

Capturing lifestyle changes and emotional experiences while having a compromised immune system during the COVID-19 pandemic: A photo-elicitation study

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Abstract

This study aimed to describe lifestyle and emotional changes individuals with compromised immune systems experienced during the early months of the coronavirus disease 2019 pandemic. A survey was distributed to online support organizations for those with chronic illness and a national research volunteer registry from April to June 2020. Participants were asked to document their experiences via three photo-elicitation prompts, followed by reflection and Likert scale questions. Forty-seven individuals responded with 282 photos submitted. Lifestyle changes noted include shifts in wellness strategies, health management, routine, stressors, and time perception. Participants described significant distress stemming from deteriorating mental health, safety fears, isolation, health management, and longing. Wellness strategies documented included finding comfort, connection, and escape, managing uncertainty, maintaining physical health, and building resilience. These findings can increase a sense of community for immunocompromised individuals who are struggling in isolation and enhance knowledge of their day-to-day health needs during times of increased stress and health risk.

KEYWORDS

coronavirus, immunocompromised, mental health, pandemic, photography, psychological, resilience

1 | INTRODUCTION

In December of 2019, the first documented case of an acute, infectious coronavirus, now known as coronavirus disease 2019 (COVID-19), was diagnosed in Wuhan, China. The virus quickly became an epidemic in this community before spreading throughout the world. The first case to reach the United States was in January 2020, and the first US death attributed to the novel coronavirus was in February of that year. By March 2020, COVID-19 has declared a pandemic, forcing many nations across the globe to shut down and enforce lockdowns to contain the spread of the virus and protect those at the highest risk for infection and subsequent complications (AJMC, 2020). This meant the closure of "non-essential" facilities such as schools, workplaces, businesses, health offices, and fitness centers, leaving many isolated in their homes without typical supports and routines. Despite these precautions, as of March 13, 2021, one year into the pandemic, there have been 118.0 million cases, with 2.6 million deaths worldwide (New York Times, 2021). With the importance of sheltering-in-place and social distancing, many have been forced to cope with the rise of illness and death in isolation, causing an increase in worry, fear, and stress with limited support (Ortiz & Sinko, 2020).

1.1 | COVID-19 and mental health

The uncertainty and unpredictability of the deadly coronavirus have caused distress throughout the world. This distress and isolation have led to increased rates of mental health problems, with some United States studies estimating a three-fold increased rate of depression during the pandemic compared to data compiled beforehand (Ettman et al., 2020). Studies from the UK corroborated these findings, showing increases in mental distress which rose from 18.9% to 27.3% just one month into the pandemic (Pierce et al., 2020). Those with increased exposure to stressors and decreased social support are at the highest risk for acute mental health changes (e.g., new or worsening depression symptoms; Aneshensel & Frerichs, 1982). Risk factors for new onset and worsening mental health problems in the setting of COVID-19 include exposure to those acutely ill with the virus, suspected threat of personal serious illness or death, death of loved ones, lack of support system, existing mental health conditions, and resource insecurity (O'Connor et al., 2021; Shultz et al., 2015; Wang et al., 2020). Thus, there is a critical need to understand and implement adequate supports for those at the highest risk of mental health concerns during current and future global health crises, particularly those who may have heightened risk of exposure or infection.

1.2 | The impact of COVID-19 on those with compromised immune systems

Populations who are at highest risk for COVID-19 include those with compromised immune systems, which includes 25 million people in the United States alone (McKay et al., 2020). Those with compromised immune systems have a diminished capacity to fight off infection, which can be caused by diseases such as cancer and HIV, or may be acquired by medications used for the treatment of conditions such as lupus, rheumatoid arthritis, or organ transplants (NIH, n.d.). In addition, the lack of a fully functioning immune system can lead to further experiences of isolation and decreased wellbeing, especially during a pandemic.

Wellbeing extends beyond a lack of illness and can be promoted in many ways, including through social interactions and by feelings of agency or control (Coulombe & Krzesni, 2019). In pandemic times, when social interactions are limited and much of one's environment is unpredictable, individual and community wellbeing is at risk of being diminished. While it is essential to protect individuals with compromised immune systems from the virus by limiting in-person interactions, experiences of heightened isolation may have many unintended consequences. For example, immunocompromised adults were more likely to adhere to recommended COVID-19 preventive behaviors at the peak of the pandemic, such as maintaining social distance and canceling healthcare

appointments due to their heightened infection risk (Islam et al., 2021). While these actions were necessary and important, limited essential trips taken by this population led to the possibility of other unintended consequences including less fresh food from the grocery store (particularly for those with decreased access to delivery services), adverse health outcomes from canceled doctor office and pharmacy visits, diminished physical and mental health from loss of fitness center access, reduced contact with social support systems, and financial impacts of job loss if unable to work from home. In addition, due to the extreme variability in pandemic response by state, combined with news coverage of individuals ignoring social distancing and masking orders, those with compromised immune systems can feel a lack of control and a lack of compassion from others, causing threats to wellbeing.

