

Acupressure and Therapeutic Touch in Childhood Cancer to Promote Subjective and Intersubjective Experiences of Well-being During Curative Treatment

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Hiroe Hu, BS^{1,2} , Deborah Shear, BA¹, Radhika Thakkar, MPH³, Ariana Thompson-Lastad, PhD⁴, Howard Pinderhughes, PhD¹, Frederick M Hecht, MD⁴, and E Anne Lown, DrPH^{1,4} 

Abstract

Purpose: Acupressure and therapeutic touch may be beneficial for symptom management and increasing general well-being for children undergoing cancer treatment. Acupressure has the benefit of stimulating targeted acupuncture points while providing therapeutic touch. We sought to explore the relationship between acupressure and the experience of well-being among children being treated for cancer who received acupressure.

Methods: In the Acupressure for Children in Treatment for a Childhood Cancer trial, hospitalized children received acupressure using specified acupressure points for symptom control as well as points for general well-being. Acupressure was delivered by professionals and by caregivers, following training by the professional. Qualitative data were collected through semistructured interviews with a purposive sample of professional acupressure providers ($n = 3$) and primary caregivers ($n = 13$), combined with participant observation during the acupressure intervention. Data were analyzed using grounded theory methods.

Results: Analysis of provider interview, caregiver interview, and participation observation yielded 3 prominent themes: (1) well-being elicited by acupressure, (2) well-being elicited by touch, and (3) well-being experienced as relational and intersubjective. These themes, taken together, illustrate the intricate ways in which an intervention like acupressure can help alleviate the difficulties of a childhood cancer illness experience by promoting well-being in the child as well as the caregiver. Acupressure brought symptom relief, physical relaxation, and comforting touch to the child, allowing the caregiver to also feel relief and relaxation as caregiver–child experience of well-being are closely intertwined.

Conclusions: Data from the 3 sources provided distinct and overlapping insights suggesting the versatile benefits of acupressure in promoting well-being during childhood cancer treatment. Professional acupressure combined with training of caregivers for childhood cancer may be a relational intervention that facilitates the experience of well-being for both the caregiver and the child.

Keywords

acupressure, childhood cancer, well-being, intersubjective, Traditional Chinese Medicine, caregiver

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Introduction

Well-being is the combined outcome of reduced experiential suffering, increased quality of life, and most importantly, the subjective experience of “positive emotions.” Positive emotions encompass perspectives from both hedonism (pleasure-oriented feelings such as happiness, joy, peace, calm) and eudemonism (sense of

¹Department of Social and Behavioral Sciences, University of California, San Francisco, San Francisco, California

²College of Osteopathic Medicine, Touro University, Vallejo, California

³Division of Pediatric Allergy, Immunology, & Blood and Marrow Transplantation, University of California, San Francisco, San Francisco, California

⁴Osher Center for Integrative Medicine, University of California, San Francisco, San Francisco, California

Corresponding Author:

E Anne Lown, Department of Social and Behavioral Sciences, University of California, San Francisco, 3333 California Street, Suite 455, San Francisco, CA 94118, USA.

Email: Anne.Lown@UCSF.edu



purposefulness, meaning, spirituality, and social connections).^{1–3}

The experience of well-being and positive emotions has particular importance in the context of childhood cancer treatment. Positive emotions are known to protect against physiological stress response to pain⁴ and negative psychological outcomes like anxiety and depression.⁵ In the face of significant illness, the experience of positive emotions is found to be protective, conferring considerable resilience.⁶ Studies that examine the experience of positive feelings in childhood cancer demonstrate that positive emotions lead to adaptive coping skills and healthy child–caregiver dynamics.^{7,8}

In childhood cancer, well-being in the caregivers is as pivotal as in the child. Patient suffering from cancer treatment-related symptoms⁹ has a major impact on caregiver health and well-being¹⁰ and may even lead to posttraumatic stress symptoms in the caregivers.¹¹ Despite heavy burden, caregivers of children with cancer often demonstrate tremendous resilience.⁷ Psychosocial interventions that involve caregivers have been shown to improve caregiver well-being and even patient outcomes.¹²

Therapeutic touch and acupuncture point stimulation are widely used for symptom management and improving general well-being in adult cancer patients^{13,14} and less frequently, pediatric cancer patients.^{15–18} Although existing studies often measure general well-being as one of the outcomes (ie, absence of symptoms or negative emotions like depression and anxiety), few studies explicitly explore positive emotions (ie, happiness) as an outcome.^{18–24} One of the major barriers to providing acupuncture in the pediatric oncology setting is the fear of needles.²⁵ Acupressure has the combined benefits of using pleasurable light touch in lieu of needles while still being able to stimulate acupuncture points. The targeted stimulation of acupuncture points, according to Traditional Chinese Medicine (TCM) Theories, provide a sense of well-being and promotes health through restoring the smooth flow of qi energy.²⁶

The element of “touch” in acupressure may also have effects on well-being in addition to the specific effects of stimulating the points.²⁷ Teaching lay caregivers to perform therapeutic touch on children with chronic illness has been also shown to increase caregiver self-efficacy.^{28,29} Therefore, an intervention providing professional acupressure to the child, as well as acupressure training for caregiver, may increase the well-being of child–caregiver dyad.

