

Understanding the Role of Mental Health Clubhouses in Promoting Wellness and Health Equity Using Piliinahā—An Indigenous Framework for Health

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Highlights

- Clubhouse members and staff in Hawai‘i participated in a multi-site photovoice process.
- This article describes what members found essential to wellness and how it can be achieved.
- Clubhouses provide a space for mental health recovery and transformative change.

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Abstract Individuals with severe mental illness need to be engaged in defining their own vision of wellness to promote equity and reduce disparities. This photovoice study helps define what wellness is and how it is achieved in mental health Clubhouses in Hawai‘i. Results from a photovoice study with 43 members and staff were analyzed using Piliinahā, a Native Hawaiian framework for health. Piliinahā envisions health through connection to place, community, past and future, and one’s better self. Within Clubhouses, connection to place included connection to *‘āina* (land) and the access to a safe space. Connection to community occurred through reciprocal social support, which developed *kuleana* (responsibility), and a sense of *‘ohana* (family) for many members who were previously isolated. Connection to one’s better self-involved positive identity change, development of hope,

and pursuing opportunities within and outside the Clubhouse. Connection to past and future was described through individual narratives, remembering members who had died, and connection to cultural traditions. Overall, wellness was conceptualized as the ability to work toward dreams, engage in cultural practice, and feel accepted, respected, and valued—to be treated with *aloha*. Findings provide a culturally responsive perspective on wellness and illustrate the value of Clubhouses as a space for mental health recovery and transformative change.

Keywords Clubhouses · Community-based participatory research · Health disparities · Health equity · Mental illness · Photovoice

Hawai‘i Clubhouse Coalition (composed of directors, members, and staff).

All authors have made significant contributions to this manuscript following the Committee on Publication Ethics.

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Disparities among People with Severe Mental Illness

In 2016, the National Institute of Mental Health estimated there were 10.4 million people living with severe mental illness (PWSMI), which represents 4.2% of the adult population (NIMH, 2016). On average, PWSMI have a staggering 10- to 25-year decrease in life expectancy compared to the general population (Liu et al., 2017). Causes of early mortality include social isolation, poor access to quality health care, iatrogenic effects of medication, less physical activity, higher rates of smoking, stigma, and discrimination (Agency for Healthcare Quality & Research, 2017; Safran et al., 2009). For ethnic and racial minorities with mental illness, these health

disparities are often exacerbated by less access to adequate or culturally relevant treatment and greater likelihood of experiencing structural inequities (such as poverty and incarceration) that increase stress and illness (Primm et al., 2009).

The severity of this public health and justice issue has led the Institute of Medicine, the World Health Organization, and the National Institutes of Health to prioritize health disparity intervention research among PWSMI (Safran et al., 2009). However, little research with this population incorporates a cultural perspective of wellness or utilizes a community-based participatory research (CBPR) approach. This limits the impact of health equity interventions, as culturally adapted and culturally grounded mental health interventions are generally more effective (Griner & Smith, 2006). Furthermore, health research that does not engage PWSMI in defining their vision of health perpetuates the discriminatory mentality that PWSMI are incapable of self-determination. For health promotion efforts to be equitable and successful, culturally diverse PWSMI *must* be equal partners in defining their vision of health and wellness and in evaluating strategies to promote those goals. This research contributes to that aim by engaging a multicultural sample of PWSMI in Hawai‘i in a CBPR process to better understand how wellness is defined and supported in mental health Clubhouses.

The Clubhouse Model

Clubhouses are voluntary day-programs for PWSMI that focus on empowerment and de-stigmatization. The Clubhouse model differs significantly from conventional treatment for mental illness because Clubhouses were designed by people with lived experience. The founders met while they were in an inpatient psychiatric ward, and they believed the support they provided each other was the most healing aspect of their treatment. After discharge, they continued meeting on the steps of the New York City Public Library and eventually established Fountain House, the first mental health Clubhouse (Fountain House, 1999; Norman, 2006).

The founding members did not intend for Clubhouses to provide “treatment” in the traditional sense, and they rejected the power dynamics and structure of the medical model (Norman, 2006). People who attend Clubhouses are referred to as “members,” and they are guaranteed four primary rights: “a right to a place to come, a right to meaningful work, a right to meaningful relationships, and a right to a place to return” (Clubhouse International, 2016). The Clubhouse philosophy asserts that boredom, stigma, and isolation increase or create illness, while

social support and meaningful activity promote recovery. Members can participate in all decision-making processes, and attendance is voluntary (Mowbray, Lewandowski, Holter, & Bybee, 2006). There are no spaces only for staff, and it is often difficult for outsiders to distinguish between staff and members at Clubhouses. The founders believed that visual distinctions between members and staff were stigmatizing and therefore worked to create an environment in which members were understood as individuals, not as patients.

