁱ

BACKGROUND

To set the scene for the literature review section that follows, a brief review of the medical history that appeared in the first article is as follows: My husband and I became parents with our first child, a boy, six weeks before my mother died of a rare malignant

tumor. Miranda was born 33 months later, in 1979, and 9 months after my father had survived complications from a triple bypass.

Miranda was diagnosed at 4 hours with Beckwith-Wiedemann Syndrome (BWS), which is caused by a mutation of chromosome 11. Children with BWS suffer from over production of insulin-like growth factor 2, causing anomalies in various organ systems. We did not know until Miranda was two years old that she would survive. As the first article describes, from birth to age eighteen, when she left home for college, Miranda endured multiple physical challenges every year, some of which required extensive and intensive medical intervention.

As of the writing of the first article, I had been diagnosed and treated for breast cancer twice, in 1988 and 1993. The treatment regimen in 1988 was arduous and lasted about one year. The second time, the initial treatment was surgical, recovery was short, but subsequent five-year treatment with Tamoxifen was challenging. Also, during the 1980's, Miranda's paternal grandparents were both diagnosed and treated for cancers, during some portion of which they lived with us. Thus we were both coping with our own physical difficulties, our profound connection to each other's suffering and our keen awareness of the medical crises the generation above was enduring.

LITERATURE REVIEW

In this section, we review major categories of literature that relate to our topic as a whole, while in subsequent sections we will refer to literature that relates to specific descriptive or analytic categories. We have attempted to present the literature in descending order of logical levels and the reader will note that we have given primacy to the mother-daughter literature over and above the literature on chronic illness. This represents a deliberate positioning of our sense of who we are and how we struggle to know ourselves and have others know us.

The Mother-Daughter Relationship

The literature by and about mothers and daughters is voluminous, has taken many forms and is of varying quality. Polarized views are common and have existed for centuries exalting (e.g. Demeter and Persephone) or demonizing (e.g. Electra and Clytemnestra) the mother–daughter relationship. Within family therapy there have been many trenchant analyses (Goodrich et al, 1988; Walters, Carter, Papp and Silverstein, 1988).

In my own book about mothering (Weingarten, 1994), I write about Miranda, but omit her medical history, as I did not believe she was old enough to give a truly informed consent. It has been my contention that very few mothers are able to write with total honesty about their feelings about a child unless the relationship has ended. A poignant example of this is Allende's book, *Paula*, in which she writes about her daughter refracted through her own history as her beloved daughter lies unconscious, soon to die (Allende, 1994). Mother loss has become its own genre (Edelman, 1994) as has writing

about being the mother and/or daughter of a child and/or mother with breast cancer (see references below).

There are now so many memoirs written by women about the experience of breast cancer that it is its own genre. Some are written from the perspective of mothers (e.g. Weingarten, 1994) and some focus on the experience of daughters facing their mothers' breast cancer (Tarkan, 1999). A few promise an interpersonal perspective, e.g.. Gabriel's 2010 memoir *Eating Pomegranates: A Memoir of Mothers, Daughters, and the BRCA Gene*. It is axiomatic now that women with breast cancer and their daughters face significant challenges both at the time of diagnosis/treatment and in the years afterward. Studies have found higher than expected rates of PTSD symptoms in affected mothers and their daughters, and over 90 % of mother and daughters in one study appraised the experience of breast cancer as traumatic (Boyer et al, 2002).

Several studies have looked at psychological stress experienced by adolescent and young adult daughters of women with breast cancer diagnoses. The data for psychological sequelae of the mother's illness seem consistent: there are effects that distinguish this group of daughters from daughters of mothers with no family history of breast cancer. For example, researchers have found that adult women whose mothers were diagnosed with breast cancer when they were adolescents had the poorest long-term adjustment to their mothers' disease (Wellisch, et al, 1992); that daughters were more likely than sons to develop depressive symptoms (Brown et al, 2007) and that relations between affected mothers and their daughters were particularly strained by the daughters' fear of inheriting

the disease and the mother's increased expectations of support from their daughters (Lichtman et al, 1987). As has been found in other contexts, i.e. in the 2007 Brown et al. study, daughters of mothers who perceived that they had social support showed the least depressive symptoms. The authors posit that the mothers' social support is protective of the daughters.

The Impact of a Chronic Physical Illness on Families

The prevalence of chronic illness in children and adults is increasing, with a quarter of all children and half of all adults experiencing a chronic health condition (Lowry, 2010; Centers for Disease Control and Prevention, 2015). This places additional stress beyond the routine stressors with which families cope. Families must now interact on a regular basis with the health care system, manage the work/family interface, draw on external networks of support and for adults, negotiate the complexities of the distribution of care that the ill and well family members receive and provide.

Family therapists have made impressive contributions to our understanding of the impact of illness on couples and families (McDaniel, Hepworth, and Doherty, 1992, 1997; Wright and Bell, 2009). Rolland's comprehensive framework identifies different dimensions along which illness and its impact unfolds. His framework accounts for the type of illness, its phases and likely prognosis (Rolland, 1987, 1994). His work remains a crucial guide for anyone trying to understand the impact of illness on families. In an important series of books and articles, Walsh (2003, 2006, 2012) has set out both normal processes in families, the ways in which they can be disrupted, of which illness is a major

way, and the resilience factors that can modulate unwelcome effects. I believe the current article illustrates several resilience factors that Walsh identifies as contributing to normal family development. I have contributed a review of the literature on the impact of chronic illness on couples, (see Weingarten, 2013).

Impact on Children of Parental Illness

Rolland's family systems- illness model remains one of the most comprehensive frameworks for conceptualizing the impact of parental illness on children. Based on a strengths-based foundation, and explicitly incorporating time horizons, Rolland (1999) identifies three distinct dimensions that can affect families coping with parental illness or disability: 1) the type of illness or disability, 2) the natural history of their phases and 3) family system variables such as the intersection of the individual and family life cycle. Both our 1997 and the present article can be considered illustrations of his model.

