

Sharing Personal Medical Stories: A Deep Dive into the Impacts of Stigma on Experiences and Advocacy

**Stigma** Refers to the negative attitudes, beliefs, or discriminatory behaviors directed toward individuals or groups based on characteristics such as health conditions, race, gender, or other identities.

In the context of chronic illnesses, stigma can manifest as prejudice, social exclusion, or judgment when individuals share their medical stories, leading to discrimination and other adverse consequences.

- Limitations**
- LIMITED SAMPLE SIZE OF 56 PARTICIPANTS
  - DEMOGRAPHIC IMBALANCE FAVORING OHIO RESPONDENTS
  - GENERALIZABILITY AFFECTED
  - PARTICIPANT CONSENT MAY INTRODUCE BIAS
  - RELIANCE ON SELF-REPORTED DATA COULD LEAD TO INACCURACIES
  - FOCUS ON STIGMA AND MEDICAL CONDITIONS MAY OVERLOOK OTHER FACTORS
  - SOME CATEGORIES HAD NO RESPONSES, LIMITING INSIGHTS
  - CROSS-SECTIONAL STUDY DESIGN PREVENTS ESTABLISHING CAUSALITY

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### Did You Know? -- Interesting Facts Regarding the Atmosphere of Chronic Illness Stigma

- An estimated **1.3 billion** people experience significant disability. This represents 16% of the world’s population or 1 in 6 of us.
- A study published in the Journal of Health and Social Behavior found that approximately **54% of individuals with chronic illnesses reported experiencing stigma**.
- Research shows that 20-30% of people with chronic conditions experience workplace discrimination.
- The stigma around mental illness is **especially pronounced in some diverse racial and ethnic communities**. Cultural values, emotional restraint, and avoiding shame can be barriers to accessing mental health services.
- Persons with disabilities find inaccessible and unaffordable **transportation 15 times more difficult** than those without disabilities.

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graph LR; IS[Internalized Stigma] --> AS[Anticipated Stigma]; IS --> ES[Experienced Stigma]; IS --> CA[Care Access]; IS --> QoL[Quality of Life]; ES --> AS; ES --> CA; ES --> QoL; AS --> CA; AS --> QoL; CA --> QoL
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**Figure 1** Carefully reconstructed from (Earnshaw et al., 2022) Path analysis of the impact of internalized, experienced, and anticipated stigma on healthcare access and quality of life.

1.

### Background and Problem Statement Behind Investigation

ICAN Kids is an international organization focused on pediatrics and especially on empowering younger youth to have courage and strength to voice their opinions to better help the community. However, the question arises, to what extent does this organization empower the youth? This study aims to fulfill answering this current gap in research by conducting a survey-based study to understand how big of an impact this organization has on the current youth populations voice.

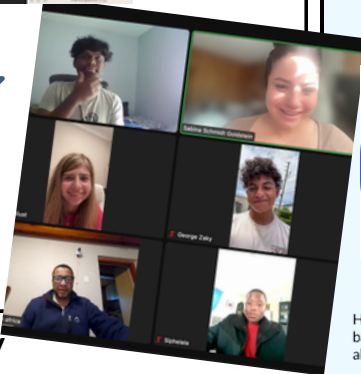
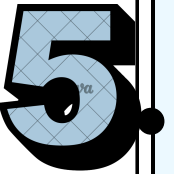
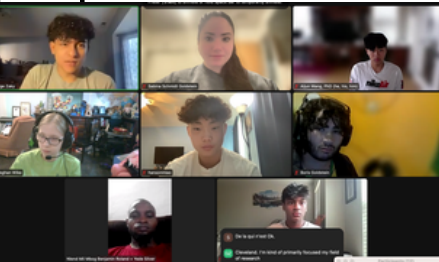
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### Research Questions

**How** have group stigmas surrounding medical conditions and chronic illnesses impacted the willingness of those who are impaired to share their stories?

**What** is the current stage of advocacy and movement for integration by the impacted communities in raising their voices and concerns to the public?

**Where** can ICAN kids help raise these communities voices and where has this organization been doing so currently?



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### Literature Study

Several studies and reviews were used as background literature research. **Firstly**, Kitzkus et al. 2009 explain in research, that narrative-based medicine is a powerful tool for both patients and physicians as long as it discounts medical facts. On a separate tangent, Danoff-Burg et al. 2007 found that focusing on positive aspects of adverse experiences, known as benefit finding (BF) appeared effective in reducing pain levels. **Similarly**, it was concluded by Hassinger et al. 2015 that sharing patient stories in primary care teams fosters connection, trust, and a shared mission of patient-centered care, enhancing team effectiveness and morale. **Finally**, Slade et al. 2009 find that the ramifications of stigma and discrimination are enduring, potentially disabling, and appear to interfere with care-seeking, rehabilitation participation, and potentially, rehabilitation outcomes.