Decreased physical, mental, and financial wellbeing can negatively impact mental health, leading immunocompromised adults to report a higher likelihood of feeling depression, anxiety, and loneliness during the pandemic compared with adults without chronic health conditions affecting the immune system (Islam et al., 2021). While the risk for adverse mental health outcomes has been documented in this population, little is known about how one's daily experiences and interactions as an immunocompromised person during a pandemic impact their health and wellbeing. As (Andrews et al., 2021) note, there was particular ableism that accompanied the public response to the pandemic, thus exacerbating a sense of fear among many patients, particularly as it related to their access to care. Given this framing around the pandemic and both a real and perceived sense of a lack of safety, immunocompromised have had to proactively shift their daily rituals to better address their fears. Thus, the purpose of this study is to use photo-elicitation to see the world through the eyes of this population at the early stages of the pandemic, to understand how lifestyle changes impacted their ability to manage mental and physical health.

1.3 | Photography to understand and promote health and well-being

Visual methods such as photo-elicitation have been used over the years to increase interactions with and the accessibility of complex phenomena (Evagorou et al., 2015; Richards, 2003). There are many key epistemological underpinnings of using visual methods as a form of knowledge generation. According to Evagorou et al. (2015), visual methods may be employed for a variety of reasons, including to represent phenomena that are not observable with the eye (i.e., experiences that are emotional in nature) and phenomena that do not exist as visual representations but can be translated as such (i.e., feelings, challenges, and memories). Further, photo-elicitation is one effective way for people in fear of COVID-19 to probe "their emotions, thoughts, events, and actions related to interpersonal and community bonds" (Di Di Napoli et al., 2021). As demonstrated with one study amongst young people in Italy, in times of crisis, "individuals and families change their relationship with the social world and community." By "being united with other human beings" through the sharing of one's story, photo-elicitation can not only be an important data gathering tool but can also create a sense of social cohesion and community (Di Di Napoli et al., 2021). Beyond data gathering, visual methods allow phenomena to be more understandable to both the public and others in the field, helping to solve complex problems, filling knowledge gaps by looking at experiences in new ways, and facilitating the rapid building and dissemination of knowledge (Lynch, 2006). In this study, our hope was to both capture the stories of this unique population as data but also to offer a space for community formation and knowledge production during a vulnerable time of life.

1.4 | The current study

We chose to use photo-elicitation to explore our phenomena of interest because by using photographs as a stimulus for discussion, photo-elicitation can illuminate complex concepts or experiences that are difficult to describe with words alone (Harper, 2002; Richard & Lahman, 2015; Thomas, 2009). In addition, using this approach as one navigates their day-to-day lives can stimulate participant expression and reflection, while also facilitating

new insights and the ability to share lived experiences in a meaningful way (Olliffe & Bottorff, 2007; Pain, 2012; Richard & Lahman, 2015). Further, photo-elicitation can serve as a way to express and amplify underrepresented voices, while also mediating one's experience safely through online means (Couldry, 2010). Mediating experience online is considered to be part of the third space of expression through which digital users can find spaces of belonging, community, or a sense of self that they cannot find in purely offline spaces (Hoover & Echchaibi, 2012). These spaces for expression are crucial to meaning-making for populations experiencing changes to routine assumptions about their life and, in providing space for mediation of experience, this study offered participants a way to narrate their own experiences (Janoff-Bulman, 1989).

While we wanted to learn from the experiences of this population, we also wanted to provide a medium to facilitate the exploration of participant needs and experiences to create pathways for healing from the stress and trauma of this time (Christensen, 2017). Specific aims of this study include: (1) describing structural changes (i.e., changes to the structure of one's daily life) within one's home, routine, or physical environment as an immunocompromised person during the COVID-19 pandemic and, (2) describing the emotional experience of this population as they process, cope, or maintain their physical and mental health during this time. Understanding the struggles and moments of wellbeing elicited through this study will allow for further understanding of the challenges this population faces and can provide insights about potential interventions to alleviate stress, build community, and promote health in this population.

2 | METHODS

2.1 | Design

We used an online photo-elicitation activity with corresponding reflection questions to better understand life and routine changes for those who self-identified as having a compromised immune system during the COVID-19 pandemic. We used a modified Photo-experiencing and Reflective Listening (PEARL) approach (see Sinko & Saint Arnault, 2021 for more details) to allow us to gather experience sampling data via participant-derived photographs. Prompts were developed based on study aims to identify structural and emotional changes individuals with compromised immune systems face during COVID-19. Prompts were created, refined, and piloted with volunteers before the start of the study. In the present study, we asked participants to take and upload photographs with their personal cellphones or cameras corresponding to the following prompts via a Qualtrics survey:

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 before engaging with this study that represent some additional facet of your experience whether physical or emotional.

Participants were asked to select 2–3 photographs per category to share with study staff, an important cognitive process of PEARL to allow for the selection of photographs that most resonate with one's experience without being too burdensome for meaningful discussion of each (Sinko & Saint Arnault, 2021).

Through the survey, participants were asked to tell the story behind each photograph and to caption each photograph via an open text format. Participants were also asked to respond to 4 additional open-ended reflection questions about their experiences with COVID thus far. These questions included:

1. In general, what has it been like for you since being asked to stay at home due to COVID-19? How do you think your immunocompromised status impacts your experience?
2. What are some COVID-19-related stressors you are experiencing outside of being immunocompromised? Is there anything else that is making it difficult for you to experience wellbeing during this time?
3. How do you normally manage stress? Have any of these strategies been impacted by needing social distance? Have any new mechanisms bloomed for you out of necessity?
4. What do you need from your community now? What supports would help make your experience easier? Is this similar or different than what you needed from your community before COVID-19?