We performed the current study within a clinical trial that is testing the effects of acupressure delivered by professionals and caregivers for children being treated for cancer. We sought to use qualitative data methods to explore whether and how acupressure, when provided

by a professional or a trained caregiver, was perceived as eliciting a sense of well-being.

Methods

Qualitative Research Methodology

Because we are concerned with the process of meaning making in the experience of well-being during childhood cancer, we adopted the constructivist grounded theory approach. This approach has its philosophical roots in symbolic interactionism and phenomenology,^{30,31} which are appropriate for investigating lived and embodied experiences of chronic illness.

Phenomenology views the human body as a lived body, “wherein subjectivity is always corporeally expressed.”³² The lived body is the main media through which acupressure is experienced (as either the provider or receiver). Symbolic interactionism assumes human action is driven by meaning, which is derived from past and ongoing social interactions.³⁰ During childhood cancer treatment, various situations and objects during the treatment course are ascribed with meanings by the child and caregiver. For example, a child may associate “touch” by a health-care provider with pain or discomfort of a medical procedure. This ascribed meaning may change over the course of receiving “touch” in different social contexts (eg, acupressure). The emphasis on social interaction in symbolic interactionism is particularly important for the role of the caregiver, as the shared interactions between a caregiver and a child continue to shape each other’s sense of self and the meaning of situations. This methodology also assumes the active role of the researcher in the meaning-making process of data collection and analysis.³¹

Context

This qualitative exploration was nested within the Acupressure for Children in Treatment for Childhood Cancer Trial (ACT-CC)—a pragmatic randomized control trial investigating the benefits and risks of provider- and caregiver-delivered acupressure for children (ages 5–21 years) receiving hospital-based cancer treatment. Both provider- and caregiver-delivered acupressure were performed based on a semistandardized protocol. Acupressure points were chosen for targeted symptom management as well as improving general well-being and mood.

We completed collection of qualitative data by June 1, 2019; at this time, 41 child–caregiver dyads had been enrolled and randomized to the intervention arm and 43 to the control arm in the ACT-CC trial, but enrollment was ongoing. For children in the intervention arm, professionally delivered acupressure was offered on each

weekday of a child's hospitalization (which includes curative and supportive care treatment). For more details on the ACT-CC trial methods, see Lown et al.³³

The caregiver (typically the mother) of the child in the intervention arm was trained by an acupressure provider in how to deliver acupressure to the child for 2 purposes: (1) to increase dose and timeliness of acupressure for symptom management for the child and (2) to improve caregiver psychosocial outcomes such as well-being and self-efficacy by giving them additional tools for participating in the symptom management process. The caregivers from the control arm received acupressure training at the end of the child's study participation.

Participant Sampling and Setting

Qualitative data were collected through semistructured interviews with purposive sample of professional acupressure providers (n=3) and primary caregivers (n=13) who participated in the ACT-CC trial. Children were not interviewed to reduce research participant burden. Ideal interview candidates for this qualitative study were identified and recommended by the ACT-CC trial staff (RT+DS), such as those demonstrating engagement in the acupressure intervention and the discussion of well-being. Caregivers who seemed to have minimal interest in the acupressure intervention or training or appeared visibly distressed or disengaged during the ACT-CC parent trial were not asked to participate. Only 2 caregivers declined to participate in the interview, both due to being overwhelmed with their current circumstances.

Caregivers from the control arm of ACT-CC were also interviewed in addition to those who were assigned to the acupressure intervention arm. Rationale for including control arm caregivers were to (1) explore whether the caregiver acupressure training that happened after ACT-CC study enrollment had any impact to the topic of our inquiry and (2) explore other avenues in which well-being was experienced during cancer treatment without the regular acupressure intervention.

In the case of caregivers from the intervention arm, most interviews occurred near the end of ACT-CC study enrollment; in the control arm, interviews occurred after the caregiver received the acupressure training. Interviews with the main caregiver from either study arm of ACT-CC typically took place in the child's hospital room. The inpatient rooms in Hematology-Oncology unit and Bone Marrow Transplant units are equipped with ample furniture for caregivers and visitors to "camp out" and stay with the child. Although a university-sponsored hotel was nearby, caregivers chose to spend most of their days and nights in the hospital room and were actively involved in the medical and nursing care of the child.