Currently, there are more than 300 Clubhouses in over 30 countries around the world (Clubhouse International, 2016). Decades of research on the Clubhouse model show that it is more effective than conventional treatments, such as day centers and assertive community treatment, at increasing social support and improving the quality of social connections (Hultqvist, Markström, Tjörnstrand, & Eklund, 2017; Pernice-Duca, 2008), as well as decreasing hospitalization frequency and length of stay (McKay, Nugent, Johnsen, Eaton, & Lidz, 2016). Existing research strongly supports efficacy of the model, but research gaps remain. Much of the Clubhouse research has been conducted within the continental United States with majority white populations (McKay et al., 2016), and to our knowledge, no research has focused on how the Clubhouse model aligns with culturally based approaches to health and wellness, or how it might differ in culturally diverse contexts such as Hawai‘i.

Hawai‘i Context

Hawai‘i is one of the most racially and ethnically diverse states, with no majority population, and “local culture” includes influences from diverse lineages of immigrants. In 2000, the percentages of the primary ethnic groups on the island were 24% *Kanaka Maoli* (Native Hawaiian), 24% Caucasian, 18% Japanese American, 16% Filipino American, 7% Chinese American, and 11% other (Park, Braun, Horiuchi, Tottori, & Onaka, 2009). There are also significant Pacific Islander populations from several island nations (Okamura, 2008). A high percentage of the state is multiracial. In 2000, 60% of the babies born in Hawai‘i were of mixed-race or ethnicity, and around one-quarter of the adult population identified as multiracial in the census (Kaneshiro, Geling, Gellert, & Millar, 2011). Due to Pacific Islander and Asian cultural influences, Hawai‘i is the state with the largest representation of collectivist cultural beliefs (Vandello & Cohen, 1999).

Prior to colonization and the overthrow of the Hawaiian monarchy in 1893, Hawai‘i was recognized globally as an independent island nation, and the movement

toward decolonization continues. This includes but is not limited to, revitalization of ‘*ōlelo Hawai‘i* (Hawaiian language), utilization of Hawaiian and ‘*āina* (land) based pedagogy in schools, the incorporation of *la‘au lapa‘au* (Hawaiian medicine) in medical centers, and a wide variety of strategies to honor Hawaiian epistemology, rights, sovereignty, and knowledge. For these reasons, culturally focused research is particularly important within Hawai‘i, and this setting provides an opportunity to incorporate indigenous and multicultural perspectives in mental health services using CBPR (Fong, Braun, & Tsark, 2003). Hawai‘i also has a high number of Clubhouses per capita. All of the Hawai‘i Adult Mental Health Division (AMHD) psychosocial rehabilitation centers follow the Clubhouse model. There are nine across O‘ahu, Kaua‘i, Hawai‘i Island, and Maui, serving nearly 1000 members per year. The goal of the present study was to understand how Clubhouse members define, conceptualize, and create wellness.

Method

Partnerships and Process

Our approach to participatory research was largely informed by the work of Israel, Eng, Amy, and Parker (2013) and Wallerstein, Duran, Oetzel, and Minkler (2017). Our research team consists of one professor, one research associate, and six research assistants. Our relationship with the Clubhouses began in 2015 through an evaluation partnership with the Hawai‘i Adult Mental Health Division (AMHD) Clubhouse Coalition. The Clubhouse Coalition consists of directors from each of the Clubhouses, Clubhouse members, and AMHD administrators. The coalition acted as a steering committee throughout all phases of this process. At the initiation of this project, coalition members decided to focus broadly on Clubhouse’s impact on health utilizing photovoice (Wang & Burris, 1997). Photovoice, a participatory, photograph-based methodology, was chosen because of its potential to be used for advocacy as well as research. Ethics approval was obtained through the University of Hawai‘i Institutional Review Board.

Sampling and Procedures

Purposeful sampling was used, following the criteria that all participants in both the prompt generation and full study were Clubhouse members or staff in Hawai‘i. Ko‘olau Clubhouse, Waipahu Aloha Clubhouse, Diamond Head Clubhouse, Hale O Honolulu Clubhouse on O‘ahu, and Friendship House on Kaua‘i participated in the

research over the two-year process. The same procedures were followed at each Clubhouse.