Participants also responded to demographic and Likert-scale items related to their experiences managing their physical and emotional health during the pandemic. 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 to better support these individuals going forward. To understand the benefit, if any, of engaging in photography research modalities, participants were additionally asked: "How did it feel to go through this activity?" This question was added to capture the potential therapeutic benefit of this sampling strategy (Sinko & Saint Arnault, 2021). This study was deemed exempt by the University of Pennsylvania Institutional Review Board.

2.2 | Procedure

Participants were recruited April-June 2020 through national online support and advocacy communities for chronic illness. This included groups on social networking sites such as Facebook and those using health hashtags on Twitter (including #highriskcovid19, #immunocompromisedcovid, #hpm (hospice specific), #btsm/#bcsn (cancer specific) and others). Our recruitment followed a purposeful sampling model that focused on group characteristics in determining spaces for online recruitment communities (Patton, 2015). A search for communities and accounts that provided information and support for those with chronic illness led to 13 identified Facebook groups, 12 Twitter influencers, and 6 Instagram accounts.

Leaders and key actors who moderated content within the aforementioned communities were sent information about our study. This information was then distributed to their members through social media posts and email listservs. To reach individuals who may not be connected to social media or who may have varying degrees of remote support, participants were also recruited through Research Match, a national health volunteer registry that has a large population of volunteers who have consented to be contacted by researchers about health studies for which they may be eligible. Three ads were sent out to individuals who identified having either primary or secondary immunodeficiency disorders (i.e., autoimmune diseases, HIV, cancer, and diabetes), with 120 individuals requesting the survey link.

Individuals over the age of 18 who self-identified as having a compromised immune system were eligible for this study. Participants were asked to upload 6 photographs in total corresponding to the prompts above to a Qualtrics survey, which took an average of 20 min to complete. Individuals who provided their contact information were entered into a lottery to win 1 of 4 \$100 Amazon gift card incentives. Upon completion of the study, photographs gathered were used for an online photography exhibit to disseminate study themes, as well as member, check our findings.

2.3 | Analysis

Thematic analysis was used to analyze the qualitative portion of this study (Strauss & Corbin, 1998). Close readings of the transcripts contributed to a preliminary sense of the interviews, and a preliminary codelist was developed separately by both the first and second author related to structural changes, distress, and wellness experiences of

those with compromised immune systems during COVID-19. Reconciliation meetings were held to synthesize the two preliminary codelists into one by discussing similarities, discrepancies, and code definitions. The first and second authors then applied the finalized code list separately to the qualitative portions of the survey. The photographs created by the participant were viewed alongside the textual data during the analysis.

Main themes were identified through abstracting codes upwards to main categories, allowing “systematic comparison” and “conceptualizing” (Strauss & Corbin, 1998). ATLAS.ti qualitative software was used for data management and analysis (Muhr, 2006). An audit trail using personal, theoretical, and analytic memos was maintained, with coding concepts being discussed at length in research team meetings for verification of accuracy.

Descriptive statistics were used to describe quantitative data related to qualitative themes identified. Quantitative data was managed through Stata statistical software (v15.1; StataCorp, 2017). We will present results from both the quantitative and qualitative data below.

Triangulation between the quantitative survey as well as member checking with advocacy group leaders and community members verified the trustworthiness of our thematic findings (Bignante, 2010). Member checking was completed via findings reports to participating advocacy organizations as well as through the online photography exhibit, where participants were invited to leave comments to share their thoughts. The gallery of results was then released via Adobe Portfolio at <https://capturingwellbeing.myportfolio.com/> where it was seen by 245 unique users to date and over 1800 unique page views. No major revisions were advised by gallery attendees.

3 | FINDINGS

3.1 | Participants

Forty-seven individuals responded to our survey with 282 photos submitted. Participants ranged in age from 21 to 82 years old. Thirty-seven of our participants identified as white, 5 of our participants identified as African American or Black, 1 participant identified as Asian, and 4 participants identified as multiracial. Forty-one participants identified as women, five participants identified as men, and one participant identified as nonbinary.¹ For highest education achieved, 20 of our participants had a master's degree or higher, 20 of our participants held a bachelor's degree, 2 participants had an associate degree, and 5 of our participants graduated from high school or received a GED. Fourteen of our participants lost their job due to COVID, 20 participants were working for payment or profit, 5 were retired from employment, and 8 were unable to work due to permanent sickness or disability. Fourteen were quarantining or following shelter-in-place orders alone, 20 were with a partner and/or children, and 13 were with a family member or roommate.

3.2 | Aim 1: Structural and lifestyle changes

This section explores the structural and lifestyle changes individuals with compromised immune systems experienced because of COVID-19. In general, participants reflected on increased caution and shifts in their wellness strategies, heightened difficulties with disease and supply management, changes in routine and perspectives of time, and an increase in stressful occurrences. While most of our participants experienced negative changes to their wellbeing because of COVID, it is important to note that for some, particularly those with more severely compromised immune systems, “not much had changed.” For example, one participant shared “those of us who are sick

¹We are acutely aware of the homogeneity of our sample. Given the purposeful sampling method used in this study and the reliance, due to Covid-19, on purely remote recruiting in part through social networking sites, our demographics parallel general trends in health-related digital media users. A study performed by Sadah et al noted that in some online health forums women participate at 4 times the rate as men. That said, future iterations of this study would redesign sampling methods to ensure a more representative sample in terms of race, gender and ethnicity.

enough do not leave on a regular basis...the world is not much different until we get outside of the home" (Participant R20). Another said, "I need my community to realize that the struggles they face with isolation is a common problem with someone who is in my situation" (Participant R45). One final participant shared a photograph of a t-shirt saying, "I wore masks long before COVID-19" (See Figure 1) and reflected, "I know once I won't have to shelter in place I will get 'the look'. Why is she still wearing a mask...she is overreacting. I am hoping this will keep some of that to a minimum" (Participant R22).