Comprehensive reviews of the impact of parental illness on children tend to look at specific illnesses, i.e. affective illness (Beardslee, Versage & Gladstone, 1998), multiple sclerosis (Bogosian, Moss-Morris & Hadwin, 2010), or cancer (Romer et al, 2002). Taken as a whole, these systematic reviews of quantitative and qualitative studies suggest that impact depends on the age of the child, the severity of the course of treatment, the degree of disruption to family life, marital satisfaction and support, and the ill parent's psychological functioning.

Mosher and Danoff-Burg (2005) have made an important contribution by reviewing and then critiquing the conceptual frameworks and empirical studies examining the adjustment of adult children of parents with cancer. While anxiety, depression and PTSD have been found in this population at higher rates than in adult children whose parents have not had cancer, the authors rightly point out that the data is cross-sectional and there are almost no studies with control groups. Further, the conceptual map seems to have only two positions: family members either suffer from “burden and traumatic stress, or [experience] posttraumatic growth and fulfillment.” As they point out, “Neither view adequately captures the reality of people’s experiences with this disease, be they patients or their family members. A contextual examination of cancer would address this dichotomy by joining together intrapsychic variables with interpersonal relationships and societal trends” (p.377).

Impact on Parents of Chronic Illness in Children

Not surprisingly, a systematic review of both qualitative and quantitative research conducted between 1980 and 2012 found that parenting stress was greater for parents of children with chronic illness than for parents of healthy children (Cousino and Hazen, 2013). Kazak’s work over a period of decades (Alderfer, Cnaan, Annunziato and Kazak, 2005) has established that parents of children with illness are at risk of suffering PTSD and from traumatic levels of stress at the time of diagnosis, during treatment and long after the onset of disease.

Without question, one of the most daunting aspects for parents of chronically ill children is the challenge to their felt sense of competence. Above all, parents wish to help children thrive. Faced with a child's chronic illness and the blow to the parents' thin sense of control, actual or perceived competence may falter (Maltby, Kristjanson and Coleman, 2003). Many services are aimed at supporting parents, believing that child outcomes are related to parental internal and external resources (Glazer-Waldman et al, 1992).

Parents are often torn among multiple roles, requiring hard choices. A constant feature of parenting is the necessity to allocate scarce resources of time and care to a spouse, well child, friend, and/or extended family member. This feature of family life often leads to isolation of the family from neighborhood and community just when support from a wider network would be most helpful. As more and more households require two incomes to meet modest economic standards, coping with employers becomes another challenge for families with a chronically ill child (George, Vickers, Wilkes & Barton, 2006, 2008). Challenges confronting parents include modifying work schedules, limiting working hours, and finding suitable coverage for children when a parent cannot be home.

Longitudinal Studies

To date, there are very few longitudinal studies of the impact of illness on family members. Longitudinal studies in general are over a short period of time; between one and two years seems modal. It is unusual for the time course to exceed five years, which both Hansson and Björkman's 6-year follow up on a study of mental illness (2007) and

Yonkers, Bruce, Dyck and Keller (2003) 8-year follow up on anxiety disorders also note. Fewer still are those studies that employ a longitudinal design to ask interpersonal questions. Stein, Mann and Hunt (2007) and Mackay and Pakenham (2011) interviewed parents of adult children with mental, but not physical, illness at one-year follow up. Stein et al. assessed congruence of strivings and hope between parents and adult children and Mackay and Pakenham studied adaption to the stress of caretaking. It is our hope that by examining each of our experiences and the reciprocal layers of impact of our illnesses on each other over time, we can help both clinicians and families appreciate how complex and overlapping these multiple strands of influence can be.

HISTORIES AND RESPONSES

Medical Histories 1995-2010

Kaethe's story

Miranda graduated from high school in 1997. Her leaving home coincided with my discontinuation of two medications that had been prescribed by my oncologist following my breast cancer diagnosis in 1993. Within a month I began having intractable migraine-like headaches, averaging 65% of the month, which lasted for three years. In 2001, Hilary Worthen, my husband, Miranda's father and an internist, finally made the correct medical diagnosis of the headaches. By that point, I had been unsuccessfully treated by several neurologists; their prescribed regimens made me toxic for weeks at a time. I

twice experienced serotonin syndrome and had one respiratory arrest as a consequence of one of the episodes. Treatment began in late 2001 for peripheral autonomic neuropathy, a late consequence of my chemotherapy in 1989 that had been camouflaged by the medications prescribed in 1993. The sudden discontinuation of these medications in 1997 had created a perfect storm of pain.

I was extremely relieved that neither child was at home during this period. I was able to maintain my work by carefully scheduling my time and by working through intense pain. I knew that I would have been unable to provide the kind of care that Miranda had needed in the past had she been at home. I tried also to keep the extent of my pain out of their awareness. During this period of intense pain, I made the decision to write a book on witnessing violence and violation (Weingarten, 2003). I wanted to live, but the pain was becoming unendurable. I believed that my family members would not want me to suffer as I was suffering. The absence of familial constraint was frightening to me. I committed to writing this book as a way of anchoring myself to life.

On the day my book was published in 2003, I was diagnosed with a new primary breast cancer. As a response, I developed the Treatment Dedication Program (Weingarten, 2005). I had previously written that I had set myself the task of turning private pain into public purpose. In this instance, I literally did so by dedicating each of my radiation treatments to a person or cause I wished to honor. It benefited me by connecting me to my work in the world even at a time I had so little to offer.