Prompt Generation and Recruitment

We wanted to ensure that the members focused on prompts that were important to them and that were not determined by the researchers or exclusively by the coalition. Therefore, we began at each Clubhouse by introducing ourselves and the photovoice process and then facilitated a group brainstorming session among members to develop prompts. Daily attendance in Hawai‘i’s Clubhouses varies between 15 and 60 members, and the average size is around 45 members per day (McKay, 2017). The introduction and brainstorming sessions included 20–30 members per Clubhouse. During the brainstorming session, members suggested topics that they found most important, worthy of exploring, and related to health. On average, around 20 ideas were generated initially at each Clubhouse. With facilitation, members narrowed the prompt ideas down to five or six top-rated choices and then voted a second time to make the final selection. Through this process the Clubhouses identified the following prompts: (a) Past, Present, Future (telling the story of our lives;Ko‘olau), (b) Happiness (Waipahu), (c) Meaning and Purpose (Hale O Honolulu), (d) Relationships and Support (Diamond Head), and (e) The Healing Power of Work (Friendship House).

Table 1 Participant characteristics

	Members	Staff
Total Participants (<i>n</i> = 43)	(<i>n</i> = 37) (86%)	(<i>n</i> = 6) (14%)
Clubhouse (<i>n</i> = 43)		
Ko‘olau (O‘ahu)	10 (27%)	0 (0%)
Waipahu Aloha (O‘ahu)	6 (16.2%)	0 (0%)
Hale O Honolulu (O‘ahu)	7 (18.9%)	1 (16.7%)
Diamond Head (O‘ahu)	8 (21.6%)	1 (16.7%)
Friendship House (Kaua‘i)	6 (16.2%)	4 (66.7%)
Gender (<i>n</i> = 43)	(<i>n</i> = 37)	(<i>n</i> = 6)
Male	25 (67.6%)	2 (33.3%)
Female	12 (32.4%)	4 (66.7%)
Ethnicity ^a (<i>n</i> = 35) ^b	(<i>n</i> = 29)	(<i>n</i> = 6)
Asian	19 (65.5%)	3 (50%)
White/ Western European	11 (37.9%)	1 (16.7%)
Native Hawaiian	7 (24.1%)	0 (0%)
Hispanic/ Latino	4 (13.8%)	0 (0%)
Other Pacific Islander	2 (6.9%)	1 (16.7%)
Native American	1 (3.4%)	0 (0%)
Black/ African American	0 (0%)	1 (16.7%)
Age (<i>n</i> = 33)	(<i>n</i> = 27)	(<i>n</i> = 6)
	<i>M</i> = 52.6	<i>M</i> = 50.5

^aThe sums of participant ethnicities are >100% because participants were asked to list all ethnicities they identified with and six participants are multiracial.

^bProviding demographic data was optional and therefore, the *n* varies.

After the prompt was generated at each Clubhouse and the requirements of participating in the study were explained to the group, members were invited to sign up for the full process. From the larger group of 20–30 people that participated in the introduction and brainstorming, a smaller group of 6–10 members and 0–4 staff at each Clubhouse joined the full project. In total, 43 participants completed the entire project (37 members and six staff). Staff were allowed to participate in the study because Clubhouse culture and standards aim to decrease divisions between staff and members, and they work collaboratively at the Clubhouse. Participant characteristics are outlined in Table 1. The most common diagnosis was schizophrenia or schizoaffective disorder (77%), and the majority of the sample (75%) also had a physical chronic condition. Participants were highly diverse in terms of race and ethnicity, and 21% of the participants were multiracial. On average, members had been at the Clubhouse nine years and staff 12 years. Most participants (77%) were not gainfully employed. Thirty-three percent lived independently, while the others lived with some type of support, either with family (21%), a group home (17%), a care home (25%), or transitional housing (4%).

Consent

After identifying prompts, members who wanted to participate in the full project went through a verbal and written consent process. Requirements of participation were explained along with risks and benefits. Members had the choice of whether they would like to be identified by their real names or a pseudonym. This decision was based on the philosophy that members have the right to self-determination and are also represented as co-creators of this work. Twenty-five percent of members, and no staff, decided to use pseudonyms. The process for obtaining consent when photographing others was explained and practiced.