Data Collection and Analysis

Data were collected using a semistructured interview with caregivers that lasted 15 to 50 minutes. The interviewer (HH+DS) used prompts, reflection, and open-ended questions to explore a range of topics: (1) acupressure intervention experience, (2) acupressure training and caregiver-delivered acupressure experience, (3) experience of well-being related to acupressure, (4) overall experience of well-being (unrelated to acupressure), and (5) caregiver perception of the role of touch in their relationship with the child. Semistructured interviews with acupressure providers lasted 60 to 90 minutes, consisting of similar questions to those asked in caregiver interviews. One additional follow-up interview (90 min) was conducted with one provider.

Interviews were recorded, transcribed verbatim, proofread (RT), coded, and analyzed for themes (HH) using DeDoose software. Semistructured interviews were complemented by 8 hours of participant observation (HH+DS+RT) during provider-delivered acupressure intervention and caregiver training in the inpatient setting over 2 to 3 weeks prior to the caregiver interviews. Ethnographic fieldnotes were collected (HH). Consistent with Grounded Theory approach,³¹ data collection and analysis were done simultaneously and iteratively. Emerging concepts from interviews and participant observations informed subsequent interviews. HH refined the list of codes through ongoing memowriting and discussion of emerging themes in the data with coauthors.

Results

All caregivers we interviewed were women, although 2 of the 13 caregivers were not mothers of the child receiving treatment (Table 1). Nearly two-thirds were interviewed during the acupressure intervention period (Table 1).

Analysis of provider interviews, caregiver interviews, and participation observation yielded 3 prominent themes: (1) well-being elicited by acupressure, (2) well-being elicited by touch, and (3) well-being experienced as relational and intersubjective. These themes, taken together, illustrate the intricate ways in which a touch-based intervention like acupressure can help alleviate the difficulties of childhood cancer illness experience by promoting well-being to the child as well as caregiver. Each theme and corresponding subthemes and illustrating quotes are provided below. Quotes are identified as follows:

C = Caregiver of child with pediatric cancer

A = Acupressure provider

I = Interviewer

Table 1. Interview Participant Characteristics.

Interview Participant Demographics		N = 13	% (N)
Study arm	Intervention arm		76.9 (10)
	Control arm		23.1 (3) ^a
Caregiver gender	Female		100 (13)
Caregiver relationship with child	Mother		84.6 (11)
	Not mother		15.4 (2)
Caregiver ethnicity	Non-Hispanic		84.6 (11)
Caregiver race	American Indian or Alaska Native		15.4 (2)
	Asian		7.7 (1)
	Black or African American		7.7 (1)
	White		53.8 (7)
	Other		15.4 (2)
Child gender	Female		38.5 (5)
Child diagnosis	Blood disorder		61.5 (8)
	Solid tumor		38.5 (5)
Interview occurrence in relation to ACT-CC trial	During study intervention period		61.5 (8)
	Within 1 month after study completion		23.1 (3)
	More than 1 month after study completion		15.4 (2)

Abbreviation: ACT-CC, Acupressure for Children in Treatment for a Childhood Cancer.

^aOne child participant from the control arm was already receiving regular caregiver-delivered acupressure prior to ACT-CC study enrollment. The caregiver learned acupressure on her own but never received professional training.

Well-being Elicited by Acupressure

Data collection from all angles explored how well-being was experienced during and after acupressure intervention.

Well-being as body-centered experience. The providers commented that a sense of well-being, experienced through acupressure, is largely somatic, such as “feeling comfortable [and present] in their body . . . [with] lack of pain . . . grief, sadness, depression” (A-3). Another provider commented that well-being experienced in the pediatric population is “not an intellectual concept that I explain with kids . . . it’s more of a visceral experience” (A-1). Providers generally perceived such experiences of somatic or visceral well-being as not necessarily consciously recognized or vocalized by the patient but nonetheless a significant part of their clinical observations during the acupressure intervention.

Based on their knowledge about the autonomic nervous system and training in theories of TCM, acupressure providers believed that well-being experienced through acupressure in this patient context may be due to “spreading health” (A-1) by restoring a proper “flow” of qi (conceptualized as vital energy or vital life force in TCM) through targeted acupressure point stimulation.

Body relaxation and symptom relief. The physical or somatic experience of well-being from acupressure was commonly described by both providers and caregivers as the process of the body unwinding and relaxing. The relaxation

and relief were described as both intrinsic outcomes of acupressure and an outcome secondary to symptom relief.

Relaxation as a primary outcome was described in terms of nonverbalized body language, postures, and demeanors that acupressure providers are trained to observe carefully. One provider, for example, emphasized the importance of monitoring the patient’s breath throughout the treatment as feedback on the patient’s relaxation:

A-1: I tend to focus on is the breath. I’ve learned to listen for that sigh [breathes deeply]. When they settle into bed a little more comfortably, their body unwinds a little more, I look for that.

Another provider noted seeing frequent yawning and signs of being “ready for a nap” following acupressure (A-2). Providers further reported that acupressure very frequently led to improved sleep. Falling asleep was one of the most obvious relaxation responses that caregivers could easily observe. Caregivers similarly frequently noticed that acupressure was able to allow their child to “just fall asleep” (C-4).