3.3 | Shifts in wellness strategies

Due to increased concerns with safety, many participants had to shift their wellbeing activities and routines around the circumstance of being at home, often with kids, spouses, or other family members around. This often meant that participants had to reorient themselves to individual wellness strategies and practices. For example, one participant captured a list of "Daily Reminders" in one of their photographs, which was created to "ensure that [they were] getting several key components to [their] wellbeing daily (including bathing, making [their] bed, taking meds, getting outside)" (Participant R49). This participant also created a "Bucket List" of things that they wanted to get done while sheltering-in-place which was shared in a different photograph. This person reflected, however, "[my bucket list] ended up being taken down, as it was a reminder of everything I 'should' be doing and I wasn't mentally in the place to experience that. However, two months later I'm still checking off my daily reminders" (Participant R49). This is an example of a common tension found amongst participants: wanting to prioritize wellness, but often feeling guilty or saddened by their new and previously existing limitations. For many of the people surveyed, the limitations of conditions that made them immunocompromised, combined with the stress of the uncertainty of the pandemic led to a restructuring of wellness in the home (in contrast to previous wellness activities outside of the home) and a need to find balance between their needs, abilities, and the needs of their loved ones.

3.4 | Caution and disease management

The danger and uncertainty of COVID-19 created an inordinate need for caution among participants. As a result, many captured through photographs the shifts in practices that allowed them to exercise caution to



FIGURE 1 Titled "proactive"

preserve their health and avoid disease transmission. Photographs included anything from mask and hygiene practices, to precautions taken when going to hospitals for various medical treatments. Multiple participants took pictures of their "hygiene stations" that included masks, gloves, and sanitizer and offered strategies for placing them in the home to make sure no one could enter or exit their homes without paying attention to safety. In one image, captioned, "Don't Leave Home Without Them" a participant displayed two floral printed cloth masks alongside an inhaler and a small bottle of hand sanitizer to demonstrate what they termed the "careful planning" involved in maintaining safety (Participant R11). Another participant noted that they don't wear a mask simply because it is recommended by the Centers for Disease Control or a government mandate, but rather, "because it makes sense to" (Participant R21). Many shared frustration and anxiety associated with the need for increased caution, particularly when others would not wear masks thus rendering all their caution less effective.

3.5 | Changes in routine

Aside from changes in wellness routines, many participants articulated how challenging it was to simply adapt to a new routine and rhythm to life overall. Noticeable and measurable shifts in routine involved a variety of factors but included things such as cleaning, balancing work demands, engaging in self-care, and managing physical spaces, health, and family needs. For example, one participant noted that before the pandemic, getting their nails done often helped them feel a sense of control over their Cushing's Disease. Since the pandemic, however, the participant expressed feeling a lack of control which they contributed to the interruption of this routine (Participant R3). Others identified changes to work routines as providing a challenge. For example, one participant reflected, "I normally manage stress by going to work and trying to stay busy. However, I can't go to work right now due to the pandemic. I have been trying to stay busy by staying inside and trying new hobbies like art, cooking, gardening, and just talking to my friends/family/boyfriend" (Participant R26).

Not all of these changes were perceived as negative by participants, however. For example, one participant mentioned that their ability to do work was already curtailed due to their health, but that a shift in routine for their family members allowed the participant to receive more help around the house, "Since I am not able to really do a lot physically, this time has been good to do things around the house and care for the yard. 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" (Participant R2; See Figure 2). This demonstrates that for those living with a compromised immune system, though COVID did increase their fear, it also offered some ways to make their life more manageable.

3.6 | Supply management

Given the increased need for supplies to keep their environments safe and sanitary as well as the inability of many participants to safely go to the store, many articulated concerns around supply management. This included articulations about spending time, energy, or resources acquiring, managing, or worrying about supplies needed to maintain health and sanitation practices during COVID-19. In addition, participants expressed concerns about everyday supplies not related to illness or immune-compromised state. For example, one person captioned a photograph of a box of gloves and a mask, "Supply Shortage" and described the challenges of making sure to have the right personal protective equipment to guarantee their safety. They mentioned the challenge too, of making sure they had what they needed for daily infusions.



FIGURE 2 Titled “Taking more time to care for our home”

I have a PORTACATH that I infuse 2 L of saline daily. I have POTS, and I am impacted by it daily. Without my infusions I have severe flare-ups that can put me in hospitals for days. During this pandemic, I have not been able to receive my full amount of supplies. It has been a struggle to find a happy medium on the amount of my daily supply usage, i.e., hand sanitizer/gloves/alcohol pads/disposable masks/etc. Without having my regular amount of supplies, I have had to cut back on my infusions, while staying as healthy as possible so that I am not getting super sick. It has been very hard and aggravating not being able to receive the treatment I need! (Participant R32).

3.7 | Time horizons

One interesting theme that emerged when examining structural changes were expressions of changes in the relationships people had with time. Many participants expressed a shift in the structure of their own time each day as well as how they considered a time for both themselves and family, both inside and outside of the home. In one particularly striking photography taken with “motion,” one participant noted their shift in their ability to make time for themselves. “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” (Participant R31; see Figure 3). Another noted that their inability to track time had had negative repercussions on their physical health, saying, “having lost track of what day of the week it is, I’ve also lost my appetite. I’ve lost 5 pounds, the dog gained 3 pounds” (Participant R10). Several participants made mention or took photos of empty calendars, articulating the simultaneous lack of connection combined with a change to how they structure, conceive of, and manage their time.