Photovoice Sessions

Photovoice sessions were organized following the procedures described by Wang and Burris (1997) and informed by several others who have used photovoice and adapted it for different populations including indigenous groups (Castleden, Garvin, & First Nation, 2008; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). There were four to five sessions at each Clubhouse. The first session was an introduction that involved teaching members how to use the digital cameras and co-developing two to three questions based on the main prompt of each Clubhouse. For example, since Hale O Honolulu focused on “Support” as a main prompt, they defined three questions

based on support. “(a) How do you receive support? (b) How do you give support to others? and (c) How can people be better supported at the Clubhouse?” Sessions thereafter involved sharing photographs from each question and analyzing each photograph as a group. In the interest of time, each member was asked to select one photograph to share with the group per session. The researchers took turns facilitating these sessions, although members and Clubhouse staff often helped with facilitation. Participants were given modified SHOWeD handouts in case they preferred to prepare comments. The form had the following questions: What do you See here? What is really Happening? How does this affect Our lives? Why does this situation exist? And, what can we Do about it? Sessions were recorded with consent and later transcribed by the research assistants. The final session was a project closing and celebration held separately at each individual Clubhouse. Food was provided. Participants returned their cameras, provided feedback on the process (including constructive advice to the researchers as well as what they enjoyed or appreciated), and shared ideas for dissemination. No compensation was provided.

Data Analysis

Following the guidance of Wang and Burris (1997), the first phase of analysis occurred collectively during the focus group sessions. As the members discussed the meaning of the photographs, memos and field notes were used to track participant responses, connections between photographs, and early themes. As is common in qualitative participatory research, data analysis was an evolving process, and because each Clubhouse chose unique prompts, it was initially unclear whether the data from each Clubhouse would need to be analyzed separately or collectively.

The second phase of analysis occurred while organizing the data for community dissemination. One Ko‘olau Clubhouse member had the idea of creating a Member Stories book, which would include content from all the Clubhouses and could be used for advocacy at the Hawai‘i State Legislature. While sorting photographs and excerpts for the book, it became clear that (a) there were cross-cutting themes among the Clubhouses even though the prompts were different at each site, and (b) these themes aligned closely with Pilinahā, a Native Hawaiian framework for health (Odom, Jackson, Derauf, Inada, & Aoki, 2019).

Pilinahā was developed in Hawai‘i by listening to the stories of Kalihi and Hawaiian community members. The framework was named for the four connections people described when they spoke about a time in their lives they felt the healthiest: connection to place, connection to

community, connection to one's better self, and connection to past and future. "*Pilina* in Hawaiian means connection or relationship. The Hawaiian language commonly has layered meanings, and here *hā* references '*ehā* meaning four as well as *hā*, meaning breath of life" (Odom et al., 2019). The visual representation of Pilinahā is designed after a "hoaka, a crescent moon representing a full bowl" (Odom et al., 2019), with each connection woven together much like a lauhala mat (a Native Hawaiian mat woven from the hala tree).

The prompts, which were chosen independently by each Clubhouse, were similar to Pilinahā's four connections. For example, Ko'olau Clubhouse's prompt, "Past, Present, Future" related directly to Pilinahā's connection to past and future. "Support" from Hale O Honolulu was similar to connection to others. Perhaps more importantly, members at each Clubhouse discussed each of the Pilinahā connections in relation to their current health. Given the coherence of themes that emerged across all five Clubhouses during the making of the Member Stories book, it made sense to analyze the data using the Pilinahā framework rather than the original prompts.

After this decision was made, the framework method was a logical next step in the analysis. The framework method is a strategy for qualitative analysis developed in public health that involves both inductive and deductive coding (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Deductive analysis utilized the four connections of Pilinahā. Inductive analysis allowed for unique subthemes to emerge within those connections. These subthemes were informed by the first two phases of analysis and were interpreted iteratively through a process of memoing and charting. Charting involves placing subthemes into a matrix, based on the framework chosen for analysis. The goal is not to identically replicate or reproduce the original framework, but to identify relationships between themes, and for new insights on the framework to emerge based on its application to Clubhouses.

Validity and Reliability

All interviews were coded in NVivo 12 by at least two researchers. Findings were shared with members and the Clubhouse coalition for feedback multiple times using a graphical representation as well as discussion. Member checking and participant involvement throughout increased the validity of this work. Because of the multi-site, multi-island nature of the project, members of the steering committee were sometimes asked to share findings and receive feedback from participants. To ensure confirmability, inter-coder reliability was calculated in NVivo 12 and Cohen's kappa was good overall (above

0.7) according to the criteria defined by MacPhail, Khoza, Abler, and Ranganathan (2016). After the inter-coder reliability was determined, discrepancies in coding were discussed and resolved with input from at least one additional researcher who was not involved in the initial coding.