Difficulty sleeping due to treatment-related symptoms, on the other hand, was common in the childhood cancer illness experience. One caregiver reported that by delivering acupressure and relieving the child’s symptoms, the child was finally able to sleep:

C-11: Yes [acupressure helped] and she was able to sleep. She didn’t sleep that whole night because she had such

heartburn and then when I got up and started rubbing her, it took about an hour to finally relieve it. I rubbed her for about 15 minutes on her feet to hopefully get it [heartburn] out.

In addition to observing improved sleep, caregivers also described the child's response to acupressure in terms of more subtle physical cues. One caregiver described that even when her child was sleeping, her child was showing signs of tension and discomfort, which slowly disappeared throughout acupressure treatment:

C-10: He would sleep with his eyebrows furrowed and she [the provider] would start [acupressure] and you could just see that [the furrowing of the eyebrows] go away...his forehead was crushed [while sleeping]... and it would just relax [after acupressure].

Participant observation also aided in understanding these reported outcomes. Following the acupressure intervention, children verbally described improvement in symptoms (eg, pain or nausea) or showed (nonverbal) signs of physical relaxation. These varied from breathing slower, putting their phone down, yawning and stretching, and dozing off to sleep.

Meaningful relief. Providers additionally described that the physical and somatic experience of relief and relaxation resulting from acupressure may have been meaningful to the child. They speculated that moments of "feeling good" are appreciated more when experienced in direct and proximal contrast to the absence of well-being, such as when they are experiencing treatment-related symptoms and the intensity of the illness experience.

A-3: I guess well-being can be subjective as well...if yesterday you had pain all over your body and you were vomiting all day. And today you've got a headache, you might consider that well-being because where you were yesterday to where you were today you feel more comfortable in your body than you did the day before...well-being is subjective but subjective on a day-to-day basis.

A-1: With all the intensity that these kids go through, especially with the bone marrow transplant kids...to have an opportunity like this to...to feel good and to receive therapeutic touch. I think it can really change the course of how they look back on it.

Increased interpersonal engagement. Another commonly observed outcome following acupressure by the acupressure provider was increased interpersonal engagement,

such as becoming "more talkative once treatment begins...laugh a little more, smile more. (A-3)" or "more present, more playful" (A-2).

When describing the illness experience, caregivers reported that they were typically able to tell that the child was uncomfortable from the lack of social reciprocity:

C-9: When he is in pain. His face is like really furious. He doesn't smile. But when he feels good, he talks... and he hugs me and kiss me you know. But when he's in pain, like, he doesn't talk to me.

Caregivers also reported that they observed noticeable changes in their child's ability to engage in interpersonal interactions after acupressure, such as talking, displays of affection, socialization, or even verbalization of their comfort states instead of internalizing.

C-2: I can see that, in her body language, I can tell that it's [acupressure is] working... She just like... more like, talkative with [provider]. You know when someone's not feeling well? They don't really reciprocate when you're talking.

This caregiver, for example, reported being able to observe her child's response from acupressure by watching the child become more talkative to the acupressure provider. The quality of the provider-child relationship was reported by several other caregivers as being inherently therapeutic. One caregiver, for example, mentioned that there was "special chemistry" (C-4) between the child and one of the providers.

C-1: She started opening her mouth [after acupressure] because before it was, "I don't feel good. Leave me alone." And now...she wants to talk more...more relaxed and it's like it's help turning her back into her old self... funny, cheerful, [having a] positive outlook.

This caregiver also observed that the symptom management and relaxation allowed the child to be her authentic cheerful self as a result of acupressure, even reporting significant improvement in the child-caregiver relationship as well.

Well-being Elicited by Touch

The accounts of increased interpersonal engagement with the child through acupressure were also meaningful to the providers. One provider described: "Because there was the aspect of touch involved... and constant contact with the patient over 20 minutes... [and] the [pediatric] age of the patients allows a little bit more connection between patient and provider" (A-3). All providers

reported that their own experience in this trial as immensely rewarding and joyful. All attributed this extra layer of meaningful interaction to using “therapeutic touch” as a vehicle for connecting with the patients and family members.

Providers described their perception of the elements of therapeutic touch: training and knowledge of specific targets (eg, of acupuncture stimulation points), healing intention, and being present. Providers also reported other outcomes of therapeutic touch, including increased body and spatial awareness in the child and rapport with the child. In this specific intervention, therapeutic touch involved light pressure on acupressure points, for both provider and caregiver-delivered acupressure. Providers noted similarities and differences between acupressure and other forms of therapeutic touch.

A-2: I think therapeutic touch is a wider net. Any type of touching is therapeutic. Even to the point of just combing their hair . . . Any therapeutic touch engages the qi. But with acupressure, we’re using the theory of Traditional Chinese Medicine and of the channels to create a desired result. It’s more focused.

