

Designing a reclamation of body and health: cancer survivor tattoos as coping ritual

Jordan Eschler^{1,2}, Arpita Bhattacharya², Wanda Pratt²

¹Northwestern University
Evanston, IL, USA
jordan.eschler@northwestern.edu

²University of Washington
Seattle, WA, USA
{arpitab,wpratt}@uw.edu

ABSTRACT

Historically, tattoos have been perceived as a mark of deviant behavior from the perspective of Western medicine. However, cancer survivor tattoos are one of many strategies used to recover from the trauma of cancer diagnosis and treatment. In this study, we seek to understand the significance of these tattoos in the context of survivorship. We interviewed 19 cancer survivors about their survivor tattoos, exploring the benefits of designing, discussing, and displaying these tattoos as elements of emotional recovery post-cancer. We found that the act of designing a survivor tattoo facilitated all three elements of *post-traumatic growth* processes, including: (1) changed self-perception; (2) changed sense of relationships with others; and (3) changed philosophy of life. Through participants' lived experiences, we discuss information about emotions, health, and recovery encoded in tattoos, and provide implications for tools to help future cancer survivors recover from the trauma of diagnosis and treatment.

Author Keywords

Personal health informatics; cancer survivorship; qualitative research; illness narrative; tattoos

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

Pain, like the tattoo itself, is something that cannot be appropriated; it is yours alone; it stands outside the signification and exchange that threatens the autonomy of the self. ([8], p. 251)

Fourteen million cancer survivors live in the United States as of 2014 [36]. Each of these current survivors has endured a

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from Permissions@acm.org. *CHI 2018*, April 21–26, 2018, Montreal, QC, Canada
© 2018 Copyright is held by the owner/author(s). Publication rights licensed to ACM.

ACM 978-1-4503-5620-6/18/04...\$15.00
<https://doi.org/10.1145/3173574.3174084>

course of treatment, and had to cope with the negative social, financial, and health impacts of cancer [57]. Cancer is considered in the psychology field as a type of trauma [49], with lasting effects causing particular harm to the emotional and physical well-being of children and adolescents diagnosed with cancer [45].

The cancer survivor tattoo is a uniquely visible strategy for coping with the trauma of cancer. For planning their tattoos, survivors seek out ideas from each other as well as non-profit support sites or online groups (e.g., [48]). Survivors are often seeking to get a tattoo to achieve one or more goals, such as to cover up scars from treatment [33] or to contain negative feelings about trauma [5]. As DeMello [15] wrote, "*The transformative power of the tattoo is especially useful for individuals experiencing crisis in their lives*" (p. 66).

In this study, we explored the phenomenon of survivor tattoos by interviewing 19 individuals whose tattoos represent their experiences with cancer. Although tattoos are not generally regarded as health information, Oksanen & Turtiainen [38] argued that the "drama" of tattoos accurately mimic the changes in the emotions, body, and social life of the survivor. Our findings support reframing of these tattoos as health information relevant to the well-being of the survivor and a possible "conduit" to better expressing feelings about survivorship.

The contributions of this paper are threefold. First, we reframe survivor tattoos as encoded health information, specifically relevant to survivors' experiences of post-traumatic growth and coping after cancer treatment. Second, we provide empirical evidence that the work of designing, discussing, and displaying a cancer survivor tattoo is itself a valuable coping mechanism for survivors. Third, we observe that the act of getting the tattoo is often socially motivated, which is also supported by the growing "lexicon" of survivor tattoos in online support groups and social media platforms.

Given this evidence, we discuss implications for the design of tools to assist cancer survivors in (1) integrating tattoos into interactions with clinicians about coping post-cancer and (2) commemorating visual expression of recovering from the trauma of cancer diagnosis and treatment. Finally, we demonstrate that our research approach builds trust and exposes the innovative behaviors of participants. This type of approach could be leveraged by other HCI researchers to

engage with vulnerable populations by inquiring about their meaningful artifacts.

BACKGROUND: TATTOOS

In this section, we introduce the history of tattoos in Western culture (primarily in North America), and the relationship of tattoos to health care, including health care provider attitudes about body modification behaviors.