Results

Results are presented through each of the four themes, followed by subthemes. Connection to place included the importance of beauty and '*āina* (land) in supporting health, as well as a safe space, sense of home, and place to progress. Connection to community involved developing reciprocally supportive relationships, which led to *aloha*—a sense of feeling loved and valued, and '*ohana*—a sense of family. Connection to place and community resulted in connection to better self as members changed their ideas of what was possible in their own lives and began to pursue more opportunities in employment and education. Connection to past and future encompassed this personal transformation over time, as well as acknowledgment of painful histories, and the importance of pursuing goals as part of health. An overview of the results and selection of photographs for each subtheme is presented in Fig. 1.

Connection to Place

Beauty and 'Āina

Several photographs and quotes reflected connection to '*āina* (land) and the role of beauty in supporting members' sense of happiness and health. When sharing one of her photographs of the sky outside the Clubhouse, Cynch described, "The sky is enormous, endless. Beautiful. Vast, very vast. It gives us a universe. The universe of the blue skies and the trees, the palm trees and the greenery that you see on the islands. If you don't have this in existence, we're lost." Another member, Maile, described the photograph of palm trees that she took to illustrate meaning and purpose. "The meaning of it for me, is that... without it we won't live... sharing this beautiful green picture... It relates to our lives because we need mother nature." Solomon shared a photograph of a Hawaiian petroglyph, or *kii pohaku*, relating that for him being Hawaiian involved an indistinguishable connection to place that makes him "feel comfortable." He shared, "Average rocks still and always will have sacred meaning, a picture too can tell a story of old Hawai'i. So what can we do about it?... Persevere, don't hold back, and always question our heritage." Connecting with nature and beauty helped



Fig. 1 Pilinahā framework in the mental health Clubhouse context [Color figure can be viewed at wileyonlinelibrary.com]

members feel grounded, at home, and linked to Hawaiian culture.

Safe Space, Sense of Home

Members described a clear need to have a safe space, a place to go, and a place to retreat. Some members, like Simo, were able to find that in their home environment.

He shared a photograph of the front of his care home and described, “This is my house and I love my house. In front of the window of the house, that’s my lanai... My life is so amazing because my house is a stay house... They are my family... this is how I find support in my life.” For others, it was exceedingly difficult to find a safe space in everyday life, which caused persistent stress.

You wanna retreat someplace, you don't really want to retreat to transitional housing. You gotta go through all this stuff. People knocking on your door. You gotta take your medication. . . You wanna understand what it is to have a quiet, comfortable moment.

(Joseph)

For some members, the Clubhouse provided a safe escape from stresses outside of the Clubhouse. “[Members] come in here feeling ostracized by society, but then come in here and feel like people here love you and accept you and support you. You don't feel stigmatized against. And I think that is kind of important. We all need a safe space,” (Kekoa). Members shared that spaces within the Clubhouses provided a destigmatized space, as well as a place to retreat while experiencing symptoms. Vernon took a photograph of the employment office and explained that he used this room to calm down and get centered when he was feeling paranoid. “Well, it's nice, coming from my little safe haven. . . The purpose of going in there is to get rid of what I'm going through. . . I have to center myself and it has to be quiet. Nobody should be in the room, and I just close my eyes. . . let the paranoia alleviate.” Vernon took multiple photographs of that room and shared that seeing the ocean through the partially obstructed views was reflective of his dreams. “I like to see the blue horizon, but I'm taking it through my safety vantage point. . . You can't see the ocean, but it's still there. If something is blocking your dream, it's still there.”

A Place to Progress

In addition to connection to *'āina*, and a safe space to return to and find peace, members described needing a place to progress. Joseph explained, “For me, no progress is death, progress builds lives and contributes to life. It nurtures life.” A combination of structure and flexibility seemed particularly important within the Clubhouse environment to support progress. Several members took photographs of the computers and described how important they were to helping them feel they could stay connected to the community. “If we're not into computers, then it's like you're falling behind. . . and may get lost along the way,” (Lionel).

Members took photographs of the daily activity board and described how that aspect of the environment helped them create opportunities to connect with others. It also provided a platform for shared decision-making and engagement. Mark reflected, “What's unique, and what I see, is an opportunity for members to get involved in

something, to bring your ideas up.” Vernon described it as a way of managing time and an opportunity to “be productive and get fulfillment.” This illustrates how the Clubhouse environment promoted progress as well as an opportunity to do something meaningful that would support others.

Connection to Community

Reciprocity—Giving and Receiving Support

Connection to place was tied to connection to community, because the physical environment of the Clubhouse provided structured support for members to contribute in accordance with their skills, and to learn new ones. These opportunities for growth allowed members to feel needed, to recognize and develop their *kuleana* (interdependent responsibility and role) within the Clubhouse, to support others, and to receive support. Giving support occurred through several means. For example, when asked about his role in the Clubhouse, Jerry described, “We can help each other by respecting each one.” Others described providing tangible support, like teaching new members skills or supporting members when they saw they were struggling with managing symptoms.