The providers would often start the intervention by gently rubbing the surrounding tissues before moving to the acupressure points. Similarly, when they taught the techniques to the caregivers, they often provided instructions, saying “I like to gently rub or massage the skin before and after pressing on the points.”

Acupressure providers emphasized the importance of obtaining permission from the child before every treatment, giving them the power to say “no” and hence a sense of agency and control. This step ensured that acupressure treatment, or more generally, being “touched,” was a voluntary decision made by the child each time. A few caregivers, in fact, appreciated the gentle and non-invasive nature of acupressure in contrast with the often painful and invasive biomedical procedures that their children must receive for curative treatment.

Touch by caregiver. Not all caregivers reported providing caregiver-delivered acupressure due to a variety of reasons including (but not limited to) their own fatigue, pain in their hands, lack of time, or “forgetting about it”; several caregivers reported providing acupressure for the child only a few times or not at all. Most caregivers, however, described how various modes of physical touch were used to show affection and offer comfort to the child. Nonacupressure touch between the caregiver and child often occurred before the acupressure training and ranged from nonspecific touch, like hugging and holding hands, to therapeutic touch such as rubbing and massaging.

C-10 [Before learning acupressure points] I would hug him and rub his back and rub his head—whatever makes him feel better.

This caregiver provided touch with the specific intention of making the child feel comfortable and calm.

Some caregivers were concerned about the medical vulnerability of their child, which sometimes affected how they engaged in affectionate touch. A few caregivers reported being worried about spreading germs or hurting the child and therefore stopped kissing the child on the lips (C-8) or only hugged and touched the child at the lower extremities (C-12) (instead of the upper extremities and torso which were perceived as being more vulnerable). In these ways, “touch” between a child and caregiver during childhood cancer tended to be variable and subject to adjustment during illness and treatment.

Acupressure reinstating touch. In general, caregiver-delivered acupressure was described as providing comfort, safety, connection, and empathy. When comparing different modes of touch, some caregivers reported that touch in acupressure felt very similar to nonacupressure touch, while some reported that it felt different and it offered a new way to provide touch to their child. In either case, providers reported that acupressure “has been an invitation to reinstate touch between child and parent” (A-1). In some instances, acupressure was an additional tool for offering comfort. For example, one caregiver reported nonspecifically rubbing or massaging the child’s legs before learning acupressure.

C-11: [Before learning acupressure] I would try to rub her legs but it was more of like a . . . just like a squeezing on her legs when they were hurt or just on her feet but I wouldn’t do it for long time, now that I’ve learned how to rub her [through acupressure], I do it now more often.

This caregiver was able to build on her baseline level of touch and begin to offer the child a more sustained and targeted way of “rubbing the legs” by combining general therapeutic touch with point stimulation. As a result of “knowing how to” through acupressure training, she reported being able to provide therapeutic touch more frequently and for longer periods. In other instances, particularly involving older children and adolescents, acupressure became a more culturally and socially acceptable form of touch when there was little to no touch occurring at baseline.

Well-being as Relational and Intersubjective Experience

The discussion of how well-being is experienced through acupressure and touch led to more general discussion of

what well-being means. Interestingly, in these discussions, well-being was almost always discussed from the viewpoint of caregiver–child dyad instead of caregiver or child as individuals. For one, regardless of the mode of touch (eg, the targeted approach of acupressure versus more nonspecific affectionate touch), the interviewed caregivers were constantly looking for means and tools to offer comfort to the child.

In taking care of the child, caregivers described the need to stay “healthy” themselves. When asked “what does well-being mean to you,” caregivers typically described their own experience of well-being in terms of various dimensions of health: overall health, physical health, emotional and mental health, social health, and spiritual health. Some caregivers also stressed the inter-related nature of their physical health and mental health. When describing their baseline efforts to maintain well-being, however, caregivers almost always described their experience of well-being as tied together with the child’s experience of well-being and vice versa.

C-8: If she’s [the child] not feeling good, or confident, or secure, or happy, then I’m not either. I think that’s just a mom’s role and intuition.

C-2: Her [child’s] well-being means everything to me... I sacrifice my well-being for her well-being, just to see her very comfortable and smiling.

Well-being in the context of childhood cancer, therefore, was very often described as an intersubjective experience; rather than being bifurcated as “child well-being” or “caregiver well-being,” the experience of well-being in this patient context was closely intertwined and constantly being cocreated between the child and caregiver. This relational or intersubjective experience of well-being was reported and observed in both acupressure-related and acupressure-unrelated contexts.

Staying strong for 2. Outside of the practice of acupressure, many caregivers reported that they placed greater value on the child’s well-being than their own. Related to the need for caregivers to stay healthy themselves, caregivers also described their perceived need to “stay strong” for the child—being able to mentally and emotionally cope. One caregiver was consciously aware that her child’s well-being was “mirroring off” (C-5) her own, making it imperative for her to “be okay” (C-5) for the 2 of them. Several caregivers also experienced having to hold back tears in front of their child because they felt that it would negatively affect the child:

C-11: I think if she were to see us crying all the time, things like that, she wouldn’t be so happy, she’d feel

sad... But if I’m healthy and happy, I feel like she will be happy.