Tattoos in Western Culture

Tattooing is an ancient and global phenomenon, with the English word adapted from a Tahitian phrase [6]. Tattoos have historically been conflated with “deviance,” and much of the literature about tattooing behavior and other body modifications (e.g., piercing, implants, etc.) is published in journals with deviant behavior as their purview. Tattoo artists themselves were historically viewed as performing “dirty work,” but the work has since professionalized, with the advent of better technology and sanitation standards [1].

Throughout history, tattooing has fulfilled four social and symbolic functions [10]:

- (1) Ritual: primarily used to signify a rite of passage for young men;
- (2) Protective: using sacred marks to protect and hallow the body;
- (3) Identificatory: symbolizing membership in a social group or class; and
- (4) Decorative: adornment and enhancement for the body.

Different cultures throughout history have used tattoos for various combinations of these reasons. There has been a surge in interest in tattoos among middle- and upper-class individuals in the West. As of 2006, approximately one in four adults in the United States reported having a tattoo [28]. Despite a resurgence of interest in tattoos among middle- and upper-class individuals in the past 25 years [10], attitudes about visible tattoos in certain contexts, such as white-collar working environments, have not necessarily changed [14]. Women face particularly high stigma for having tattoos, with images of tattooed female bodies often displayed in traditionally “promiscuous” or “pin-up” poses [33].

DeMello [15] argues that “tattoo narratives”—or the stories of tattoo symbolism—have become much more significant, as a way to bridge the historic “low-class” projection of a tattoo with the values of the middle class. DeMello’s assertion about “tattoo narratives” aligns with subsequent research that found that the most prevalent motivation for tattoos are to celebrate an occasion or mark a catharsis [50, 56]. This assertion lends itself to the concept of a narrative in explaining the motivation and meaning of a tattoo.

Despite their popularity, individual attitudes about tattoos continue to differ based on individual characteristics such as socioeconomic class, occupation or profession, and cultural literacy of tattoo symbolisms [15]. A tattooed individual’s attitude also changes about tattoo artifacts over time (e.g., placement and symbolism; [30]).

Tattoos and health care

The act of tattooing can be a powerful statement, which is always deeply related to an individual’s relationship with, and attitudes about, their body. Atkinson [4] interviewed 40 Canadian women with tattoos and framed the decision to get a tattoo among North American women, as “*acts of personal reclamation [and] self-definition*” (p. 228). This point of view intersects with coping mechanisms of surviving cancer, which involves recovering from a “*biographical disruption*” through a “*complex re-negotiation of social identity*” ([51], p. 1; see also [21]).

However, health care professionals still harbor pre-conceived notions about patients with tattoos, continuing to associate tattoos with deviant behavior, poor mental health, and/or self-harm [3]. In past studies, tattoos have been previously linked with depression [41], high-risk behavior [42], and illegal activity [26] among young people. Dhossche et al. [17] suggested that young white individuals with tattoos were at greater risk of lethal suicidal behavior.

Even studies that are meant to cast a more positive or accepting light on patients’ tattoos continue to send mixed messages to health care providers. For example, although Millner and Eichold [34] urged nurses engaging with tattooed patients to respect their tattoos as part of the “whole person”, they also emphasized potential health risks of tattooing, such as blood-borne diseases. In September 2017, the American Academy of Pediatrics issued guidance to its members about talking to teens regarding the risks of infection and professional stigma related to tattoos [37]. Rarely, a study will refute the historical correlation between tattoos and “deviant behavior” (e.g., [35]), although these studies remain few and far between in the medical literature. We build on this historic dilemma to further understand the significance of validating and reframing tattoos as meaningful artifacts that potentially encode information about an individual’s emotional and physical health.

BACKGROUND: CANCER AND THE SOCIAL GAZE

Here, we introduce the experience of cancer and its relationship to the “social gaze.” By *social gaze*, we refer to the presence of the tattooed survivor out in the world, and the psychosocial impact of appearing sick (or sometimes perfectly healthy, with an “invisible illness”; e.g., [21]). For survivors, this experience proves to be an important consideration in the design and placement of survivor tattoos.

One of the most potent examples of trauma from the social gaze of the cancer experience is the disfigurement resulting from some mastectomy-related treatments of breast cancer [33]. Attitudes about the absence of the breast range from impact on femininity and motherhood [51] to use of language to describe an absent body part [31]. Ucock [52] framed diagnosis of cancer as one viewed to be “an aesthetic challenge” in an analysis of institutionalized images of women with breast cancer in the “Look Good, Feel Better” campaign supported by the American Cancer Society.