Her illness is schizophrenia, and I talk to her because she hear voices. I telling her, just don't think about the voices, li 'dat. You know, do something. . . keep yourself busy. . . and she said she likes to color or like that crossword puzzle. So, I bought her coloring book. I bought her the crayon, li 'dat. That's how I support her.

(JR)

For members who were too unwell or who had decided to stop coming to Clubhouses, other members did outreach to try to connect with them. “I keep in touch with members who don't come. . . to see how they're doing. We talk about their problems and kinda encourage them to come back to the Clubhouse, 'cause we miss them,” (Sharon). Members described that having gone through similar experiences made it easier to relate to members who were struggling. “Well if you've been exposed to [mental illness], you kinda get some idea. You don't know what's going on if it's something new. . . It's shocking and scary,” (Karen).

Providing support for others, whether emotional or tangible, gave members a sense of pride and accomplishment. When describing the importance of his work in the kitchen, David said, “It makes me feel good that people will be satisfied. . . I am responsible for giving you something appetizing, refreshing, and healthy, and just being

able to cook food for everybody. It just makes me feel like I've accomplished something." Many members took photographs of their roles within the Clubhouse, highlighting how they supported others. They explained that supporting others made them proud of themselves or made others proud of them, particularly their families.

Aloha—Feeling Loved and Valued

Many members used the words *aloha*, respect, and love to define their relationships within the Clubhouse. When we encouraged members to describe what they meant by *aloha*, they shared that it meant "honoring" (Karen) and "giving you a chance to be with the community," (Loren). Simple acts, like greeting people at the door, were frequently described as acts of *aloha*. When sharing his role at the Clubhouse and how he supported others, Hubz stated, "The first thing I do each day is I say, is say, 'Hello! Good morning!'" These gestures were brought up frequently as strategies to make new members feel welcome and at home. Laura described how she made members feel humanized and accepted:

Part of love is trying to be non-judgmental and supportive. You learn to see the person and not the stigma. You think this person is *this* or *that*, all of this bad stuff. You don't do that. You look to see the person as the person.

'Ohana—A Sense of Family

The norms of respect, acceptance, and reciprocity within the Clubhouse led many to describe it as a second family. "This is like a big '*ohana*. We're like family, friends. This is good people, they teach good stuff and good things," (Hoku). When describing the purpose of outreach (calling members who hadn't come for a while), Karen shared, "It's a family thing." Another said, "The members treat me like one brother," (Hubz). The sense of family at Clubhouses was particularly important for members who were isolated outside of the Clubhouse.

Connection to Better Self

Changing Ideas of What's Possible

Many members described feeling hopeless or incapable at times because of their illness. They also reflected some internalized stereotypes about people with mental illness which were reflected in surprise at their capabilities. One member, Sharon, took a photograph of a poster of Monet's *Water Lilies* and explained that she took it because "it surprised me that even though he has mental illness he

can still paint beautifulness into a picture." She went on to describe, "I noticed that the Christmas cards in the Clubhouse are painted by [people] with mental illness. And you cannot tell if the person had mental illness or not because it's so nice." Perceived limitations of people with mental illness were challenged as members saw other individuals with mental illness achieving steps in their recovery or succeeding in their goals. "It shows that even with mental illness you can still accomplish things in your own life," (Sharon).

Breaking down stereotypes and self-stigma from mental illness was a collective effort in the Clubhouse that required recognizing members' unique skills and interests. Members were known for their role in the community. Not as a patient, but as a chef or a gardener, or a handyman. Several members took photographs that defined their role, and some shared how they helped other members realize their talents. "A person is capable of anything, actually. So you just give them attention, acceptance, and love. This means you pay attention to what they are presenting to you. You accept it as it is... and you smile at them," (Laura).

Connection to place and to community set the foundation for connection to better self because it provided supports and opportunities for identity change. Kawika described, "I never thought I could be better. I found myself slowly improving, and having people here who helped me, saved me from illnesses that I have... I feel like my life has changed." When members were recognized for their role in the Clubhouse rather than their illness, they began to think of themselves differently. Alexia, a fairly new member at the Clubhouse, described a similar change in herself: "I noticed the difference in my personality, ever since I became a member this Diamond Head Clubhouse. I seem to be more happy and joyful. I feel good about myself and I'm proud to come here. I try not to miss a day, but everybody has their days. Where we work to improve our lives is a good quote for this place."