Other caregivers also stated that they had to remain strong to focus on their caregiving responsibilities and solve the problems that were being presented to them. These caregivers also reported feeling more “in charge” by being actively involved in the child’s medical and nursing care.

C-2: In the beginning, I was crying all the time, just ‘cause I was, like, helpless. I didn’t know what else, you know, to do that I can help her... but I just knew that if I get weak, if I give up and just be all depressed and blame everybody for the situation, it wouldn’t help [child]. So I just knew that I had to remain strong.

In other cases, the role was reversed where the child’s resilience served as an anchor to the caregiver’s well-being.

C-12: I just feel that he [child] tries to be strong you know... there’s times when I do go in there and lay on him and I cry. And he’d say “don’t cry mom.”... He’s a tough man.

C-7: Just seeing [child] so happy through it all in spite of everything, he’s just always smiling, so I think that really is encouraging to me too, when he’s doing well.

Coping together. The need to stay strong and healthy for the child required the caregivers to be proactive and disciplined in their efforts to cope. The most frequently described way of coping involved faith and prayer. Often these spiritual and religious practices were shared among the caregiver–child dyad or the entire family unit. In addition, many caregivers stressed the importance of keeping positive thoughts. These 2 coping strategies were not only vital to the caregiver’s own well-being but were also being actively taught to the child. For example, one caregiver described that she used a combination of faith/prayer, positive thinking, and finding benefit/meaning in adverse events to encourage her child:

C-5: I believe in faith, so if you believe that He’s listening and He’s there, your body is your own church, you don’t need to go to church to pray. You build that relationship and you have that spiritual connection, and that means more than anything. So, trying to deliberately get him [her child] to understand that was kind of hard, but once he [her child] started feeling the spiritual connection and building his relationship with Christ, then it was easier for him to stay positive and understand the

things I tried to get into his head. Like, [I would tell him,] “you’ve got to stay positive, the sickness is in your body, it’s not in your spirit, you got to keep your spirit, you got to pray. I don’t know why he’s putting us through this but we’re going to know later. But right now we don’t know why and we just have to go through it and be strong and stay positive.”

Social support. The pivotal importance of social support from other family members, friends, and even health-care professionals, such as nurses and physicians, were echoed as a key element of caregiver and child well-being.

C-8: You have to kinda heal, to get through something like this, you have to heal your whole body, mind, spirit, ailments, everything that’s going on. I think that especially some of the nurses are just incredible, showing empathy, and kindness and care. And it just makes you feel like, “Okay, they’re here for me. I think I can do this.” And friends that come to visit, it just changes your mood.

This caregiver described healing as an ongoing process that is supported by the people who are there to provide care for the children as well as social support networks from outside of the hospital. Some caregivers also spoke about being a source of support to others by extending kindness and compassion.

C-10: [Well-being means] Love and happiness (crying). It’s, you know, we teach them [their children] all the time it’s compassion and gratitude.

Other participants who brought supplies for their own creative activities were also seen giving away their art work as presents to their health-care providers and other children. The importance of extending kindness and joy to their surrounding community highlighted the bidirectional nature of social support in maintaining well-being in the hospital.

Contagious relief from acupressure. The relational and social nature of the experience of well-being also translated into how well-being from acupressure was experienced in the hospital room. The experience of well-being from acupressure was occasionally reported as “contagious.” The providers described this phenomenon of contagious relief—even the caregiver, who was not directly receiving the intervention, vicariously relaxed through watching the child relax. One provider attributed this phenomenon to the caregivers “taking cues off the child, and how they are doing, and the child is also taking cues off the parents and if the parents are stressed out” (A-1).

With or without acupressure, many caregivers reported being highly attuned to the body language of the child. When the child was feeling stress or pain, the caregiver also experienced stress. When the child was able to relax from acupressure, the caregiver could immediately tell from the child’s body language and demeanor that the child was feeling better.

A few caregivers also indirectly described the phenomenon of palpable physical connection with the child when the caregiver delivered acupressure, resulting in an intersubjective experience of relief and relaxation.

C-1: [What] I notice [during acupressure] it’s like a load’s lifted off her shoulders. She kind of just relaxes and goes, “Ahh...[breathes deeply]”... You can feel the stress and the tension leaving her body... And it relaxes me too, so we both go to sleep pretty good.

C-2: When I’m giving [child] the acupressure, and I see that it’s working, and she’s calm... like yesterday, she was starting to feel nauseous right after chemo, and she called for me to sit next to her, and she put her hand out like this. So then I started [acupressure] just slowly... and her anxiety just kinda went away, so that made me feel at ease. So whenever [child]’s not feeling nauseous or not feeling bad, it makes me feel more at peace. I’m also relaxed, so I think it does help both of us.