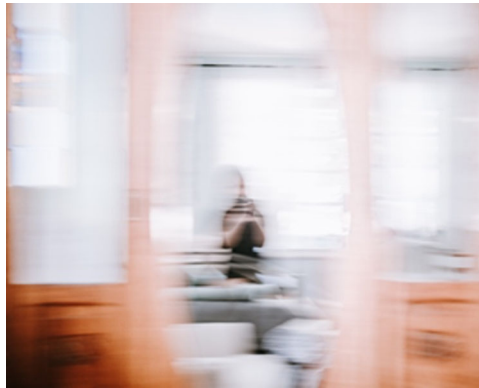


FIGURE 3 Titled “Noise”

3.8 | Stressful occurrences

The final structural theme we identified were life changes that were expressed as stressful and largely existed beyond the control of the individual. These lifestyle changes included job loss, homeschooling, inability to go to a doctor at required frequency, missing important milestones or celebrations, and shifts in responsibilities leading to feelings of stress or overwhelm. One participant who was a parent, for example, identified fear of job loss and homeschooling as having changed the structure of their everyday life. They shared, “My biggest concern is the loss of work by way of layoffs. We have been fortunate to be able to continue to work. My new added job as a 1st-grade teacher has given me the most stress. I’m sure that my daughter is handling the work. However, I’m not 100% sure that she is retaining it as if we’re in a classroom setting” (Participant R18). Another participant who lost their job shared a picture of their plants and reflected, “This is a picture of some of my indoor plants. I know taking care of my plants is a positive activity for me and helps take my mind off of the pandemic, being sick, and being laid off of work. I know that I am safe when I am gardening” (Participant R26). One additional participant noted that their stresses did not come from having a compromised immune system, but rather because as a result, their husband was the sole household income. “The stressors I am experiencing is dealing with the stress that my husband has due to fear of his job and his pay. That is the only thing that has been stressful about this for me. As I said earlier, my life hasn’t really changed other than I have to wear a mask. He is our sole support being that I am on disability so the financial aspect is the main source of stress...” (Participant R2).

3.9 | Distress caused

This section explores the emotional stressors or self-expressions of distress that participants identified as a result of living with a compromised immune system during COVID-19. This included a noticeable deterioration of their mental health, concerns surrounding health management and safety, and experiences of isolation and longing.

3.10 | Deteriorating mental health

Because the fear, isolation, and uncertainty of COVID-19 participants described a noticeable deterioration of their mental health. This manifested into symptoms of depression, anxiety, and difficulty focusing or sleeping. For example, one participant who was unable to work due to his compromised immune status shared “I am drinking

more from an emotional standpoint because I feel like without income coming in I am worthless. I am now becoming more dependent on alcohol which can be scary. I never want my circumstances to change who I am" (Participant R53). Another shared a photograph of an old exercise bike saying, "I used to exercise daily on this bike. In the last 3 months, I've only been on it 4 times. I'll probably die from Covid 19, why leave a nice looking corpse" (Participant R10). This highlights the extreme mental health challenges individuals faced as they coped with their high-risk status and the changes in their life they have had to make as a result.

Participants not only faced mental health challenges while sheltering-in-place at home, but also as they interacted with the outside world during essential encounters. For example, one participant shared a photograph of her face waiting in the emergency room during COVID saying "I may look bemused but it belies the anxiety I am feeling, waiting in the emergency room during the COVID-19 epidemic... 'Are you dying tonight?' one ER doctor asks me. 'Then go home.' I'm not dying tonight. But something is really wrong. And so many like me – those with chronic health care issues, invisible diseases, and immunocompromised states – are slipping through the cracks of the U.S. health care system" (Participant R35). This feeling of being "left behind" was shared by many, as they noticed the lack of thought or concern others in their community seemed to have about their compromised immune status. What made managing these deteriorating mental states so hard, however, was the fact that many of our sample's previous coping skills were unavailable due to pandemic-related constraints. For example, one participant shared, "[I am now unable] to go for my wellness program. I have exercised 2–3 times a week at a small physical therapy practice. I miss seeing all of the regulars & the staff. I now simply don't have the energy to exercise. Just waking to the kitchen in front of the house wipes me out" (Participant R5).

3.11 | 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. For example, one participant with rheumatoid arthritis shared "I have had to worry about medications since I am on hydroxychloroquine and the pharmacy has had some delays in their orders" (Participant R11). Another participant shared a photograph of her tracheostomy supplies saying, "Since mid-February, I've been unable to obtain all the supplies that I need to keep my tracheotomy stoma clean...the cost of the items is also greater than the costs I have had in the past" (Participant R15). Participants also shared feeling afraid to take medications prescribed that compromised their immune system, causing many of them to stop taking these medications all together, often without consultation of a healthcare provider. For example, one participant with Sjogren's disease shared, "I have had to see my rheumatologist on an e-visit. To say it was not satisfying at all would be an understatement. Because of COVID-19 I don't dare take immunosuppressant drugs" (Participant R25).