Developing Independence through Structured Supports

Members described that thinking differently about their own potential led them to pursue more opportunities with support from staff. Iris illustrated this in her photograph of a member and staff working together on a project.

What's really happening here is building a relationship side-by-side. Felina originally said, 'I no like do um, you do um' [laughter]. With the patience of Debbie, and encouragement, she was able to say, 'Okay, I can do this' and boost her self-confidence and self-esteem.

Members described that the confidence built in Clubhouse activities, and the support there, helped them feel more able to pursue opportunities outside the Clubhouse as well. Kawika reflected on his transition back to employment. “Yeah, I mean it’s just big you know? Going back to work. Just because I’ve been out of work for a while. I never thought I could accomplish this but I am. I’m doing a successful job.” Members who had started working said that the income from transitional or supported employment helped them afford things that most people take for granted, like a phone, a tablet, or going out to a movie. Work was also often a source of pride, and taking the first step toward employment was highly celebrated within the Clubhouse. When describing a member beginning supported employment, Linda, a staff member, shared:

If it doesn’t work out, that’s okay too, and the main thing is he tried. Because some people haven’t worked at all. Doing that first job and doing one day is great because everyone is at different phases in their life. We’re so proud of him. He teaches me more than I can support him. But should he not be able to go to work, I would be there.

Here, Linda expresses pride in one of the members, but the members also frequently described feeling proud of the staff. This is another illustration of how different Clubhouses are from mental health settings that follow a medical model. For example, Lito shared, “I learn from Hannah and Nikki. They help me. They support me. I’m proud of these two staff. They’re doing their job and they are good people.” Staff also described relying on Clubhouse members, feeling free to share personal details with them about their lives. This built trusting relationships where members also had a chance to play a supportive role.

Connection to Past and Future

Painful Histories and Transformation

Although what Clubhouse members and staff shared in the photovoice sessions was generally positive, they also acknowledged pain, especially when reflecting on the past. Several members shared photographs and stories of scars, both physical and emotional. Keomi shared a photograph of cuts on his wrist, saying “this is because of homelessness.” Another member shared a photograph of a scar down the center of his belly, describing that it was from a poorly done appendectomy, and that it had been a source of shame for many years. Incarceration, substance abuse, psychiatric hospitalization, and fractured families came up

repeatedly in the sessions. Rob described his experience in jail saying:

Jail is hurtful to people. Jail makes people worse, much worse. . . it makes people terrible. But here, we learn. We learn how to cope with our illness and substance abuse. We learn better ways of living to sustain a good life in the public.

Members often shared stories of change and also their development of hope. Pain was not described as something to be ignored or omitted, but as something to be incorporated into a complete life story. Nancy, who completed a series of photographs reflecting transformation in her life through falling leaves, shared:

This picture shows both death and life. There’s a lot of dead leaves on the ground. . . When I’m depressed it becomes a challenge to do anything, and that’s the way I have of turning off the future. I’m not in the present. I’m not in the past. I’m not in the future. I’m nowhere. I’m shut down. So. . . what we can do about it is recognize death and rebirth and the cycles of life. . . It’s okay to ask for help, but we have to go through those challenges to be strong, to be who we want to be today.

Another member, who was responding to the prompt, “What makes you happy?” shared an image of a flowering tree that was planted to honor and remember members who had passed. Los described, “The flowers represent the members that have died at the Clubhouse. Many of them passed on from smoking. The flowers that represent them, they grew back so I could see them.” Both Los and Nancy’s choices show that opportunities to remember the painful aspects of their histories were important to understand their current experience as well as their individual stories and wellness process.

Pursuing Dreams and Opportunities

Just as members at every Clubhouse shared painful histories and experiences, they all saw dreams and goals as essential to health.

It’s a photo that represent my future. I was drawing for years ago, I wanna be da kine photographer and take picture and draw and make the picture.

(Hoang)

In the future I’d like to sell an album, instead of making music for free and putting it on the internet.

(Darth Daniel San)

Maybe someday I drive a car.

(Sharon)

I didn't really have goals before, so [Clubhouse is] kinda like preparing me for a role that I'm taking on my own. . . It's preparing me for my future.

(Lionel)

Stated dreams were both an important aspect of wellness and were actively supported by other members and staff during the photovoice sessions. In that way, photovoice provided an opportunity to develop a clear vision and to receive emotional support, encouragement, and hope from other participants.