However, discourse about the social gaze among survivors—i.e. perceptions of onlookers about an individual’s body upon the illness-affected body—has been essential for reducing stigma around the cancer illness [40]. For example, Jo Spence and Martha Hall, both artists, produced visual representations of bodies impacted by breast cancer and presented their work as artifacts meant to face down stigma. In fact, one of Martha Hall’s limited-edition art books, explores the application of tattoos for administering radiation therapy [7].

In contrast to Hall’s work in hand-making representations of herself and other cancer survivors in her small-scale book-displays, cancer survivors are increasingly posting visual expressions of their experiences online (e.g., [44]). Cancer survivors routinely share images of their tattoos online; because tattoo culture is enacted online, its widespread visibility may contribute to changing attitudes about tattoos. Social sites that commonly return search results for “survivor tattoos” include Pinterest, personal blogs, and cancer survivor forums. Cancer survivor organizations occasionally post on their public pages asking their followers to share survivor tattoos (Figure 1).

This sharing “scales up” the visual gaze—particularly related to cancer survivor tattoos—now that survivors can share images of tattoos with thousands of people at once. Sharing on social media at once disembodies and re-embodies information about the cancer experience. This type of visual sharing is similar to that previously studied related to expressions of eating disorders [39], depression [2], and other mental illness [32] in online social spaces. These trends



Figure 1. Call for followers to share their tattoos on a public Facebook survivor support group page

point to a ‘language’ that is developing in subcultures online using visual information such as cancer tattoos (Figure 2). Further, the trends point to an important set of behaviors and a lexicon for HCI researchers to understand, as in prior examinations of the connection between computing and emotion [16, 53], and technology design in the context of the materiality of the human body [9, 24].

METHODS

Increasing online and offline visibility of cancer survivorship tattoos indicates a shift of perception and platforms for expression and sharing of an otherwise underrepresented and stigmatized form of coping. We seek to understand this phenomenon and its implications for health care and technology. In this study, we engaged in two phases to examine this phenomenon: (1) we conducted an online ethnography among individuals sharing survivor (and other) tattoos online, in online cancer support groups, as well as more general forums for tattoo enthusiasts and artists, and (2) we conducted one-on-one interviews with cancer survivors who had tattoos. All procedures described below were approved in advance of field work by the authors’ Human Subjects Division.