The synchronicity of the body language in the child and caregiver was noted several times during participant observation. The most notable example was when an adolescent received professional acupressure for the very first time. Due to a tumor in her low back, she complained about the constant pain and kept on moving restlessly in her bed, changing from one position to another. Her mother was at bedside, sitting quietly but fidgeting her hands and fingers. Within the first 5 minutes of acupressure, the young woman began to breath slower and laid still in a supine position. As the demeanor in the young woman changed from restless and uncomfortable to still and relaxed, her mother stopped fidgeting her hands and began to sit still with her eyes closed as if she was meditating.

Discussion

The present study was undertaken to explore the experience of well-being in the child-caregiver dyad and how that well-being interacted with the acupressure intervention.

Caregiver Well-being and Coping

Recent work in pediatric psycho-oncology demonstrates that post-traumatic growth, marked by adaptive coping

and resilience, can take place in the survivors^{34–36} as well as their parents/caregivers.^{7,11} Consistent with this, our interview participants reported being able to cope using a variety of strategies, regardless of whether they were providing acupressure. Many of these strategies could be classified as either problem-focused coping (solving the problems presented to oneself), which is associated with higher levels of positive feelings,³⁷ or meaning-focused coping (looking at difficult situations from a wider perspective to find benefits and blessings), which is associated with lower levels of depression.³⁸

Considering the importance of coping abilities in the caregiver, providing a touch-based modality for symptom management may offer an additional tool to manage their child's symptoms and thus provide more resources for coping. In our study, not all caregivers delivered acupressure after being trained. Caregivers who frequently delivered acupressure reported feeling more helpful or resourceful in the care that they could offer to their children. The act of caregiving for cancer patients is often burdensome and taxing but can also come with positive outcomes such as a sense of purpose.¹⁰ Similar to previous studies, family training in a touch-based modality that potentially improves symptoms may offer a sense of self-efficacy and caregiving confidence,^{28,29} leading to improved caregiver well-being.

Acupressure and Well-being

Acupressure and therapeutic touch consistently elicited pleasurable sensations in the children. Several possible explanations are presented. The general somatic experience of well-being, beyond specific symptom relief, could be due to the effects related to stimulation of acupuncture points creating a feeling of balance in the body and the promotion of parasympathetic nervous system states³⁹ (sometimes known as the “rest and digest” state). Acupressure providers and caregivers both described frequently witnessing signs suggestive of parasympathetic activation after acupressure such as yawning, muscular relaxation, sleeping, and slower breath. Other possibilities are nonspecific therapeutic effects, such as general benefits from touch, which is known to have intrinsic benefits via numerous sham studies.⁴⁰

Qualitative accounts of acupressure and well-being experience led to rich discussions of touch in acupressure as well as other physical contact as a therapeutic component, beyond symptom relief and activation of acupuncture stimulation points. Even without adherence to caregiver-delivered acupressure, however, most interviewed caregivers regularly provided some type of affective or therapeutic touch. The present study suggested that training caregivers in acupressure during childhood cancer can capitalize on the caregivers' natural effort to

use touch to heal by offering tools for effective symptom relief.

Well-being, Touch, and Body Ownership

The positive effects of acupressure from the present study are consistent with a previous study on massage and acupressure among children undergoing Hematopoietic Stem Cell Transplant, where parents reported that children felt peacefulness, pleasure, relief, and being in touch with their bodies instead of dissociating due to painful and invasive medical procedures.²⁹ The pleasure associated with therapeutic touch perhaps contributed to increased body awareness or body ownership. Concepts in mind–body medicine and contemplative science suggest that a sense of mind–body integration and physical relaxation extending beyond the affective and cognitive experience is an integral part of subjective well-being.⁴¹ Having a sense of body ownership (ie, a sense that “this body belongs to me”) through increasing “moments of feeling good in the body” may be important during cancer treatment, considering the amount of physically and psychologically traumatizing experiences associated with curative treatment that often causes children to dissociate from their own body.

The literature on touch and body ownership suggest that caregiver touch is crucial to the development of the child's embodied selfhood and health. Early developmental and social antecedents of interoceptive awareness (ie, awareness of internal physiological states), including child–caregiver emotional relationship, are implicated in the trajectory of the individual's physiological homeostatic abilities.⁴² In fact, studies on a preterm infant massage intervention show remarkable differences in health outcomes.⁴³ The development of interoceptive awareness through affective touch marks the first milestone of self-formation by embodied interactions with other people, where the infant realizes the self-other boundary and the physical confines of its own embodiment.⁴⁴ This process is likely to remain important throughout the child's development, and it is therefore important to study the role of touch in pediatric illness.

Acupressure Facilitates Relational and Intersubjective Experience of Well-being

Touch, an important piece of acupressure delivery, is inherently an embodied form of social interaction. The social and interactive nature of this intervention led to one of the most prominent themes from this investigation: well-being could be reconceptualized as a relational or intersubjective experience between 2 or more individuals in the context of childhood cancer.

