

Special Issue: Aging - It's Personal: Forum

## Dismantling the Silence: LGBTQ Aging Emerging From the Margins

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### Abstract

Historical, environmental, and cultural contexts intersect with aging, sexuality, and gender across communities and generations. My scholarship investigates health and well-being over the life course across marginalized communities, including LGBTQ (lesbian, gay, bisexual, transgender, and queer) midlife and older adults, native communities experiencing cardiovascular risk, and families in China living with HIV, in order to balance the realities of unique lives in contemporary society. By probing the intersection of age, sexuality, and gender, my analysis is informed by both personal and professional experiences. With the death of my partner occurring at a time of profound invisibility and silence before HIV/AIDS, I found my life out of sync, experiencing a loss without a name. My life was thrust into a paradox: My relationship was defined by a world that refused to recognize it. This essay provides an opportunity for me to weave together how such critical turning points in my own life helped shape my approach to gerontology and how gerontology has informed my work and life. Reflecting on this journey, I illustrate the ways in which historical, structural, environmental, psychosocial, and biological factors affect equity, and the health-promoting and adverse pathways to health and well-being across marginalized communities. Although gerontology as a discipline has historically silenced the lives of marginalized older adults, it has much to learn from these communities. The growing and increasingly diverse older adult population provides us with unique opportunities to better understand both cultural variations and shared experiences in aging over the life course.

**Keywords:** Life course, Equity, Gerontology, Sexuality, Gender, History

As a gerontologist, my scholarship focuses on understanding life and aging across differing historical, social, and cultural contexts; how marginalization intersects with age, sexuality, and gender; and what approaches are most effective to promote the well-being of people of all ages and cultures. Of the many joys and concerns in the lives of older adults and the field of aging, I ask myself how these priorities, and the dilemmas they present, have surfaced as my primary substantive interests. Over the past 25 years, I have investigated health risk and health-promoting pathways in aging and well-being across diverse communities, for example, working in LGBTQ (lesbian, gay, bisexual, transgender, and queer) aging (Fredriksen-Goldsen, Cook-Daniels, et al.,

2014; Fredriksen-Goldsen, Emlet, et al., 2013), reducing cardiovascular risk in native communities (Walters et al., 2012), and supporting caregiving of older adults and their families living with HIV in China (Fredriksen-Goldsen, Shiu, et al., 2011; Simoni et al., 2011), a highly stigmatized disease within a global context.

This essay provides an opportunity for me to reflect on the turning points in my life and how these have informed my work over time, especially now that I'm old enough to complete my own aging-related surveys. My goal is to reflect on the intersection of how gerontology as a flourishing field has influenced my life and how my life has informed my work in the field. As a university professor,

I have a bulging folder, in which over the past several decades I've tucked away reflections, saving tattered clippings and thoughts jotted on scraps of paper or a corner torn from a napkin; I pulled a few to share here.

### Change in Perspective

Life's turning points unfold within historical and environmental contexts, having the capacity to profoundly alter life trajectories. In early gerontological work, Neugarten, Moore, and Lowe (1965) theorized social clocks and age-appropriate expectations, norms, and behaviors related to the timing of transitions, as "on-time" or "off-time," such as marriage, childbearing, and widowhood. The off-time non-normative life transitions, as unusual occurrences out of sequence, have potential to influence life choices. My childhood and early adult life was relatively on-time—in my early 20s, for example, I worked part-time to pay full-time college tuition preparing to attend law school.

I had been living with my partner, Diane, for 3 years. I was committed, yet there were larger societal constraints imposed on our relationship. I will never forget dancing at a women's nightclub, which, typical of the era, had no windows, when a man raised himself from a veiled corner seat, crashing a beer bottle across the table edge, swinging the remaining ragged shards of glass, threatening our existence. This for me reflected the double-bind nature of marginalized lives: visibility and openness creates opportunities, yet can result in exposure and vulnerability. Although my life was shrouded in a cloak of vulnerability, I resisted in various personal and collective ways.