Within the same week as my diagnosis, Miranda was given the opportunity to be a research associate on a project in Sierra Leone, Liberia and Northern Uganda, working with former girl soldiers. Once we worked out how we could stay in touch with each other, I was unambivalent about her taking this opportunity, which continues to this day to be a significant part of her professional work.

From 2003-2008, I became sick again, this time in response to a class of medications (of which I tried all three) called aromatase inhibitors, prescribed for women following breast cancer diagnosis. The two first years of this regimen made me sicker than chemotherapy did. However, it was not until 2006, when I was diagnosed with a rare lung infection, a late consequence of my radiation treatment in 1989, requiring one year of IV antibiotics every six hours and a lung resection operation in the spring of 2007, that I dramatically cut back work commitments, so that I could take care of myself as needed.

During these years, Miranda was at school at Oxford and then in California. Visits home were occasionally strained by my having fewer resources. I felt awkward prioritizing my needs, having spent 20 years prioritizing my children's needs, and I wasn't as graceful at it as I might have been. Miranda's engagement and preparation for her wedding took place during the time I was hooked up 24/7 to an IV pole, in 2006-2007. Miranda and her husband did virtually all the work to arrange their wedding, which was a beautiful and moving affair. I think that symbolically for both of us it expressed the message that she was able to function on her own in the world without intensive emotional parental – maternal *and* paternal – support. The conjunction of events, my lung infection and her

wedding, produced a dramatic recalibration in the relationship, whereby she was finally “launched” as an independent adult in the way her brother had been years earlier. Neither her father nor I had perceived the difference between our son’s “launch” and Miranda’s as clearly as Miranda had. However, once we felt the seismic shift, it felt wonderful – and as it should have -- to all of us.

In December of 2007, our first grandchild was born to our son and his wife. I arranged to spend two months where that family lived. I then began a pattern of visiting for a week every eight weeks so that I could realize my passionate ambition: to care for grandchildren. Having lost my mother before she could be a grandmother to my children, I had said to myself that I would make it up to them by being a grandmother to their children. My cancers had been traumatic in large measure out of a fear that the resting place I had arrived at in relation to my grief over my mother’s early death might be undone by my own premature death.

In 2008, Hilary was diagnosed with multiple myeloma and given a 3-5 year prognosis. In the Spring of 2010, he began chemotherapy every two weeks, which continues to this day. That same year, I was diagnosed with yet another rare lung infection and began a year of oral antibiotic treatment. Again, I became extremely ill from the medical regimen. This did not stop me from being present before, during and after Miranda’s pregnancy with her first child.

In December, 2010, three months after Miranda's first child was born, I woke up blind. One of the antibiotics I had taken to cure the lung infection had been toxic for me not only systemically but specifically toxic for my optic nerves. I was legally blind for 15 months, during which time I tried to maintain my professional commitments and also my activities as a grandparent. My article on reasonable hope was written during this time; the construct grew out of my need to find ideas that offered me comfort (Weingarten, 2010).

Miranda's story

The end of high school, where our last article left off, was a period of multiple medical complications and isolation from my peers. While I had many acquaintances that I enjoyed seeing at school, I had almost no friends with whom I felt I could share what was really going on with my body. I experienced pain unpredictably, sometimes daily. I had no coherent short answer to why my shoulder was dislocated and I was not interested in sharing the long answer. While I didn't have friends my age, I did have a rich community of older friends – mostly my parents' friends – who were interested in and able to support me.

My decision about where to apply to college was largely based on where I could be that was within easy driving range for my parents and known medical specialists. I ended up at Harvard College, a mere 6 miles from home, not just because it was a good school, but because I felt I would be safe there. When I went to college, my experience with my peers changed. In my first few weeks of school, I became fast friends with my roommate.

After I was hospitalized for an unexplained cardiac event, I worried that she would not want to remain friends. But she matter-of-factly told me that, while she was concerned for me, it just wasn't a big deal to her: she could easily "handle" being friends with someone whose body was unpredictable.

I came to realize that there were many more people like her: people my age who were mature, thoughtful, fun and passionate and could maintain an intimate friendship with someone who was experiencing physical health problems. In fact, many of my friends had issues that they thought of as a "big deal" that were not a challenge for me. Perhaps more than in high school, I had long stretches of time where my body was strong, I was not in pain, and there was nothing that required follow-up. During those times, I could easily forget that there was anything unusual about me.

Towards the end of my first year of college, I began dating a man who is now my husband. Brian met my father for the first time in the elevator on his way up to my hospital room. My health problems did not deter him and, while we bonded over activism, poetry, hiking, and singing, his ability to be present with me during periods of pain, uncertainty, and physical distress made me think of him as a "keeper."

In the first two years of college, my friends and boyfriend became peers to whom I told the truth about my body, but my parents were still the people that I called when something was wrong to help me figure out what to do and then to accompany me to whatever appointments were necessary.

Brian and I decided to take the first semester of our junior years off, interning for organizations in Washington, DC. One evening, I noticed my tongue swelling. We consulted my parents and headed to the hospital, where I was admitted overnight. Brian stayed with me, sharing the narrow hospital bed. A few weeks later, after experiencing sharp abdominal pain, we were back in the hospital. Brian held my hand as the radiologist told us he saw a solid mass in my ovary. That felt like too much for the two of us to deal with alone, and we flew to Boston the next morning. During the exam by my familiar gynecologist, Brian stood on one side of the table and my mother stood on the other; the doctor diagnosed a hemorrhagic cyst, which would dissolve on its own. That night, with my father traveling, I slept in the middle of the bed with Brian on one side and my mother on the other – neither wanting to be apart from me and I wanting both of them close.