### Objective

This study aims to explore the experiences and perceptions of individuals with chronic illnesses as they navigate sharing their personal narratives. The primary focus is on understanding how stigma and discrimination affect those who choose to share their medical stories, and what impact this has on their relationships, sense of identity, and well-being.

- Methodology**
- Survey Design:**
- The survey aimed to gather insights into the impact of stigma on advocacy and storytelling using multiple-choice questions, Likert scales, and open-ended questions to collect both quantitative and qualitative data.
- Data Analysis**
- Descriptive statistics were used for quantitative data, while thematic analysis identified key themes in qualitative responses related to stigma’s impact on advocacy and storytelling.
- Ethical Considerations**
- Participants were informed about the study’s purpose, their voluntary participation, and their right to withdraw. Anonymity and confidentiality were maintained.

### Research / Findings

A survey conducted to dive deeper into the impacts of stigma on advocacy and storytelling received 56 responses of which 52 were valid. 23 participants were below 18 and 33 were over age 18. The survey consisted of participants mostly White (Approx. 64. 3%) and African American (Approx. 28.6%). The others identified with another race. The majority (exactly two-thirds) had a college degree as their highest level of formal education.

#### Finding 1

How concerned are you about facing stigma when sharing your story about your medical condition? If you have never shared your personal story, how concerned would you be about facing stigma?

Concern Level	Percentage
Very Concerned	61.5%
Somewhat concerned	30.8%
Not very concerned	7.7%
Not concerned at all	1.0%

#### Finding 2

Have you ever experienced discrimination or faced stigma as a result of sharing your story about your medical condition?

Response	Percentage
Yes, frequently	59.6%
Yes, occasionally	30.8%
No, never	9.6%
I have never shared my personal narrative	0.0%

#### Finding 3

Hey do you handle concerns about potential backlash or discrimination when sharing your story about your medical condition?

Handling Method	Percentage
Share anonymously or pseudonymously	34.6%
Only share with trusted individuals	34.6%
Utilize support networks for guidance	30.8%
I have never shared my personal narrative	0.0%

#### Finding 4

Would you recommend others to share their story about medical conditions despite potential risks?

Recommendation	Percentage
Yes, strongly recommend	88.5%
Yes, with some reservation	11.5%
No, not necessarily	0.0%
No, definitely not	0.0%

#### Finding 5

In what ways do you believe sharing your medical experiences can help reduce stigma for people who share similar conditions?

Way to Reduce Stigma	Percentage
By raising awareness	71.2%
By fostering empathy	28.8%
Both a and b	0.0%

#### Finding 6

How do you maintain a balance of sharing your medical experiences for advocacy purposes and also maintaining your privacy?

Balance Strategy	Percentage
It's a constant struggle	32.7%
I prioritize advocacy over privacy	30.8%
I prioritize privacy over advocacy	36.5%
I have never shared my personal narrative	0.0%

- Analysis**
- This study examined the impact of chronic illness related stigma on peoples likeliness and degree of expressiveness in sharing their story to build awareness. Because advocacy is a powerful tool for reform, its important to understand how outside factors may hinder its growth.
  - While understanding the limitations this study may hold, such as a small population group which is primarily focused in the Ohio region, there are some significant conclusions.
  - When comparing ages, over 61 percent are 18 or up and 39 percent are younger than 18.
  - Furthermore, regarding participants who are affiliated with ICAN are shown to be much more likely to have better responses to the questions presented in the finding section. For example, in finding four, all the people who were affiliated with ICAN kids who answered the question responded they strongly recommended sharing their stories.
  - Furthermore, it was shown through this study that most the members who answered the survey were actually not apart of ICAN.
  - Most the questions that further discussed about sharing stories often had responses highlighting they would share their story. However, other questions such as the results in finding two allude to the fact that even with all the positive impact of ICAN and other factors in society, their still remains a lot of stigma for expressing stories and ideas.

- Conclusion**
- Sharing stories is a way to increase engagement and prevent others from facing similar challenges as you. This is even more prevalent among those with chronic illnesses because there are few people to relate with. As **Finding 1** shows, at least half of all individuals in the survey are concerned about sharing their stories due to potential stigma
  - **Finding 2** corroborates this by displaying that more than 55% of individuals in the survey have experienced some level of discrimination when sharing stories about their medical conditions. Relatedly, **Finding 3** highlights that close to half of all individuals in the survey lean to their support networks when facing this discrimination. It is likely that this tendency could be increased if more have access to support networks.
  - Ultimately, 100% of participants in the survey advise others to share their stories despite potential risks and a majority (60.5%) believe that doing so can both raise empathy **and** foster awareness