One early morning when I was 24 years, Diane, 27 years, woke me in the middle of the night with an excruciating headache. By the time the medics arrived, she could no longer talk and her breathing was deeply labored; the medics splayed her on the living room floor assessing her for signs of life. She was immediately rushed alone to the hospital; I was told to wait patiently at home for their call and to not worry, that my "friend" would be fine. Instinctively, I knew I needed to be at her side so I made my way to the hospital and crept my way through the corridors, despite the triage nurse's poignant instructions to remain in the waiting room. I found her in an emergency room, unconscious, half of her head shaven, tubes and electrodes connected. The nurse informed me they were waiting for her father, her legally, biologically, and geographically closest "relative," to make a decision about ending life support. Stunned by the impending realities, I did not leave her side. With her one last breath, I found myself alone, a life out of sync—a loss without a name. Within a time of profound invisibility and silence, before HIV and AIDS, I immediately plunged into a tumultuous storm, without guidance, cues or models. Suddenly, I had more in common with widows, most of whom were old, than my peers. Some of those closest to me lamented that I was not a widow because I had not married; they, too, were trying to make meaning

of Diane's death. My life was thrust into a paradox: The loss of my closest relationship, defined by a world that refused to recognize it.

### Reaching Out: Serving Those in the Margins

As I grieved Diane's death, I became acutely aware I had been relegated to the margins and rendered invisible; at the time, there were no services or supports for lesbians and gay men grieving the death of a partner. As a result, my life shifted course, and I embarked on a new career and pursued a Master of Social Work (MSW) degree at the University of Washington. I and three others started Shanti/Seattle in 1982. The agency was mirrored after the original Shanti, meaning "inner peace" in Sanskrit, started in Berkeley in 1974 by Dr. Charles Garfield (Garfield, Spring, & Ober, 1995). Shanti/Seattle provided peer support to meet the emotional and sociocultural needs of persons with life-threatening illnesses and those grieving the death of loved ones; it was designed to be responsive and serve everyone, regardless of age, sexuality, gender, or culture.

One of my first phone calls was from an old woman whose life partner, or "liaison" as she termed it, of 50 years had just died. She was adamant in her yearning to end her life because not another living being knew about their outlawed love. I came to understand her profound social isolation; how very alone she could be but never should be. Each day we talked; she refused to share her phone number or address, just a promise to call back. After a week of sharing her loss with complete desperation, she failed to call. I witnessed a history I had not fully understood; still today, I have no way of knowing if she took her own life or survived the intense isolating grief. Through this experience, I started to wonder about those much older in our communities, about the countless yet unseen LGBTQ people my grandparent's age whose lives were laced with invisibility and social stigma. These were memorable reflections as a budding gerontologist.

Soon death and dying became all too familiar in our communities. Shanti was facing a burgeoning threat as an impending pandemic was unfolding. Very quickly we became overwhelmed trying to meet the mounting needs of people with AIDS, and those grieving the loss of partners, multiple friends, and family members. In the early 80s, I remember going to visit a Shanti client in a large public hospital. Suited with sterile medical gown and mask, I walked down the endless corridor, room after room full of dying men young and old, and every age in between. We didn't know the cause of "gay-related immune deficiency," but I did know countless members of our community were dying and desperately needed support. A major public health epidemic yet no public response. It became evident that the isolating events in my own personal life with the death of Diane reflected much broader societal conditions of LGBTQ people everywhere. The demise of our community seemed inevitable without action, so we started

the AIDS Funding Coalition, which I co-chaired, advocating for public health resources. Another advocacy group of the time, ACT UP, brought the demands to the street. I was soon appointed by the Mayor of Seattle to the first city-sponsored Gay and Lesbian Task Force. This stretch of collective activism taught me that action in the face of inhumane isolation can change lives.

### Gaining a Foothold in Gerontology

As a cofounder of Shanti/Seattle, I gave my first talk on sexual minority aging in the mid-1980s, within the context of the AIDS pandemic. The timing of the talk was fitting because President Reagan's administration had proclaimed the homosexual party was over. I'm still mad about that because I don't know who had the party and why I wasn't invited. During my studies, when I told a sociology professor I wanted to study lesbian and gay people who were ill or bereaved, I was quietly yet tersely warned not to—that such work would harm my career. When I asked other academics—a few of whom were gay—I was told to avoid this work because it was too controversial and impossible to receive research support. These early academic experiences helped me to understand how fear and repression maintain as well as reinforce silence in science and gerontology. Yet, these overt warnings did not discourage me, rather they framed tremendous possibilities for change.