After graduation, I took a long trip to South Africa with my parents. While I enjoyed being with them, I had terrible migraines and was stunned to realize that Brian knew how to rub my head just the right way and my dad didn't. When I returned to Cambridge, where Brian and I were living together, I felt terrified by my discovery. It felt like when I had given up sucking my fingers when I was a child and, weeks later when I was sad, I had tried to comfort myself with my fingers again only to realize that the callouses were gone and my fingers did not fit. While I knew that my parents would always be there for me, I realized they were no longer the best ones to help me. On the other hand, Brian and

I were 18 when we met, our relationship was becoming a little rocky and I certainly did not feel like it was “safe” for me to depend on him always being there for me.

In fact, over the next several months, we fought more and more. I worried that we were becoming codependent. During one conversation about our future in which Brian asked about having children, I raised the point that I did not know whether BWS was heritable or what it might be like for me to have children. Though we did not talk more about it then, I could tell that Brian was worried. I found out later that Brian at this time also asked a friend in medical school to research BWS and, hearing about worst-case scenarios, became fearful of losing me at an early age to BWS complications. When we broke up that summer, I felt as though I had been rejected because of BWS. A few months later, when Brian was interested in getting back together, he acknowledged that he had been afraid both of losing me and of not being able to have children but told me that he was now ready to commit. Instead of reassuring me that he had thought about it deeply and still wanted to be with me, that statement affirmed my worst fears – that he had broken up with me in part because of BWS. We remained apart for five years.

In the period after Brian and I broke up, I realized that I would have to learn to manage my health independently. Of course, I would also use the support of my parents and friends, but I recognized that I would not be able to depend on any one person except for myself. Given my mother’s continuing health problems, I thought explicitly about her mortality and my need to be able to care for myself. I actively assembled a broad team of supporters so that I would never have to rely on just one person and could be flexible in

the face of changes to my situation. I also set out to learn everything I could about BWS, sought genetic counseling and began to read the medical literature for myself.

Just as in college, I was uninterested in expanding my friendship network to include people whom I doubted would be there for me when a crisis hit. When my mother was diagnosed with breast cancer again in 2003, I cut short a new romantic relationship so I would not have to find out that he couldn't be present to what that might bring.

When it became clear that my brother was in a serious relationship, I asked his permission to go out to brunch with the two of them so that I could explain directly to the woman who is now his wife about my health problems. I wanted her support for whatever would come to pass for me – and I wanted her to know what an extraordinary brother I had.

In this way, my mid-twenties was a time of taking charge of creating a social support network and developing the capacity to navigate medical crises with a team of supporters, not just my parents or a partner. The main benefit of this new capacity was that I stopped wanting to talk about what was going on with my health all the time and that I felt more able to take risks because I felt like I would be able to manage the consequences. I traveled independently and with friends, including to countries where good medical care would have been very hard to find. Though I returned with my share of parasites and infectious diseases, the diseases were ordinary and my reactions were ordinary. My unpredictable body became more and more predictable and my sense of self and

possibilities changed accordingly. I lived in England for two years, completing a Masters degree. I became a rower and had one of the best times on my team. I ran for miles every day. While my body became reliable, I never took it for granted.

When I had health problems, I still consulted with my parents – sometimes they consulted with colleagues – before seeing my doctor. My ability to take the lead in managing my health did not come at the expense of including my support system.

When Brian and I decided to get back together in 2006, I had far more compassion for what it must have been like for him as the young boyfriend of someone with serious medical problems. In the intervening years, we had discussed our breakup and I had realized that what I had experienced as rejection was instead a reasonable response to the fear of an unknown future. Looking back, we are both grateful to have had our time apart - each of us now knows that we can navigate the world without a partner; we just also know how much sweeter it is to do it with each other.

I was close to peak fitness when I conceived my older daughter. There have been no studies about what happens to women with BWS during pregnancy and so we only had our own speculations about what might happen. Early on, my ligaments began to hurt and loosen more than usual for a pregnancy. While things were uncomfortable and occasionally scary, the pregnancy went vastly smoother than I had expected. Brian and I asked my mother to accompany us for our daughter's birth and she came out three weeks before Anna was eventually born. By the last month, I was unable to walk forwards

because of looseness in my hip and sciatic nerve pain. And, in fact, I walked backwards into the hospital to deliver my first child.

Kaethe's Response to Miranda's Story

I had anticipated being much more distressed reading Miranda's writing than I was. The only piece of it that I didn't already know was how intentional her decision not to rely on us was and that, at first, her motivation was fear. My experience was that the process of transferring responsibility for her care was gradual, that it had started by design when she entered college in 1997 and that by the time she was at Oxford, in 2004, we were clearly consultants.

I had expected to read more about the impact of my illnesses on her during this fifteen-year time period and though breaking up with a boyfriend is significant, it wasn't what I expected to learn. I understand now that during the years I was so worried about my children learning about how much pain I was in and how compromised I was on the five-year course of hormone therapy starting in 2003, that Miranda's psychological and developmental trajectory was tracking other issues.

Similarly, the impact of my third breast cancer on her is little mentioned. During this fifteen-year period I had genetic testing twice for the BRCA1 and BRCA2 genes, both of which were negative. Although we know that this accounts for only a percentage of heritable risk, perhaps this allayed some fear on both of our parts. I distinctly remember thinking, "Just let her get through breast feeding two children before anything happens,"

knowing that this secular wish could have no impact on anything at all. However, at the time of this writing, Miranda has achieved this and I do feel intensely grateful for that.

I was also struck by the binary nature of Miranda's writing about her identity. She has two fairly distinct identities. I do not. I have shades of myself. When I am well, I feel like an indigo person and when I am ill I feel like a pale blue person. I have learned to live well in both hues. They both feel like me, now, although I learned to live well as a pale blue person during my year of chemotherapy, in 1989, when I was 42 years old.