3.12 | Safety fears

Participants expressed safety fears, particularly when those around them were not following protective guidelines. For example, one participant shared "I need people to get their heads out of their asses (excuse my language). This is not fake. Your rights aren't being taken away by being required to wear a mask (welcome to my life, jerk). The total disregard and the entitled sentiment that is being displayed is ridiculous" (Participant R22). 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 was demonstrated by an image of a sanitizing station captioned "germ battlefield" saying, "While many are wearing masks, many still choose to not wear masks. Unfortunately, we don't know who does or does not carry the disease. It's critical to be even more vigilant because of those who think this is no big deal and that means wearing masks, wearing gloves, and sanitizing repeatedly when in public" (Participant R16). This lack

of clarity caused fears of dying and many to feel that their wellbeing was not valued by society. This was highlighted by one participant's reflection, saying "I watch and read about the people who are defying scientific recommendations because it inconveniences them. I realize I'm inconsequential to them and that's real depressing" (Participant R19).

3.13 | Isolation

Isolation caused many to feel trapped or alone. One participant shared a photograph of her empty planner saying, "I took this photo because earlier this year I had plans I could mark out and look forward to, instead of empty time without a solid end date. I'm stuck where I'm at right now just waiting for this all to be over someday" (Participant R31; see Figure 4). Because so many participants were unable to take the same risks as those around them, many worried that they were losing connections. For example, one person shared, "I'm craving the person to person contact but I'm not willing to take unnecessary risks; it's just hard to know what's a risk and what is not outside of the CDC guidelines. Everyone has different opinions; those who are more liberal and feel like this is nothing have a hard time understanding and accepting my need to be more careful and still shelter in place. So it's frustrating and it feels like I may lose those connections over time if I don't start doing things with them" (Participant R16). By limiting exposure to others, participants often had to miss events or gatherings, causing them to feel guilt and regret. One participant shared a photograph of a parade in the distance saying,

My neighborhood association planned a parade celebration for all 2020 graduates...My daughter graduated 8th grade this year, so I urged her to walk in this parade with her friend. I was busy planting my garden when I heard the police sirens and music from the parade. Feeling guilty for not supporting my daughter in the parade, I quickly ran to catch a glimpse and immediately started sobbing at the sight. Why was I crying?? I NEVER cry... well hardly ever...The past 2 and a half months have been especially isolating and perhaps I missed the outside world more than I realized (Participant R17).

3.14 | 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. For example, one participant shared, "The social



FIGURE 4 Titled "Empty Plans"

distancing makes me sad as I feel that we as a society are being driven apart.... the very thing that makes being human wonderful (hugging, hand shaking, saying hello, visiting with others) has been taken away" (Participant R2). Participants also discussed feeling trapped inside their home, longing to be outside, but struggling to balance their infection risk. This was illustrated by a photograph of a participant looking out the window saying,

I miss the sun on my face, wind in my hair, the cushion of the air, the sounds, the smells...making peace with the idea that while I **COULD** go outside and walk around, I actually really **SHOULD NOT** due to my compromised immune system and low b-cell count...I push back this curtain and look outside and people watch (when there is anyone walking by) or just look at the sky and think that someday I will be able to go outside -really go outside and not just for a short walk-again soon" (Participant R33).

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. One person highlighted this by saying "It's been a mess. Working from home as a parent of a toddler has been incredibly stressful. I'm barely able to work or continue my child's education so I also feel like I'm failing. This stress is hard to keep in check since it's also a trigger for flares with my Crohn's disease. It took 2 years to recover from my last flare" (Participant R47). This often caused people to need to carve out space and set boundaries. One participant illustrated this sharing, "I think I'm finding more creative ways to feel like I'm alone when I'm not so that I can process my own experience. I think I am making more clear boundaries now because I need them all the time now" (Participant R31).

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.

3.15 | Wellness strategies

In this final section, we examine participants' self-articulated strategies for self-care and wellness given the changes to their structural and emotional ways of being due to the circumstances of the restrictions resulting from COVID. These strategies included finding comfort, managing uncertainty, maintaining connection, finding escape, managing their physical health, and building emotional resilience. Interestingly, many participants identified participation in this study as offering a chance to reflect on and share their experiences of navigating their health given a moment of acute danger for them. This demonstrates that in addition to offering input on the needs of immunocompromised individuals, photo-elicitation, as a powerful offering of voice to communities, can itself begin a process of meaning-making that is crucial to community engagement during times of crisis and trauma (Egnew, 2009).

3.16 | Finding comfort

With so much fear surrounding one's health, participants sought to find comfort amid their socially isolated lives. Many found comfort through household pets, reflecting on their ability to calm anxieties, bring a sense of routine, and provide "unconditional love." This was highlighted by reflections including: 1) "[my dog] has kept my mind and body distracted from dwelling on COVID" (Participant R10), 2) "[my dog] has given us a reason to walk, a happy face to look at, and some routine. The dog and I are both old ladies with arthritis so

we understand each other" (Participant R21), and 3) "[my dog] calms the anxiety that co-occurs with being immunocompromised during the pandemic" (Participant R29). Outside of pets, participants found comfort by leaning on social support, beautifying their space, and spending quality time with people in their home. While people found comfort through various activities, it seemed important for individuals to engage with something that helped them focus on what they could control and feel supported or valued as they coped with challenging feeling that arose during this time.

