

Building a Bright Future for  
Diabetes Care & Management by

# WRITING WHERE IT HURTS

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Illness experience has become an increasingly important cornerstone of understanding health and well-being for people living with chronic conditions [1, 2]. Even if you've never heard the term "illness experience" before, you probably understand what it means on a more intuitive level. Think about the health journeys you and your loved ones have taken in your own lives. What decisions did you make about how to manage your health? What did you come to understand about your condition that you didn't know at first? What emotions did you experience when you were diagnosed and as you continued to seek care? How were your social relationships affected by changes in your health? Did you encounter challenges in your professional life as you learned to live with your condition? What did you learn from each of these experiences? And how did you change along the way? Illness experience is a complex constellation of elements, all related to how a person moves through life with one or more specific health conditions [3].



Getting insight into the illness experiences of people with highly prevalent chronic conditions like diabetes is positively critical for all of us in the health world, whether we're more on the clinical care side or more on the research side or experiencing things from the patient or family perspective. Illness experience has become a key emphasis in research and outreach for several reasons. These reasons are nuanced and complex, but fall generally into two basic groups: quality of services and affirmation of self. First, the ability to envision what the experience of diabetes is like for people living with it and their loved ones can transform others' ability to provide effective clinical care [4, 5] and social support [6, 7]. Second, sharing these experiences can be incredibly nurturing and healing for people with diabetes [8, 9] and those who share their lives [10]. Examples of these benefits are as diverse and complex as all the people in our communities whose lives are touched by diabetes.

One major area of impact is food access and preparation. By sharing stories and ideas, people with diabetes have helped to transform nutritional options in homes and public spaces alike. For instance, the voices and advocacy efforts of people with diabetes in the African Methodist Episcopal (AME) church led not only to changes in food offerings at AME community picnics across the United States, but also to the development of evidence-based resources for home cooks [11]. The American Diabetes Association partnered with AME churches to develop cookbooks and supportive tools, all focused on the preparation of nutritionally balanced versions of traditional soul food dishes appropriate for the macronutrient needs of people with diabetes. Prevention of insulin resistance in people at risk for Type II diabetes was also a major emphasis in this effort [12]. The partnership between AME churches and the ADA represented a major step forward in person-centered, culturally affirming community approaches to diabetes care [13].

Other examples include but are certainly not limited to:

- Peer mentorship opportunities for people newly diagnosed with diabetes
- Development and continuous improvement of insulin pumps
- Greater understanding of intersectionality between diabetes and social determinants of health
- Educational tools for patients and families with different learning needs
- Development and use of metformin therapy for insulin resistance

- Better and more diverse tools for self-monitoring
- Increased and more varied funding for diabetes research and outreach
- Reduced stigma surrounding diabetes diagnosis and management
- Social activities for patients and their loved ones
- Attention to how diabetes affects others in a person's life
- Widespread awareness of diabetes and potential associated patient needs

These domains of benefit and many others are often intertwined [14]. To illuminate these complex interplays between clinical and community elements of living well with diabetes and other chronic conditions, we need narratives and critical analysis of all aspects of illness experience. We need stories of crisis points that bring about transformational change in people's understanding of their health and the care they receive [15]. We need stories of routine clinical care and what health professionals can do to achieve positive impact in partnership with patients and their loved ones [16]. We need stories of the everyday ups and downs of living with a disease that never goes away [17]. And we need stories told from the perspective of clinical care professionals [18] and family caregivers [19] as well as patients themselves. Narrative medicine [20] is a powerful tool for health promotion within and far outside of clinical settings.

To promote sharing of these narratives—both from people with diabetes and from a diverse array of others living with chronic physical and mental health conditions as well as experiences within and between marginalized communities—we started the Write Where It Hurts project. You can find us on the Web at [www.writewhereithurts.net](http://www.writewhereithurts.net), and also on Facebook and Twitter. WWIH is a narrative-based blog and social media outreach hub focused on disclosure and critical analysis of experiences in health and the social world that are challenging and/or traumatic in nature. We expect that many PLAID readers and contributors will have diverse experiences in these areas and many more. The project grew out of our own realization, as scholars and activists, that the insights we ourselves have gained from our own adverse experiences have fundamentally transformed our ability to make an impact for others.



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is on the faculty at Florida State University in Medicine and Sociology, and proudly serves on the editorial board for PLAID.

Xan lives with a chronic autoimmune disease of the mucous membranes that is similar to cystic fibrosis, as well as post-traumatic stress disorder. Their work focuses on the experience and management of chronic conditions, including advocacy for members of marginalized populations. Racial and ethnic inequality and the experiences of sexual and gender minorities are particular emphases in Xan's research and outreach. Xan has a PhD and MS in Medical Sociology from FSU, an MPH in Health Systems and Policy from Rutgers University, and a BA in Political Science from Columbia University.



**J SUMERAU**

is on the faculty at the University of Tampa, and previously taught at FSU while earning a PhD in Sociological Social Psychology.

J lives with bipolar, depersonalization, and PTSD as well as chronic leg pain due to severe injuries. J also experiences this world as a bisexual, genderqueer agnostic, and in so doing, experiences many ways marginalized identities interact with chronic conditions throughout our daily lives. J's work focuses on gender, sexuality, religion, and health, and a diverse array of social inequalities that intersect with these areas. Advocacy is likewise a major emphasis for J in all pursuits. In addition to holding a PhD and MS from FSU, J has a BS in Sociology from Augusta University, serves as the director of applied sociology at J's institution and regularly conducts evaluation research on the effectiveness of social programs for diverse communities.



**LAIN MATHERS**

is a doctoral student at the University of Illinois at Chicago, and is active in both research and advocacy for people with chronic conditions and especially those who occupy marginalized gender, sexual, and religious locations in contemporary society.

Lain also wrestles with generalized anxiety experience, stress-induced panic attacks, and experiences as a bisexual, genderqueer person. Before embarking on doctoral study at UIC, Lain earned a BA in sociology and international affairs from FSU and has committed J's efforts to advocacy for sexual and gender minorities as well as people managing varied chronic conditions throughout J's graduate endeavors.

Our team consists of three people who live with chronic conditions. All three of us have a deep passion for championing the unique voices and contributions of people with diabetes and other chronic conditions. Perhaps as a result, we understand firsthand that the best person to share your story and make an impact with lessons learned from your own experiences is you! Whether you're a researcher, a clinician, a caregiver, a patient, a supporter, an advocate, or any combination thereof, we welcome your contributions at Write Where It Hurts. Indeed, we enthusiastically encour-

age you to get in touch with us and contribute a guest post to our blog! We also realize that some experiences may lend themselves to better comfort if shared in an anonymous post, so we always offer that option for writers who feel apprehensive about attaching their name to a piece. Our primary focus is on working with you to offer a positive and affirming outlet for your story, and for the unique lessons it has instilled in you about living well with diabetes and helping others to do the same.



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