Miranda's Response to Kaethe's Story

Reading my mother's narrative felt very familiar. The only piece of new information for me was how profoundly untethering her pain had been when I was in college and how she had used her work to give purpose to her life. Every detail, however, felt known though sad to recall.

As we are working on this article, I am in a particularly sleep-deprived and exhausted state, having had my second child not too long ago and dealing with continuing health problems. But I think even if I were not exhausted, I would feel stunned by how productive my mother has been not "in spite" of her health problems, but flowing out of her health problems. I admire her ability to "turn private pain into public purpose," and to find meaning in her suffering through her ability to imagine it as having a use for others. Her modeling this is an extraordinary gift she has given me, and one that I have

attempted to draw on when dealing with my own ill health or fears. (Worthen, Leonard, Blair & Gupta, in press).

At the same time, I wish for my mother what I know she wishes for me, too: that she could reliably prioritize her self-care. The most vivid example of my concern about her ability to do this well occurred three weeks after my mother's lung resection in 2007, a few months before my wedding. I went home for a week to help care for her. She was raring to begin her recovery. To me, she looked like she should still be in bed and drinking warm fluids, not pushing herself to do physical therapy. One morning that week, following her doctor's instructions, she got on her treadmill and after a few minutes, she fell off. I heard her scream from the basement and ran down to see her sprawled on the floor, bruised and with her skin rubbed raw in patches. It was a horrifying moment for me, but the next day she wanted to resume the treadmill. Her determination to overcome physical adversity is so admirable yet it also feels excessive to me at times, like that one.

She is clearly better at gauging the right balance with others than she is with herself.

With my recent health problems after my second child's birth, she told me that I was "still in crisis mode, not yet in recovery." It was helpful for me to think of myself as getting that pass to not yet be strengthening or shedding our family's extra help – including my parents' help. Though I was worried about depleting my parents, I heard the echoes of my mother's basement scream in her wisdom and gratefully accepted her help.

I know my mother explicitly wants her experience of pain to help others through her writing and clinical work. Clearly, it has also helped me. In the balance of our relationship now, I am able to accept this help in a way that during my twenties, as I was learning to navigate my life's challenges myself, I may not have been able to do so as gracefully.

DISCUSSION

This article provides one answer to the question, "How does illness impact the normal developmental processes necessary for a family to launch a member?" As other researchers have found (e.g., Mattanah et al. 2004; Seiffe-Krenke, 2006), adolescents with solid relationships to their parents and whose parents support their autonomy "launch" more successfully than their peers who do not have these advantages. Clearly, these primary dimensions were not compromised by either Miranda's or my illness experiences. As research and theory predict (Skowron, Stanley and Shapiro, 2008), Miranda launched successfully.

Miranda's narrative also makes clear that the developmental stage of launching took place in the context of factors unique to the medical issues and crises in our family. While she was engaged in the developmental task of taking over her medical care, Hilary and I were engaged in the parental task of letting go of the primary role in her care management. Miranda's perception that I had "a lot going on" contributed to her belief that she needed to have her own supportive group of friends who could accept her unpredictable body. She was also clear that she would need to find a life partner who

could take on not only her own medical history but mine as well.

During these years, Miranda was able to pursue her educational and work pathways without compromise. While it was difficult for both of us for Miranda to be in Africa during my third cancer treatment, we both wanted her to do it. I had more limited emotional resources with which to manage my daily anxiety about Miranda's safety than I would otherwise have had. Miranda felt concerned about what I was experiencing but felt like she was doing the work in Africa for both of us. As most of the trip was in remote Sierra Leone – inaccessible for communications – it was easier for her to focus on just being present for the work. When back in the capital, where spotty email was a possibility, Miranda was desperate to be in touch and find out how I was doing.

The theme of separation-individuation is prominent in many schools of psychological thought. Family systems thinkers (Bowen, 1978; Carter and McGoldrick, 1999), psychoanalysts (Chodorow, 1978) and relational-cultural theorists (Jordan, 2010) have all looked at mother-daughter relationships during late adolescence and young adulthood through this lens. Psychoanalysts tend to focus more on psychopathology and disruption, citing more intensity and less differentiation in the mother-daughter dyad than in other parent-child dyads. Others find that the skills one has going into this phase (e.g., emotional regulation, boundaries, ability to be self-reflective and communication) have implications for navigating it (Slade and Cohen, 1996).

We both believe that we experienced less conflict than most mother-daughter pairs during

high school. Rebellion against her parents, and even conflict with her parents, would have been counter productive to Miranda's goal of having as much support as she could to face the many challenges her medical condition placed on her. I felt Miranda's need for me viscerally every day. During Miranda's senior year in high school, I took my longest trip away from the family to attend a narrative therapy training in Adelaide, Australia. I consciously wanted to preview being apart from Miranda to see what would happen if I "withdrew the IV gratification of her needing me," a phrase from a journal entry I wrote during that time. We both survived. The trip helped start processes of change that were inevitable with Miranda's leaving home for college.

We believe that Miranda's work of individuation, or differentiation, occurred less during high school than it might have had she not had such severe medical challenges. In college and through her middle to late twenties, she developed rich friendships that provided joy and support – her parents were no longer her primary authentic relationships. If intimacy is the sharing or co-creation of meaning, as I have written, (Weingarten, 1991,1994), then I was not Miranda's primary confidant. No information was withheld, but neither was it richly elaborated with each other. It has really only been since Miranda has married and moved on to parenthood herself, in her early thirties, that the fullness and richness of mutual knowing, of intimate connection, has flourished. Nor, is the sharing exactly equal. Whereas Miranda does not protect Kaethe from what she is experiencing medically, Kaethe prefers to titrate the intensity of her feelings in the service of not overwhelming Miranda. Because she has Hilary and intimate friends, Kaethe can easily do this. They also meta communicate about the timing of sharing

challenging experience. This contributes to the durability of their connection.