3.17 | 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. For example, one participant shared "The anxiety I have since COVID is unprecedented for me. Therapy is an absolute must to keep my sanity" (Participant R7). Another shared a photograph she titled "cleaning out the clutter" saying, "Since I must stay home, I have been trying to find things to do that would make my life less stressful. I have been meaning to get to most of these tasks for a long time. There is much more to do, but I am trying to not watch so much television" (Participant R23; Figure 5). Keeping one's mind and hands active often helped individuals "not dwell on things" this was highlighted by one participant saying, "I normally manage stress by concentrating on the hear-and-now instead of the past or what might be. Unfortunately, the current uncertainties make that difficult. I have started small things to keep my mind and hands active in an effort to keep me from dwelling on things. I crochet when I am tired and just binge watching on my computer. It keeps my hand busy and keeps my mind from wandering too much" (Participant R50).



FIGURE 5 Titled "Cleaning out the clutter"

3.18 | 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. For example, one participant shared a photograph titled "writing" saying, "I've found that writing is one of my only escapes where it feels like I can be with myself and express my experience without a filter. I'm able to write my own world when the world around me is so unsure. It helps me to process my own experience and what it feels like to be undergoing a health crisis on a massive societal level, versus my own personal health journey like it was before" (Participant R31). Other connections were cultivated or maintained through virtual modalities, sending letters, or through helping others. For example, one participant photographed her letter stationary saying, "Sending (and receiving) cards has been a critical step to my mental health. I added, "send a card" to my daily reminders list, as well. I have received some amazing cards from loved ones and am frequently revisiting them as a reminder of love and support. Walking to the mailbox has been a highlight of my day, as well" (Participant R49).

3.19 | 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. One participant shared a photograph of a lake titled "my calm place" saying, "I do not live far from a beautiful lake. When being cooped up gets to me I go and sit on the pier. I absolutely love storms and the water will splash up on my windshield and I laugh like a little kid" (Participant R22). Another shared a photograph of books saying, "I would not be able to survive staying away from the rest of the world if it weren't for the world I can escape into with books. I spend the entire time during my infusions, reading and escaping into the world these stories create for me" (Participant R30).

3.20 | 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. For example, one participant shared a photograph of a treadmill saying, "Keeping active is an absolute must when you have autoimmune diseases and are immunocompromised. I used to go to the gym, however since Covid I had to find a way to exercise. Exercising outdoors is not feasible in my neighborhood; I had to make space for this machine so that I could continue exercising" (Participant R7). Another shared a photograph of a thermometer saying, "With RA [rheumatoid arthritis] I often feel feverish. I purchased this thermometer to tell in an instant if it's my normal low grade or a fever. This thermometer does not leave the kitchen counter and all family members can use it as it's temporal" (Participant R21).

3.21 | Building emotional resilience

For many, they recognized how trying emotionally it was going to be for them to maintain isolation long term. For example, one participant shared "I hate staying home. I feel trapped. Knowing that I'm at a higher risk of catching Covid with severe consequences has impacted my sanity" (Participant R7). Because of this, many 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. For example, one participant photographed the sunrise outside of her window saying, "I do enjoy nature's colors. I want to enjoy being alive as long as possible. This is a photo that reminds me of hope" (Participant R10). Another shared a photograph titled "passing time with old photos" saying, "Since I couldn't go anywhere to have new adventures, I decided it was a good time to revisit some of my favorite memories and trips by sorting through all the photos on my computer. I printed several photo albums in hard copy of important recent phases of my life. It helped me think about where my life is going and what is most important" (Participant R6). One final participant shared a photograph of her elderly grandmother and shared,

My 99-year-old mother is quarantined in an assisted living facility and has had no contact with family (other than video calls) for three months. However, I sent her fabric and elastic, and she has spent hours making masks that they are using in her facility. It has made her feel useful, and as she told her granddaughter when asked about the virus: "Well, it is strange, that's for sure. But, you know, people are capable of quite a bit. I think we don't know quite what we can handle until we have to. We need to be kind. We need to help. When I was a child there were other farms near ours and we'd swap what resources we had to help each other. The war efforts were the same type of thing. Sure would be nice if we could make all the bad stuff go away, but I've never seen that before. What you need to watch is what we do when it's over. A challenge like this is only good if we become better from it (Participant R3).

While we asked for non-identifying photographs to protect participant privacy and confidentiality, this participant and her mother gave explicit permission to publish Figure 6 to allow us to put a face to the population of interest, further humanizing our findings.

Importantly, while our participants discussed the need to build resilience and find creative solutions to cope with their experiences and keep themselves safe, many noted the community and structural failures that perpetuated safety risks and distress making it necessary for them to do this in the first place. For example, one participant noted, "It's easy to get caught up in all the conflicting news stories and confusing information presented in media" (Participant R16). Another said, "I need quicker processing of unemployment reviews from the state!" (Participant R49). Another recalled, "Before COVID-19, treatment and testing was easy to come by. Now it's hard for us to get what we need. I'd like there to be ways to receive those testing at home." Ultimately, while people were willing to build resilience in themselves, many wished there were structures in place that made meeting their unique health needs more feasible during pandemic times.