During this time, the courageous work of several early pioneers in the field were questioning commonplace misconceptions of lesbian and gay aging (Fredriksen-Goldsen & Muraco, 2010). The prevailing stereotypes portrayed “old gays” as depressed and undesirable. The early work in the field countered these stereotypes (Berger, 1984; Berger & Kelly, 1986, 2002; Gray & Dressel, 1985; Quam & Whitford, 1992); through “crisis competence,” (Friend, 1980; Kimmel, 1980) and “mastery of crisis” (Berger, 1980), it was hypothesized that the management of a stigmatized identity (e.g., gay) could result in the positive management of another identity (e.g., old age), with sexual minorities better prepared for aging compared to older adults in general (Adelman, 1990; Butler & Hope, 1999; Kehoe, 1986, 1988; Sharp, 1997). Following the early research, more studies also began to explore the critical support provided by “families-of-choice” in the lives of older sexual minorities (Adelman, 1990; Beeler, Rawls, Herdt, & Cohler, 1999; de Vries, 2007; Orel, 2004) as well as the need for increased access to formal services and legal protections (Brotman, Ryan, & Cormier, 2003; Cahill & South, 2002; Quam & Whitford, 1992). During this time, colleagues and I conducted an agency-based case study of Shanti/Seattle, integrating a feminist analysis that underscored the pivotal nature of community engagement and resistance in creating organizational and cultural change to support marginalized communities (Hooymann, Fredriksen, & Perlmutter, 1988). I became increasingly interested in how historical forces and earlier life experiences influence

the life span, given the dynamic nature of social interaction and structural location intersecting with time, period, and cohort effects over the life course (Bengtson & Allen, 1993; Elder, 1994, 1998).

At the same time, invisibility reigned as the primary barrier to applying such concepts to those living in the margins. During my doctoral studies at the University of California Berkeley (1989–1993), I worked closely with my exceptional mentor, gerontologist Dr. Andrew Scharlach, investigating family caregiving over the life span, which resulted in my first book *Families and work: New directions in the twenty-first century* (Fredriksen & Scharlach, 2001, Oxford University Press). We examined how caregiving distress was differentiated by age (Scharlach & Fredriksen, 1994), gender (Fredriksen, 1996), employment status (Fredriksen & Scharlach, 1997), and race/ethnicity (Fredriksen-Goldsen & Farwell, 2004). Yet, when I sought to add a question on sexual orientation to a large workplace survey, I was prohibited at an institutional level because some feared it would breach the privacy rights of participants. Despite obstacles, I ascertained relationship status as well as the gender of both partners and completed one of the first caregiving studies of same-sex couples. Based on this and other studies, we documented extensive care responsibilities among lesbians and gay men, despite limited support and access to family caregiving services (Fredriksen, 1999). Increasingly, the “B” for bisexual, “T” for transgender, and “Q” for queer and questioning were added to our community's awareness and lexicon, which expanded the dimensions of my own work addressing inequities by age, sexuality, and gender.

As my scholarship on the intersection of aging and marginalization across social groups intensified, O'Rand's (1996) work, in particular, was illustrative for me in terms of the application of a life-course analysis to better understand how heterogeneity and inequality within and across social groups and aging cohorts result in cumulative disadvantage. The University of Washington, School of Social Work, hired me as an Assistant Professor in 1993, and I became the first openly identified faculty member in the school.

I was soon to receive my first federally funded grant, from the National Institutes of Health and the National Institute of Mental Health (NIH/NIMH) in 1999, to investigate the role of informal and formal supports on the dyadic nature of HIV/AIDS caregiving. Based on a resilience framework, this study identified several key risk and protective factors predictive of mental health among chronically ill sexual minorities (Fredriksen-Goldsen, Kim, Muraco, & Mincer, 2009), laying the groundwork for several future studies. During these times, I was cautioned by many to not use the words “lesbian, gay, or bisexual” in articles, grant titles, or abstracts. From the time I entered my MSW program in 1984, when I was told I shouldn't, couldn't, and wouldn't study LGBTQ aging and health to the time I became an Associate Professor in 1999, I was surprised to find, despite

all the prevailing stereotypes, LGBTQ older adults were excited to join our research efforts.