Issues of identity are ubiquitous for all adolescents and young adults (Erikson, 1968; Kroger, 2007). Miranda's account points to the particular concerns a young person with chronic health issues must integrate into her understanding of herself. Her account suggests that she experiences two identity positions and must "decide" which one is active, or which one to activate, depending on circumstances. Sometimes she feels like a healthy person with medical problems and at other times she feels she is a disabled person who is coping exceedingly well. The fact that she has had long stretches in each mode is relevant to how she frames her identity.

My description pivots from a different developmental point. Having developed serious chronic health issues in my early forties, after a stable identity was in place, as were matters of marriage, family, career and friendship, I use the metaphor of hue. The exterior surface changes color around an invariant healthy core. The sense of a healthy core dominates even my illness experiences.

A significant portion of the literature that looks at mother-daughter issues in the context of breast cancer focuses on the "assault" to the daughter's identity due to the mother's diagnosis. The focus of the majority of research is on psychopathology not on resilience (Mosher and Danoff Burg, 2005). In the writing we have done on the impact of my illness on Miranda we describe how fear of my dying was initially traumatic for Miranda but we have also written about the many ways Miranda coped, and Hilary and I helped

her cope, with these fears. This intense fear does not seem to have had an impact on aspects of identity that have been singled out in some of the mother-daughter breast cancer literature, for instance, self-concept (Wellisch et al, 1992). Miranda and I wonder whether the fact that Miranda grew up in a household in which a critique of the discourse of breast cancer was part of routine conversation might have been protective of Miranda? It is also Miranda's sense that after my third cancer, she internalized the belief that she would develop breast cancer at some point in her life. Given my successful treatment history, she did not fear this so much as accept that early detection and excellent medical care would be key to her future also. There is little to no traumatic activation for her with this idea; it sits relatively comfortably. Subsequently, she married a man who also accepted this as part of his likely future. He formulates the issue as "when" they have to deal with cancer, not "if." Naturally, we all hope that this adaptation is wrong. Additionally, Miranda now has several friends whose mothers have had breast cancer. The disease is sufficiently common that a woman doesn't need to seek out friends with this family medical history. It has become just one part of the tapestry of several of her friendships.

In the years under review in this article, 1995-2010, which include my third breast cancer diagnosis and treatment, the framework of trauma is not germane. Perhaps having coped two other times, neither of us experienced this third cancer as traumatic after the initial diagnostic period. It was grueling but not traumatizing. Nor is the concept of post-traumatic growth apt (Milam, Ritt-Olson & Unger, 2004). We were both adapting to changing circumstances, creating the internal and external resources we needed as best

we could as we faced a variety of challenges. We intuitively arrived at many of Walsh's categories of resilience (Walsh, 2006). Of note, other researchers have also found that young adult survivors of serious childhood illnesses do not attribute their worldviews to their illness experiences without prompting (Devine et al, 2010). It is not that either of us is denying personal growth; it is that we are not attributing it to trauma.

In retrospect, we can see that some of the stress of the years 2003-2007, which included major illness for me and major life changes for Miranda, might have been moderated if there had been more conversation between us about what was happening for each of us. In these years, my depleted reserves and Miranda's interests being focused away from her parents contributed to less adequate resolution of tension between us than might have otherwise occurred. At the same time, we were often inspired by the other. In this regard, the framework of "vicarious resilience" (Hernandez, Gangsei & Engstrom, 2007) seems more appropriate than post-traumatic growth. Watching Miranda carve out work, love, family and friendship brought indescribable joy (and relief) to me. Miranda has written about her admiration for my active coping.

CONCLUSION

This article, while written twenty years after an earlier article (Weingarten & Worthen, 1997), and unique in that regard, records events in our lives up to 2010, a fifteen-year interval from the first article. The most recent five years take us into life stage and medical events in our lives that are too fresh to consider writing about. These events

include Miranda's pregnancies and the births of her two daughters; Hilary's and my move in 2013 to be near our children and grandchildren; Miranda's having a significant number of evaluations for possible cancerous breast masses; a recurrence of one of my lung infections and a third round of genetic testing related to hereditary cancers for me. The impact of sleep deprivation, traumatic reactivity to new medical events and managing self-care in the context of pain and responsibilities for other people would be analytic themes for this material, as would the concept of self-loss/other-loss (Weingarten, 2012, 2013).

Interestingly, with one exception, we don't believe that the themes that anchor this article would apply to an analysis of our experiences from 2010-2015. Miranda's independence is established and her ability to use maternal and paternal support, sometimes daily, is unencumbered by identity or separation-individuation concerns. Miranda's identity as a professor, mother, wife, friend, householder, daughter, sister, aunt is firm. She continues to work with the bi-modal nature of the healthy-sick continuum.

The exception is the topic of self-care. While each of our dilemmas with self-care is openly discussed by us -- and the fact that I am both a caution and a role model causes no conflict -- we both wish we were better at it. I am pulled by the desire to be productive and to be of service to others. When I am with others, I never wish to interrupt the intensity of moments of connection even to take a pill. I allow this to trump what my body clearly tells me it needs me to do. Miranda is motivated by the needs of others, prioritizing them -- her children, students -- over her own. We clearly see the gendered

socialization in both of our self-care habits. Should there be a third article, we would theorize this topic at some length.

Our communication has been clear and tension-free for years, even now that we live a mile apart. The joy that we all feel as a three-generation family is intense and often creates overwhelming feelings of gratitude. These feelings provide welcome context for more challenging moments.

Writing this article did not prove as emotionally difficult relationally as did writing the first. In fact, we both felt like “old hands” around most of the topics we discussed at length in order to write this article. Certainly, we explored new feelings and had new insights but the conversation between us created no tremors, like happened the first time. I can’t say I feel *more* integrated but I would say I feel more dialogically confirmed in what I thought I knew.