3.22 | Reflections from participants about participation

Overall, participants seemed to enjoy the photo-elicitation approach and noted its unique ability to "reflect on what has changed in just three months" (Participant R18). Participants shared that, they "liked the idea of story-telling with photos" (Participant R47), that "it was similar to talking to a therapist" (Participant R52), that "it made [them] put into pictures what [they were] feeling inside" (Participant R7), that it was "really cathartic" (Participant R9), and "brought emotions to the surface" (Participant R3). This revealed the promise of using photography to help people be mindful of their day-to-day activities and emotions, while also allowing them to process their experiences and bring new awareness to the research space. For example, one participant shared, "It made me realize all the changes that I made and how much they made a difference...It also brought back some of the emotions I was feeling early on when we were first quarantined" (Participant R25). One participant also mentioned the task's ability to help them focus on the positives saying, "When looking at the photos, I was able to focus on the positive outcome, not get



FIGURE 6 Titled “elderly quarantine”

mired down in the pain & fear I experienced during the process. Looking at our decontamination room, instead of thinking how onerous that was, I feel thankful we have the space to do it & could buy supplies. While we don't have a lot (my husband is retired high school teacher & I have been disabled for years) we have a home & could afford to have groceries delivered” (Participant R5).

4 | DISCUSSION AND CONCLUSION

This study used photo-elicitation to amplify the lived experiences of those with compromised immune systems navigating the COVID-19 pandemic. Structural changes to daily life participants noted included shifts in wellness strategies, health management, routine, stressors, and time perception. Because of the uncertainty, emotional distress was extremely prevalent in our sample, similar to previous studies focused on this population in early stages of the pandemic (Pierce et al., 2020). Mental distress was attributed to deteriorating mental health, safety fears, isolation, health management, and longing to be with loved ones again. Wellness strategies employed to mitigate emotional distress included finding comfort, connection, and escape, managing uncertainty, maintaining physical health, and building resilience. These findings were displayed in an online photography exhibition and participants reflected on many emotional benefits of sharing their stories through a photographic medium.

Hearing the voices of those at high risk for COVID-19 disease transmission has important implications as we continue to move forward in such uncertain times. First, our results support the need to continue to prioritize the wellbeing of those at high risk and be aware of how our adherence to guidelines impacts the mental health and safety of these individuals. Communities must also think about the daily support for these individuals outside of pandemic times, as many have had these struggles long before COVID-19. Importantly, while participants in the study reported feeling resilient, many noted that resilience was necessary to adapt to the community and structural failures that perpetuated safety risks and distress for those at high risk.

Participants seemed to derive some benefit from the reflection facilitated during this photo-elicitation study, with feedback that aligned with other hard-to-reach populations who participated in studies using PEARL as a data collection method in the past (e.g., Sinko et al., 2020; Sinko & Saint Arnault, 2021). For example, in a study focused

on survivors of campus sexual violence, individuals who participated in the PEARL method noted that the experience helped them understand how to improve their situation, gave them new ways of looking at their problems, and gave them a good understanding of what changes they needed to make (Sinko et al., 2020). While we were unable to implement the in-person interview aspect of the PEARL method, we did develop and apply an experience-sampling photography task in this study in line with PEARL principles (Sinko & Saint Arnault, 2021). This shows that while the in-person discussion element may be important, independently responding to the photography focusing prompt itself may still provide tangible benefits for participants.

Literature reviews of photo-elicitation generally have revealed three main benefits: (1) the photographs it generates to provide the stimuli for “deep” analysis of complex phenomena, (2) it can produce different types of information than other narrative techniques, and (3) and it addresses concerns about power relations between researcher and subject (Van Auken et al., 2010). This study adds to this body of literature highlighting the promise of using photography in research data collection. This study also brings into focus how we might use creative and innovative methods for populations that are typically hard to engage in research or those with experiences and conditions that make other forms of participation difficult. Future research should test how PEARL or other participant-driven photo-elicitation methods may improve participant wellbeing, self-understanding, and hope in times of stress or discomfort. This will demonstrate the potential promise of photography-based interventions for individuals facing significant health challenges.

Limitations of this study included the inability to interview participants to gather more extensive data on their lived experiences, the homogeneity of our sample, and our limited sample size. Despite these limitations, this study highlights how, when given the opportunity to share their experiences, those who suffer from and contend with the challenges of living with a compromised immune system, will authentically engage in the narration of the self.

MacRae (2008) and Kleinman (1988) note that the meaning of illness is culturally constructed and that there is great significance in creating meanings around experiences of situations that remove individuals from cultural spaces and normative frameworks of wellness. For those living with chronic health challenges, their unique “suffering must be heard and accepted, as the denial of the patient’s story of suffering and sacrifice is a denial of the patient’s identity as a sufferer” (Egnew, 2009). In making a selected gallery of the images publicly available, this study offers others with chronic illness an opportunity to share frameworks of wellness from their perspective, while providing additional opportunities for meaning-making and community building through engaging with the images of others. This mediated ritual of looking at others who might share in one’s own experience can create new spaces for inclusion, that can “protect us from chaos, fend off the constant threat of being left alone, of being excluded” (Sumiala, 2012).

Overall, this study offers insight into what it was like, at the beginning of the COVID-19 pandemic, for those with compromised immune systems as they navigated their health along with conditions of uncertainty caused by lack of information about this novel virus, no clear sense of when circumstances would change, and the urgent upheaval of many aspects of social life. Through sharing of images and experiences, participants expressed that despite the fear surrounding one’s health status, they creatively engaged in ways that allowed them to seek comfort and pockets of escape to manage uncertainty amid their socially isolated lives. Participants also made efforts to reconnect with things that brought meaning in their lives, while safely maintaining social and familial connections. Together, our findings highlighted not only the extent to which individuals can creatively find solutions for survival, but also the unintended consequences that can occur when public health approaches do not create appropriate supports for the most vulnerable.

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DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

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