### In Sync and On-Time: Growing National Interest in LGBTQ Health Disparities

When I asked one of our oldest participants, a 95-year-old gay man: “How old were you when you first *considered* yourself gay?” He responded, “15 years old.” When asked, “How old were you when you first *told* someone that you were gay?” his answer was, “90 years old.” Social norms were changing rapidly with growing interest in sexual orientation and gender identity and in 2009 *Aging with Pride: National Health, Aging, Sexuality and Gender Study* (K. I. Fredriksen-Goldsen, Principal Investigator [PI]) was the first national study of LGBTQ aging, health, and well-being of midlife and older adults, federally funded (R01) by the National Institutes of Health and the National Institute on Aging (NIH/NIA). In conducting this landmark study, we collaborated with 11 community agencies and reached 2,560 LGBTQ midlife and older adults, enabling us to investigate how age, sexuality, and gender intersect with risk and protective factors in aging, health, and well-being.

The Institute of Medicine and the U.S. Department of Health and Human Services both released reports in 2011 recognizing health disparities among LGBTQ people. Yet, still today, most public health- and aging-related surveys do not include sexual orientation or gender identity measures. Even when a sexuality question is included, it is often only asked of young- and middle-aged adults. Older adults have often been excluded from these questions, likely anchored in several outdated assumptions, including older adults are not sexual, will not understand the questions, will not respond, or the questions are “too sensitive.” Yet, when we analyzed some of the earliest population-based data available, we found more than 2% of older adults self-identified as lesbian, gay, or bisexual in a random digit-dialed telephone survey (Fredriksen-Goldsen & Kim, 2015; Fredriksen-Goldsen, Kim, & Barkan, 2012); in fact, the sexual identity question had a higher response rate than income. These findings paved the way for us to advocate for the inclusion of sexual orientation and gender identity questions in large-scale population-based surveys, including the National Health and Retirement Study. Our ongoing work on best practices for measurement of sexuality and gender reveals the dynamic, evolving nature of sexuality, gender, and age.

When investigating health disparities, we found that lesbian, gay, and bisexual adults, age 50 and older, compared to heterosexuals of similar age, are at an elevated risk of functional limitations and mental distress, even when controlling for age, income, and education (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013). We also found substantial differences within subgroups in these communities. Analyzing national probability-based data, we recently documented higher incidence of 9 out

of 12 common chronic conditions, with disability among lesbian, gay, and bisexual adults having earlier onset compared to heterosexual adults (Fredriksen-Goldsen, 2016). Transgender older adults report even higher rates of disability, poor physical health, depression, victimization, and discrimination (Fredriksen-Goldsen, Cook-Daniels, et al., 2014) than nontransgender lesbian, gay, and bisexual older adults. Despite using LGBTQ for short hand, this work illuminates the heterogeneity within these communities and distinct aging and health risks of unique groups, including transgender (Fredriksen-Goldsen, Cook-Daniels, et al., 2014) and bisexual older adults (Fredriksen-Goldsen, Shiu, Bryan, Goldsen, & Kim, in press), LGBTQ older adults of color (Kim & Fredriksen-Goldsen, 2012), those of lower socioeconomic status (Fredriksen-Goldsen, Kim, Bryan, Shiu, & Emler, in press), and those who define themselves as queer or something else (Fredriksen-Goldsen, 2016).

### Health Equity

As the PI of *Aging with Pride*, we are now conducting the first longitudinal study of 2,450 LGBTQ adults 50 and older, investigating trajectories in health and aging. Interestingly, as we assess disparities, we also find that most LGBTQ older adults are enjoying good health, with high satisfaction and good quality of life. In fact, LGBTQ older adults’ resilience, likely forged from adversity, seems to strengthen their fortitude and enhance their well-being (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emler, 2015). We also found that among lesbian, gay, and bisexual older adults, most report higher levels of education and yet comparable or lower incomes (Fredriksen-Goldsen, Kim, et al. 2013), associated with discrimination in the workplace. In addition, nearly 70% experienced verbal assault and nearly half were threatened with physical violence (Fredriksen-Goldsen, Kim, et al., 2011). Yet, despite the adversity, or perhaps because of it, we’ve documented countless demonstrations of individual and collective agency.