The hospital room setting and the nature of acupressure delivery and training were also beneficial for promoting the relational or intersubjective experience of well-being. It was common for caregivers and family members in the intervention arm to stay in the room during the treatment, which was occasionally followed by caregiver training. Providers often invited the caregiver by statements such as, “let me show you what I just did; if it’s okay with [child], we can do it together [one] on each side of the leg.” Providers also frequently used the collective “we” pronoun during training (eg, “we’ll find these points together”). Thus, the acupressure intervention and training may further improve the preexisting relational well-being, which is constantly being cocreated by the child, caregiver, and other family members and health-care providers in this patient setting.

It was also observed that providing acupressure to the child vicariously relaxed the caregiver (and other family members in the room). Such contagion of relief and relaxation may be subtle and mostly subconscious but was nonetheless reported by several caregivers as well as observed. The “shared manifold hypothesis” posits that this intersubjective enactment of embodied states of stress or relaxation is facilitated by mirror neurons and serves as the phenomenological and neurobiological basis of empathy.^{45,46} Our findings present preliminary qualitative evidence in a relationship that is presumably empathic by nature. It is interesting, for example, that one participant (C-5) who consciously acknowledged that her child’s well-being “mirrors off” her own, happened to become very engaged, and adept at providing acupressure to her child. Future studies on touch-based intervention to patients can explore the interactions between caregiver and patient synchronicity during the clinical intervention. If the touch-based modality is taught to caregivers, the quality of the caregiver–patient relationship could be explored as a potential mediator of outcome and adherence.

Study Strengths and Limitations

A strength of the study was the inclusion of both caregiver interviews and interviews with acupressure providers and participant observation of the intervention. These 2 data collection methods strengthened the quality of interpretation by data triangulation. Considering the role of reflexivity in constructivist grounded theory approach,³¹ another methodological strength is that data collection and analysis were done by HH, who is clinically trained in another mode of touch-based healing modality. This led to a refined understanding of the studied phenomena, which was balanced by input from other coauthors via discussion of emerging codes and concepts. The findings and interpretations from this qualitative exploration need to be considered with

several limitations. Due to purposive sampling, the interview sample was composed of 13 caregivers who showed at least a basic level of interest in acupressure care and training and could afford the time to participate in the interview. Because caregivers knew we were investigating the experience of well-being, those with interest in the subject may have been differentially interested in being involved in the present study and thus underrepresent caregivers less engaged in the subject. Future research should also incorporate child interviews to investigate the subjective experience in addition to caregiver perspectives.

Conclusion

Studies of parental adjustment during a child’s cancer treatment have rarely provided information on how parents can be more actively engaged in symptom management using integrative medicine, such as acupressure with one exception.²¹ We found that caregivers generally appreciated the opportunity to be engaged in the medical and nursing care of the child, including learning non-pharmacological tools for symptom management and improving overall health. These findings point to promising new strategies to engage caregivers in symptom management and at the same time provide an experience of well-being.

Qualitative data collected from 3 perspectives provided distinct and overlapping insights about how well-being can be experienced by the child–caregiver dyad through provider- and caregiver-delivered acupressure. Well-being was often described as a relational and intersubjective experience between the child and caregiver. Even when the caregiver was not actively engaging in acupressure, the child’s symptom relief from provider-delivered acupressure also promoted caregiver well-being through contagious relief. Drawing on this, acupressure in this patient setting is likely a relational intervention that facilitates moments of “feeling good” for everyone involved.

Our findings lead to several possibilities for future investigations. Studies on nonpharmacological interventions geared toward the patient should examine the concept of relational well-being and measure well-being outcomes in the caregiver as well as the patient. It may also be fruitful to study the emotional and relational aspects of touch in therapeutic interventions geared toward pain and symptom management in medically ill young patients. Finally, the use of qualitative methodology that draws from symbolic interactionism and phenomenology was essential in studying embodied, touch-based, and inherently social intervention like acupressure. In the aforementioned areas of potential exploration, the importance and efficacy of qualitative research method cannot be understated.

Authors' Contributions

HH (first author) and EAL (senior author) contributed to study goals, methodology, and manuscript drafting. Data collection was carried out by HH and DS. Participant observation and interview consents were done by HH, DS, and RT. Interview transcripts were proofread by RT and HH. Data analysis was done by HH under the mentorship of ATL and HP, who both contributed to discussion of codes, categories, and themes, as well as analysis plan. All authors reviewed the manuscript.

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ORCID iD

Hiroe Hu  <https://orcid.org/0000-0003-1587-2736>

E Anne Lown  <https://orcid.org/0000-0002-7502-4459>

Trial Registration

The parent trial from which the data were drawn, ACT-CC, was registered in ClinicalTrials.gov ID: NCT03313193, NCI Trial ID: NCI-2017-02409, Lead Organization Trial ID: 170820 (first posted October 18, 2017 and revised on April 17, 2019).

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