Likewise, I continue to find the concept that the future is uncertain, unknown but influencable enormously helpful in general and in managing the medical issues that assault our family (Weingarten, 2010). Creating a productive work, friendship and family life in a new city in the context of so much medical management and uncertainty has been challenging. It is also what the context requires so it must be done. Hilary is still alive and thriving. I have realized my adult ambition to be an active participant in my grandchildren’s lives. There have been many years when it wasn’t so clear this could happen. I remember once in the 1980s seeing Olga Silverstein present at a conference

with her daughter, Laura, and thinking how amazing it would be if some day I could work with my daughter...if she lived. This fantastical wish has also now been realized. Actually, my cup runneth over.

The literature is replete with stories of hardships experienced by families coping with major medical illness. Few articles deal with the double whammy of child and parental illness and none that we could find provide a long-term follow-up. If this story is boring, that is precisely our contribution. Despite significant life-threatening illnesses and consistent medical problems, despite some life-threatening medical errors, our lives are rich, rewarding and “appropriate” for our life stage. That is the news.

REFERENCES

- Alderfer, M., Annunziato, R., Cnaan, A., & Kazak, A. (2005). Patterns of posttraumatic stress in parents of childhood cancer survivors. *Journal of Family Psychology, 19*, 430-440.
- Allende, I. (1994). *Paula*. New York: HarperCollins.
- Beardslee, W. R., Versage, E. M., & Gladstone, T. G. (1998). Children of affectively ill parents: A review of the past 10 years. *Journal Of The American Academy Of Child & Adolescent Psychiatry, 37*(11), 1134-1141.
- Bogosian, A., Moss-Morris, R., & Hadwin, J. (2010). Psychosocial adjustment in children and adolescents with a parent with multiple sclerosis: A systematic review. *Clinical Rehabilitation, 24*(9), 789-801.
- Bowen, M. (1978). *Family therapy in clinical practice*. New York: J. Aronson.
- Boyer, B. A., Bubel, D., Jacobs, S. R., Knolls, M. L., Harwell, V. D., Goscicka, M., & Keegan, A. (2002). Posttraumatic stress in women with breast cancer and their daughters. *American Journal Of Family Therapy, 30*(4), 323-338.
- Brown, R. T., Fuemmeler, B., Anderson, D., Jamieson, S., Simonian,
- Carter, E. A., & McGoldrick, M. (1999). *The expanded family life cycle: Individual, family, and social perspectives*. Boston: Allyn and Bacon.
- Centers for Disease Control and Prevention. (2015, August 26). *Chronic Disease Overview*. Retrieved from <http://www.cdc.gov/chronicdisease/overview/>
- Chatman, S. (1978). *Story and discourse*. Ithaca NY: Cornell University Press.
- Chodorow, N. (1978). *The reproduction of mothering: Psychoanalysis and the sociology of gender*. Berkeley: University of California Press.
- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal Of Pediatric Psychology, 38*(8), 809-828.
- Devine, K. A., Reed-Knight, B., Loiselle, K. A., Fenton, N., & Blount, R. L. (2010). Posttraumatic growth in young adults who experienced serious childhood illness: A mixed-methods approach. *Journal Of Clinical Psychology In Medical Settings, 17*(4), 340-348.
- Edelman, H. (1994). *Motherless daughters: The legacy of loss*. Reading, Mass: Addison-Wesley Pub. Co.

- Erikson, E. H. (1968). *Identity: Youth and crisis*. New York: W. W. Norton.
- Gabriel, S. (2010). *Eating Pomegranates: A memoir of mothers, daughters, and the BRCA gene*. New York: Scribner.
- George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2006). Chronic grief: Experiences of working parents of children with chronic illness. *Contemporary Nurse*, 23(2), 228-242.
- George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2008). Working and caring for a child with chronic illness: Challenges in maintaining employment. *Employee Responsibilities And Rights Journal*, 20(3), 165-176.
- Gladstone, Boydell, Seeman & mothers, daughters, and the BRCA Gene (McKeever, 2011).
- Glazer-Waldman, H. R., Zimmerman, J. E., Landreth, G. L., & Norton, D. (1992). Filial therapy: An intervention for parents of children with chronic illness. *International Journal Of Play Therapy*, 1(1), 31-42.
- Goodrich, T. J., Rampage, C., Ellman, B. & Halstead, K. (1988). *Feminist family therapy: A casebook*. New York: Norton.
- Hansson, L., & Björkman, T. (2007). Are factors associated with subjective quality of life in people with severe mental illness consistent over time?--A 6-year follow-up study. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care & Rehabilitation*, 16(1), 9-16.
- Hernández, P., Gangsei, D., & Engstrom, D. (2007). Vicarious Resilience: A New Concept in Work with those who Survive Trauma. *Family Process*, 46(2), 229-241.
- Jordan, J. V. (2010). *Relational-cultural therapy*. Washington, DC, US: American Psychological Association.
- Kroger, J. (2007). *Identity development: Adolescence through adulthood*. Thousand Oaks, Calif: Sage Publications.
- Lichtman, R. R., Taylor, S. E., & Wood, J. V. (1987). Social support and marital adjustment after breast cancer. *Journal of Psychosocial Oncology*, 5, 47.
- Lowry, F. (2010). Prevalence of Chronic Illness in US Kids Has Increased. *Medscape Medical News*. Retrieved from <http://www.medscape.com/viewarticle/717030>