As I continued to unpeel the layers of how marginalization intersects with aging and health, neither a resilience nor stress framework was sufficiently comprehensive to capture the range of positive and negative experiences that I encountered. As a result, colleagues and I developed the Health Equity Promotion Model (Fredriksen-Goldsen, Simoni, et al., 2014), illuminating the importance of reaching full health potential for all ages, generations, and backgrounds. This perspective illustrates how the intersectionality of social positions intersects with the larger historical, structural, and cultural context as well as health risk and health-promoting psychological, social, behavioral, and biological processes to influence aging, quality of life, and both positive and negative health outcomes.

From a generational perspective, the LGBTQ midlife and older adults in our longitudinal study include three generations: the Invisible Generation, the Silenced Generation, and the Pride Generation. The Invisible Generation came of age during the Great Depression and many fought during World

War II—a period wherein LGBTQ identities were largely absent from public discourse. The Silenced Generation came of age during a time when same-sex behavior was severely stigmatized and criminalized; the American Psychiatric Association's first edition of the *Diagnostic and Statistical Manual of Mental Disorders* in 1952 listed homosexuality as a sociopathic personality disturbance. LGBTQ older adults have shared with me how they were involuntarily committed to mental institutions and subjected to brutal procedures, including castration and lobotomy. Many came of age during the backdrop of the McCarthy's "lavender scare," when a new era was ushered in and sexual and gender minority identities not only entered into the popular public discourse but also were cast as a threat to the security of the nation (Canaday, 2009). LGBTQ midlife adults, like myself, as part of the Pride Generation, came of age at a time of transformative social change reflected in the Stonewall riots in 1969, the catalyst for the gay liberation movement. Along with the civil rights and women's movements, and the changing landscape as a result of the AIDS pandemic, we witnessed the beginning of the decriminalization of same-sex sexual behavior and in 1973 the removal of homosexuality as a sociopathic personality disturbance from the *Diagnostic and Statistical Manual of Mental Disorders* (Silverstein, 2009).

Although many resisted and profound strengths were evident across the generations, we observed unique configurations of risks and resilience within each cohort. I also began observing a "breaking point" when too much adversity seemed to result in vulnerability and deleterious consequences across the generations of LGBTQ older adults. We are using these findings to promote early identification of those most at-risk. Across several studies, we found some of the greatest strengths of LGBTQ older adults include their fierce independence and reliance on deep personal relationships built on commitment and care. Most LGBTQ older adults rely heavily on their friends and age-based peers for support, which is an important source of strength in these communities (Fredriksen-Goldsen, 2016). Yet, the availability of such support may have limits, particularly in advanced age when peers may experience their own potential health and mobility problems. The heightened probability of premature mortality looms over these historically disadvantaged communities (Fredriksen-Goldsen, 2016; Hatzenbuehler et al., 2014). For these reasons, I'm especially concerned about LGBTQ older adults who are most frail and vulnerable, and the long-term survivors, who outlive their peers. These older adults, I believe, have few opportunities to feel safe and to be themselves and are at elevated risk of social isolation and suicide. LGBTQ older adults themselves fear having to return to the closet at the time they are most vulnerable and need the most support.

### Where Do We Go From Here?

Although my professional life seems to be relatively on-time, at least for now, some key transitions in my personal

life remain somewhat off-time, to which I have become well accustomed. With Neugarten and colleagues' (1965) social clocks and the timing of transitions—marriage, childbearing, then widowhood—my social clock was reversed: widowhood, childbearing, then marriage. After a 31-year engagement and the birth of two children, my partner and I were legally married 3 years ago. Up until the time of federally recognized legal marriage across the nation, I punned that it wasn't if we could get married, but how many times we had to get married. We acquired differing legal documents given our changing geographic locations and shifting legal statuses, including domestic partnerships in 1989 and 1994, and marriage licenses in 2005 and 2012. That's a change in legal status, accompanied by one more reason to celebrate, each and every decade. Our two children (now young adults attending college) and their friends always considered us married like the other coupled parents around the soccer fields. Our research shows the same positive social and health benefits of partnership status for same-sex couples (Goldsen, Bryan, Muraco, Kim, Jen, & Fredriksen-Goldsen, in press; Williams & Fredriksen-Goldsen, 2014) as compared to those in different-sex couples. Yet, as a confirmation of the double bind nature of marginalized lives, the legally married same-sex partners are more likely to openly disclose and experience higher levels of everyday bias than the unmarried same-sex partners.

