

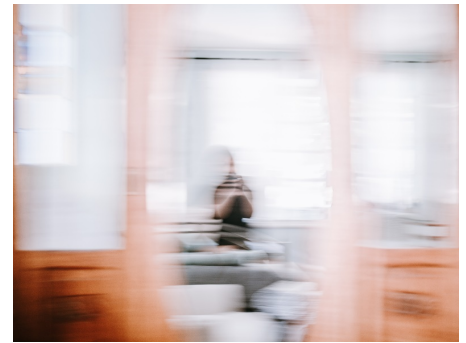
“Capturing Wellbeing While Immunocompromised: A photo-elicitation study”

Laura Sinko PhD, RN, Samira Rajabi PhD, & Raina Merchant, MD MS

Project Activities

In this study, we asked individuals who self-identified as having compromised immune systems to respond to the following prompts:

1. Please take two photographs that showcase what has changed in your home, routine, or physical environment as an immunocompromised person during the COVID-19 pandemic.
2. Please take two photographs that highlight your emotional experience thus far while processing, coping, or maintaining your physical or mental health during this time.
3. Please go through your previously saved photographs and select two that you have taken while sheltering-in-place prior to engaging with this study that represent some additional facet of your experience whether physical or emotional.



Noise

“I took this picture with motion because it's hard to find time for yourself on quarantine. I'm home with my family because I can't work and it's a loud house with everyone home. I'm used to be home alone during the day, but now it's a full house all the time and I'm trying to find time for myself in the midst of it all.”

Participants were asked to upload and tell the stories behind their photographs prior to responding to five general reflection questions along with some demographic and COVID-related items. The purpose of this was to learn more about the wellness and distress experiences of individuals who are at high risk for COVID disease transmission, while also learning how we can better support these individuals going forward.

Recruitment Strategy

We recruited individuals through online support and advocacy communities for chronic illness (e.g. Patient's Rising, Chronic Illness Advocacy and Awareness Group, Spoonie Project, among others). Leaders within these communities were sent information about our study. This information was then distributed to their members through social media posts and email listservs. 47 individuals responded to our survey with 282 photos submitted. Main themes found can be seen on page 3.

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Key Takeaways

- ❖ Our participants revealed structural changes due to COVID including the need to exercise heightened caution in managing their health and being intentional about developing new routines and engaging in wellness strategies to manage distress.
- ❖ While most of our participants experienced negative changes to their wellbeing as a result of COVID, for some, particularly those with more severely compromised immune systems “not much had changed.”

Implications

- ❖ We must recognize the unique challenges this population faces and be aware of how our adherence to guidelines impacts the health and safety of these individuals.
- ❖ We must also think about the daily supports for these individuals outside of pandemic times, as many have had these struggles long before COVID-19.
- ❖ While, this study revealed the resilience of this group, this resilience was recognized as necessary to adapt to the community and structural failures that perpetuated safety risks and distress for those at high risk.
- ❖ We must consult those at highest risk for infection as we begin to think of creative solutions to improve this community’s wellbeing while also reopening our country.



Taking more time to care for our home

“I can't do a lot of the work but since my husband and kids are home due to cut work hours, we have set up a family plan to help each other and get more done around the house. This is a picture of our yard. I may only be able to sit in a chair and watch but I can hang out and spend time with the people I love.”

Resulting Products

1. Online photography and research dissemination exhibit **September 21st**
2. Manuscript detailing structural changes, distress, and healing themes to be submitted to *Journal of Community Psychology* by **October 30th**
3. Audience study on those who attend virtual exhibit to be presented in manuscript alongside participant perspectives of engaging in research process to be submitted to *Communication Research* by **November 30th**

DISTRESS THEMES

DETERIORATING MENTAL HEALTH



Because of the fear, isolation, and uncertainty participants described a noticeable deterioration of their mental health. This manifested into symptoms of depression, anxiety, and difficulty focusing or sleeping. These symptoms were often difficult to manage, however, due to many of their previous coping skills being unavailable due to pandemic-related constraints

HEALTH MANAGEMENT CONCERNS



Many expressed concerns about managing their underlying health conditions. Particularly due to limited access to supplies, difficulty traveling to places outside of the home, and changes in interaction modalities with providers.

SAFETY FEARS



Participants also expressed safety fears, particularly when those around them were not following protective guidelines. Because of higher infection risk, caution was needed in all aspects of their lives, particularly in the beginning of the pandemic when guidelines were unclear. This lack of clarity caused fears of dying and many to feel that their wellbeing was not valued by society.

ISOLATION



Isolation caused many to feel trapped or alone. Many worried that they were losing connections because they were unable to participate socially in the same way as others around them. They also often had to miss events or gatherings, causing them to feel guilt and regret.

LONGING



Because participants needed to limit their in-person social interactions, the desire for physical connection with individuals outside of one's home was significant. Conversely, individuals who were sheltering-in-place with people and were unable to have outlets outside of the home often longed for privacy and some alone time.

DIFFICULT FEELINGS



Overall, participants felt many challenging feelings throughout their sheltering-in-place experience including frustration, guilt, sadness, and loneliness. Additionally, the inability to maintain one's self or health often led to poor self image or feelings of weakness. These feelings, while potentially common reactions to stressful or traumatic experiences, often could be overwhelming to participants.

MANAGING DISTRESS WAS AN IMPORTANT ELEMENT OF SHELTERING-IN-PLACE SUSTAINABLY FOR PARTICIPANTS, CAUSING MANY TO ENGAGE IN INTENTIONAL WELLNESS STRATEGIES

WELLNESS THEMES

FINDING COMFORT



With so much fear surrounding one's health, participants sought to find comfort amid their socially isolated lives. This was accomplished through leaning on social support, engaging with pets, beautifying their space, and spending quality time with people in their home.

MANAGING UNCERTAINTY



With the lack of clarity surrounding how long individuals will need to be sheltering-in-place for, managing uncertainty was an incredibly important practice. This was done through creating routine or structure, engaging in projects, setting boundaries with distressing stimuli, or through reaching out to a mental health professional.

MAINTAINING CONNECTION



Looking inwards and connecting with oneself as well as maintaining social and familial connections was also an important coping practice. Self connection was maintained through journaling and other self-reflective activities, meditating, and engaging in faith communities. Other connections were cultivated or maintained through virtual modalities or through helping others.

FINDING ESCAPE



Because many of our participants were unable to leave their home without fears of infection, finding pockets of escape was necessary. This was done by setting technology boundaries, spending quality alone time with oneself, reading and writing, or spending time outdoors.

MAINTAINING PHYSICAL HEALTH



Prioritizing one's health and wellbeing was important, as our participants were aware that many unhealthy habits could emerge during sheltering-in-place that may complicate their underlying health conditions. Because of that, eating well, maintaining sleep, getting moving through exercise or walks, as well as prioritizing their disease management was critical.

BUILDING EMOTIONAL RESILIENCE



For many, they recognized how trying emotionally it was going to be for them to maintain isolation long term, and thus strove to build emotional resilience in themselves. This was done by practicing gratitude, finding hope, acknowledging small victories, coping with humor, and reflecting on what holds importance to them.

ULTIMATELY, WHILE INDIVIDUALS DEMONSTRATED CREATIVE SOLUTIONS AND RESILIENCE, THE COMMUNITY AND STRUCTURAL FAILURES THAT PERPETUATED SAFETY RISKS AND DISTRESS IN THIS COMMUNITY WERE EVIDENT.