Discussion

By engaging a culturally diverse sample of Clubhouse members in a qualitative, CBPR process to understand wellness in Hawai'i's mental health Clubhouses, this work addresses several literature gaps and can contribute to health equity in this population. Although there are some exceptions (Clements, 2012), past Clubhouse research has primarily relied upon conventional research methods (McKay et al., 2016) which can lead to limited knowledge and may perpetuate a deficit model. If the lead researchers in this study had chosen the prompts and research questions, we likely would have focused on causes of health disparities among PWSMI: isolation, discrimination, etc. But in every Clubhouse, the members chose prompts that focused on strengths. Additionally, it was not our original intention to focus on place or past, but because of the participatory nature of the project, the importance of place and past in wellness emerged clearly. The findings of this study underscore the importance of the continued use of CBPR in community psychology research, particularly with marginalized groups such as PWSMI or indigenous populations (Jason, 2004).

Our findings also align with other indigenous perspectives on health and wellness within and outside of community psychology, in that they emphasize connection to place, past, and others (Gislason, Morgan, Mitchell-Foster, & Parkes, 2018; Kaneshiro et al., 2005; Panelli & Tipa, 2007). For Clubhouse members in Hawai'i, individual well-being is only one aspect of wellness. Environmental health is not distinct from human health, and health is not understood solely in the present moment or exclusively on an individual level. Most commonly cited definitions of health, including the World Health Organization's definition, do not address or acknowledge place, and ignore the past. According to Clubhouse members, severed connection to place (*'āina*, safe space, or opportunity) led to a feeling of being lost. The importance of place in wellness also aligns with the Clubhouse standards. The founding members of the Clubhouse

recognized the role of physical space in mental wellness, and Clubhouses standards require that Clubhouses are "a dignified space" as defined by members (Clubhouse International, 2016).

Finally, this research contributes to community psychology literature on social support and transformative change in mental health (Nelson, Kloos, & Ornelas, 2014; Townley & Sylvestre, 2014). The relationship between social support and health is abundantly clear, but our findings from the connection to community theme clarify that *giving support* is equally as important as receiving it. Solely receiving support is the role of a patient and replicates a disease model. Giving and receiving support—reciprocity—is the foundation for empowerment, transformational change, and improved long-term health (Väänänen, Buunk, Kivimäki, Pentti, & Vahtera, 2005). More empirical research on the value of reciprocal social support can further transformative mental health research in community psychology and inform community-based strategies to reduce disparities among PWSMI.

Limitations

Although this research offers a substantial contribution, it is not without limitations. Selection bias and social desirability bias are the main limitations to this work. Members who participated in the Clubhouse project may have had uncharacteristically favorable views of the Clubhouse, felt especially connected within the community, or sensed implicit pressures to share positive experiences over negative ones. However, members did share personal challenges as well, and their responses aligned with the strength-focused topics they chose. Another limitation is that the project leads are neither Native Hawaiian nor born in Hawai'i (i.e., "local"). Despite living here for several years, our knowledge and understanding of Hawaiian epistemology and views on wellness are limited. While we did not initially set out to focus on culture and place, the importance was clear from the outset. For cultural expertise and guidance, we relied upon Clubhouse members, staff, and our co-authors who were local and/or Native Hawaiian.

Utilization for Advocacy and Equity

The goal of this work was to promote improved services for PWSMI by understanding the unique cultural aspects of wellness in Hawai'i. For non-academic dissemination, findings were developed into a member stories book titled *Picturing Recovery in Hawai'i's Mental Health Clubhouses*. This book was shared with legislators and mental health organizations at the Hawai'i State Legislature on Mental Health Awareness Day and made available to

Clubhouses to disseminate in their own venues. Members and staff from the Ko'olau Clubhouse also developed a presentation on using photovoice as an advocacy and research tool, which they shared at the national Clubhouse Conference. Based on feedback from members and staff, the research process promoted equity by involving members and staff in all phases of the research process and by encouraging them to describe what wellness is in their own words.

Conclusion

Considering members' reflections on health and wellness through each of the connections has provided new insights on how wellness is actualized within Clubhouses in Hawai'i and how it might be improved. We found that health was envisioned as stability in life, access to nature and beauty, feeling loved, respected, and needed as an essential member of a community, ability to practice cultural traditions and contribute to the happiness of family or friends, and opportunities to pursue goals. It did not require absence of illness, pain, or loss. In fact, acknowledging pain was part of health and maintaining connection to the past. Wellness was cultivated through respect, kindness, a safe space, and a sense of family. By highlighting the views and voices of Clubhouse members in Hawai'i and understanding wellness through this lens, this research has the potential to improve our understanding of culturally based approaches to mental health in Hawai'i and how they might be supported in community mental health treatment settings.

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