About half of the study participants are partnered; among those that are partnered, only half are legally married. Furthermore, many experienced the death of a partner when legal marriage and access to federal benefits did not exist. We now have a chasm dividing experiences by generations: those with access to spousal benefits and those that never did nor never will have access to such support. It is important to consider the consequences of prior social and legal exclusion as they relate to life events (i.e., marriage) and acquisition of social roles (i.e., legally recognized spouse).

I am often asked, "Don't LGBTQ people age like everyone else?" I respond from both personal and professional perspectives, "Yes—in countless ways we do age the same, but at the same time we must understand the historical, social and cultural realities in contemporary society on real lives." When working in any marginalized community, I feel a distinct responsibility to surface, and be responsive to, the real issues and problems that exist in communities and yet at the same time to ensure that existing strengths and resources are considered. When working in marginalized communities, how can we raise tough issues without simply reinforcing stereotypes—interpreted as representative of a community? How can we, as gerontologists, understand common trends yet simultaneously attend to the vast range of experiences in any community?

My goal in this work has always been to surface and understand both the commonalities and distinct strengths and challenges facing these communities and to consider how individual choices and individual agency as well as

collective action influence the ways in which people live and age. The longitudinal study *Aging with Pride* allows us to distinguish LGBTQ older adults at most risk of adverse health outcomes and to better understand those aging well. The next step is to ensure the use of the information to generate new solutions to old problems through evidence-based interventions and programs as well as prevention (Fredriksen-Goldsen, 2016). For example, Generations with Pride (<http://caringandaging.org/wordpress/generations-with-pride-about/>) is a nonprofit organization we initiated to develop and test evidence-based interventions to reduce isolation and enhance optimal aging as LGBTQ older adults age-in-community.

As I ponder where this field is headed, both locally and globally—I reflect upon the countless lives I have witnessed and the symbols of differing histories and cultures as they unfold. A participant in one of our studies lamented “labels are for cans,” whereas others cling to the comfort of lesbian, gay, bisexual, transgender, or queer or homosexual or their “liaisons.” And there is the next generation who poignantly remind me that “LGBTQ” is becoming outdated so we must continue to investigate ways to incorporate a greater range of emerging identities and experiences into research. I’ve been told by some that increasing acceptance will alleviate the need for such terms. Yet, there are the emerging scholars who still share with me that they have been told by mentors to not risk their careers by conducting research with sexual and gender minorities or other marginalized communities. Many of our participants have never identified as LGBTQ to anyone yet have taken a risk to participate in our studies. When asked in interviews why they participated, they most often responded that they want to create a legacy—a better world now and for future generations. They, like so many others, want their lives to have meaning by making a difference.

## Conclusion

If I leave a legacy, I hope my work, and that of others, will shed light on the diverse and unique life experiences and aging of those who have been relegated to the margins. To retain diversity of experience is to move the field of aging forward. Recently, I found myself pondering, how can historically disadvantaged groups shift from the margins but not to the mainstream? Indebted to the richness of the field of gerontology, I do contemplate my own aging. When I embarked on my career, my parents and grandparents were engaged in my life, and now, I, as the oldest generation, share past stories and create new ones for the two new generations of my family. Today is tomorrow—I believe what we do today creates the conditions of tomorrow.

Although gerontology as a discipline has historically silenced the lives of LGBTQ older adults and the intersection of age, sexuality, and gender, as a field, it has much to learn from these older adults and their kin as well as those in other historically disadvantaged communities.

Interestingly, the lives of LGBTQ older adults mirror many of the changing and growing societal and demographic trends, including smaller families, and increasing numbers of older adults cohabitating, never marrying, not having children, and living at a distance from family members. The margins provide critical lessons such as these for the field of gerontology. The diverse older adult populations in which I work provide me with rich opportunities to better understand how my own personal experiences intersect with the historical, cultural, and social context as they contribute to cultural variations and shared experiences of aging. Gerontology, as a dynamic area of scholarship, has always demanded of me an openness to new realities and possibilities. A cornerstone of life, to me, as a human being, mother, spouse, friend, and gerontologist, is to have the courage to uncover what others fear to encounter.

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