- Mackay, C., & Pakenham, K. I. (2011). Identification of stress and coping risk and protective factors associated with changes in adjustment to caring for an adult with mental illness. *Journal Of Clinical Psychology, 67*(10), 1064-1079.
- Maltby, H. J., Kristjanson, L., & Coleman, M. E. (2003). The parenting competency framework: Learning to be a parent of a child with asthma. *International Journal Of Nursing Practice, 9*(6), 368-373.
- Mattanah, J. F., Hancock, G. R., & Brand, B. L. (2004). Parental attachment, separation-individuation, and college student adjustment: A structural equation analysis of meditational effects. *Journal of Counseling Psychology, 51*, 213–225.
- McDaniel, S. H., Hepworth, J., & Doherty, W. J. (1992). *Medical family therapy: A biopsychosocial approach to families with health problems*. New York, NY: BasicBooks.
- McDaniel, S. H., Hepworth, J., & Doherty, W. J. (1997). *The shared experience of illness: Stories of patients, families, and their therapists*. New York: BasicBooks.
- Milam JE, Ritt-Olson A, Unger J. Posttraumatic growth among adolescents. *Journal of Adolescent Research. 2004;19:192–204.*
- Mosher, C. E., & Danoff-Burg, S. (2005). Psychosocial impact of parental cancer in adulthood: A conceptual and empirical review. *Clinical Psychology Review, 25*(3), 365-382.
- Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process, 26*(2), 203-221.
- Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York, NY, US: Basic Books.
- Rolland, J. S. (1999). Parental illness and disability: A family systems framework. *Journal Of Family Therapy, 21*(3), 242-266.
- Romer, G., Barkmann, C., Schulte-Markwort, M., Thomalla, G., & Riedesser, P. (2002). Children of somatically ill parents: A methodological review. *Clinical Child Psychology And Psychiatry, 7*(1), 17-38.
- Seiffe-Krenke, I. (2006). Leaving home or still in the nest? Parent-child relationships and psychological health as predictors of different leaving home patterns. *Developmental Psychology, 42*(5), 864-876.
- Skowron, E.A., Stanley, K.L. and Shapiro, M.D. 2008). A longitudinal perspective on differentiation of self, interpersonal and psychological well-being in young

- adulthood. *Contemporary Family Therapy: An International Journal*, Vol 31(1), Mar 2009, 3-18.
- Slade, A., & Cohen, L. J. (1996). The process of parenting and the remembrance of things past. *Infant Mental Health Journal*, 17(3), 217-238.
- Stein, C. H., Mann, L. M., & Hunt, M. G. (2007). Ever onward: The personal strivings of young adults coping with serious mental illness and the hopes of their parents. *American Journal Of Orthopsychiatry*, 77(1), 104-112.
- Tarkan, L. (1999). *My mother's breast: Daughters face their mother's cancer*. Dallas, TX US: Taylor Publishing Co.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, 42(1), 1-18.
- Walsh, F. (2006). *Strengthening family resilience (2nd ed.)*. New York, NY, US: Guilford Press.
- Walsh, F. (2012). *Normal family processes: Growing diversity and complexity (4th ed.)*. New York, NY, US: Guilford Press.
- Walters, M., Carter, B., Papp, P., Silverstein, O., & Women's Project in Family Therapy. (1988). *The Invisible web: Gender patterns in family relationships*. New York: Guilford Press.
- Weingarten, K. (1991). The discourses of intimacy: Adding a social constructionist and feminist view. *Family Process*, 31, 285-305.
- Weingarten, K. (1994). *The Mother's voice: Strengthening intimacy in families*. New York: HarcourtBrace.
- Weingarten K. (2000). Making Sense Of Illness Narratives: Braiding Theory, Practice and the Embodied Life. In: Dulwich Center Publications, editors. *Working with the Stories of Women's Lives*. Adelaide, Australia: Dulwich Centre Publications, 2000:111-126.
- Weingarten, K. (2003). *Common shock: Witnessing violence every day: How we are harmed, how we can heal*. New York, NY, US: Dutton/Penguin Books.
- Weingarten, K. (2005). Cancer, Meaning Making, and Hope: The Treatment Dedication Project: Comment. *Families, Systems, & Health*, 23(2), 155-160.
- Weingarten, K. (2010). Reasonable hope: Construct, clinical applications, and supports. *Family Process*, 49(1), 5-25.

- Weingarten, K. (2012). Sorrow: A therapist's reflection on the inevitable and the unknowable. *Family Process*, 51(4), 440-455.
- Weingarten, K. (2013). The 'cruel radiance of what is': Helping couples live with chronic illness. *Family Process*, 52(1), 83-101.
- Weingarten, K., & Weingarten Worthen, M. E. (1997). A narrative approach to understanding the illness experiences of a mother and daughter. *Families, Systems, & Health*, 15(1), 41-54.
- Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. (1992). Psychological functioning of daughters of breast cancer patients. Part II: Characterizing the distressed daughter of the breast cancer patient. *Psychosomatics*, 33, 171–179.
- Worthen, M., Leonard, T., Blair, T.R., Gupta, N. (2015) Experiences of parents caring for infants with rare scalp mass as identified through a disease-specific blog. *Journal of the American Board of Family Medicine*. In press.
- Wright, L. M., & Bell, J. M. (2009). Beliefs and illness: A model for healing. Calgary: 4th Floor Press. (<http://www.cdc.gov/chronicdisease/overview/> retrieved September 14, 2014).
- Yonkers, K. A., Bruce, S. E., Dyck, I. R., & Keller, M. B. (2003). Chronicity, relapse, and illness--Course of panic disorder, social phobia, and generalized anxiety disorder: Findings in men and women from 8 years of follow-up. *Depression And Anxiety*, 17(3), 173-179.

ⁱ As with our first article, there are significant people in our lives whose support, love, expertise and care are crucial to both of our lives and who do not figure centrally in these pages. Fortunately, they have not had to contend with serious medical issues for decades as we have, and it is this feature of our lives that is our focus. Were we to focus on joy, for instance, they would appear prominently.