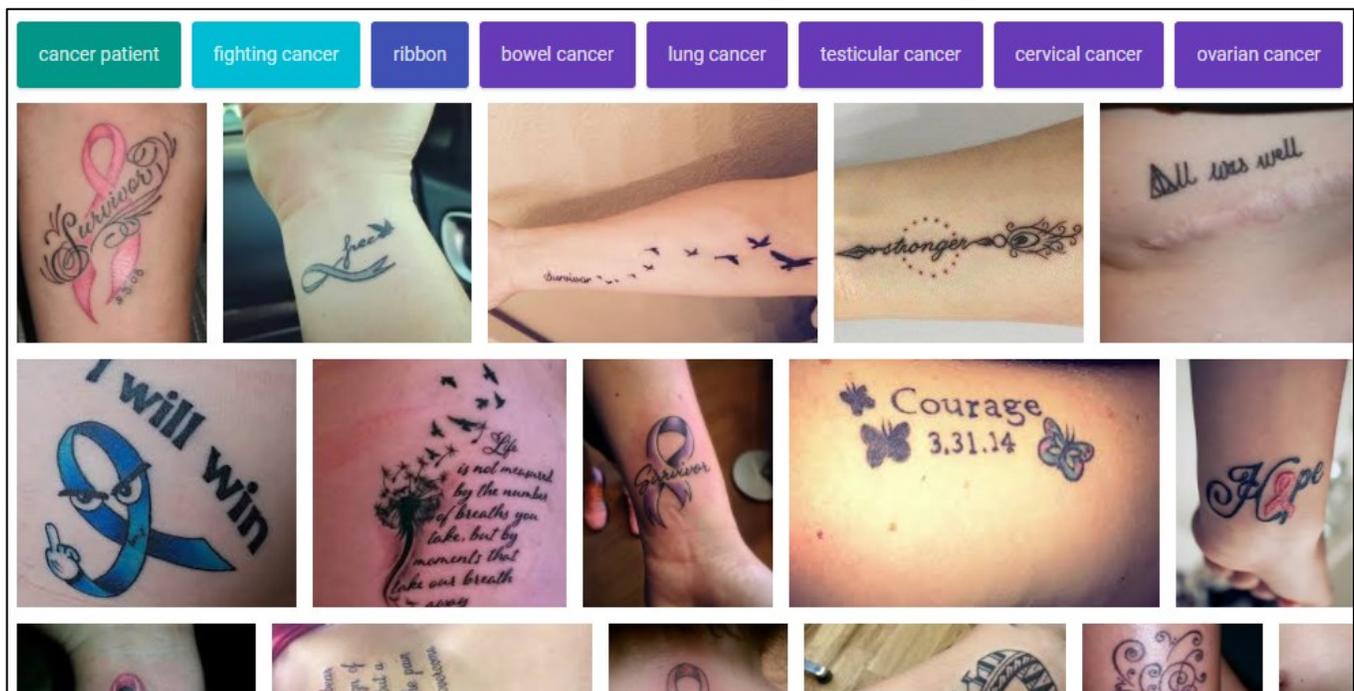


Figure 2. Example of an image search for "cancer survivor tattoo"; search executed in August 2017

Data collection

In preparation for writing the interview protocol and engaging with participants, the first author conducted ethnography related to these images and accompanying text from people who posted the tattoo (similar to the ethnography of nursing tattoo visual themes in [19]). This ethnography spanned online “cancer spaces,” such as support forums and Facebook groups for survivors in general, in diagnosis-specific discussion boards, as well as in tattoo forums. This ethnographic background work indicated survivor tattoos were a common enough phenomenon that interviewing a sample of survivors would be feasible for the study design.

The first author then invited people who were cancer survivors and had, or were actively designing, a survivor tattoo to participate in one-on-one interviews. We recruited people largely online, resulting in convenience sampling—mostly individuals who followed cancer survivor groups on Facebook, Twitter, and other social sites. We also recruited a small subset of individuals through snowball sampling of participants’ and researchers’ contacts. More than forty individuals signed up to participate in the study. We stopped interviewing from the recruitment pool when we reached theoretical saturation, and we made efforts to maximize variation among participants with regard to time since diagnosis, race, age, and survivor status (e.g., in remission, facing cancer recurrence, in maintenance).

Participants

All participants (n=19) picked their own aliases (see Table 1). The average age of participants was 37 years, with 13 female and 6 male participants. Two participants were African-American, one was Latinx, and all others indicated they were white or Caucasian. Ten participants (53%) had been diagnosed more than five years prior to the interview. Participants had a wide variety of cancer diagnoses: blood cancers such as non-Hodgkin’s lymphoma, breast cancer, testicular cancer, colon cancer, and pancreatic cancer. Two of the participants, who self-identified as survivors in recruitment, had lost a close family member to cancer (both had memorial tattoos), but never had cancer themselves. Two of the participants were cancer survivors, but were not yet medically cleared to get their tattoos; they were still able to discuss their process of researching and designing their tattoos, as well as motivations to get a tattoo.

Data analysis

The interviews were audio recorded and transcribed. Two of the authors worked on a subset of the 19 transcripts for an open coding period; after a week of transcribing three overlapping transcripts, the authors met to aggregate their codes. After testing the initial codebook, the two authors continued to meet over three weeks to iterate on the codes, refine definitions, and assign representative quotes to create a final guide for axial coding. Each author read at least half of the transcripts, wrote memos, and took notes while coding to track questions for resolution in meetings. The themes we report below are derived from this coding process.

Finally, we note here that none of the images included in this paper depict the tattoos of our research participants, as tattoos are quite literally uniquely identifying, and sharing them would breach anonymity and confidentiality. Instead, the images displayed were collected from public social media sites (no login required) and blog or news coverage of cancer-related tattoo phenomena.

Alias	Gender	Age (years)	Lapsed time since initial diagnosis	Tattoos besides survivor tattoo?
Robin	Female	28	1 year	N
Anne ²	Female	36	1 year	N
Gorgeous	Female	32	11 years	N
Veronica	Female	26	17 years	N
Bruce	Male	55	3 years	N
Scott	Male	37	31 years	N
Paul	Male	35	4 years	N
Luke	Male	31	1 year	Y
Rich	Male	35	14 years	Y
Susan	Female	42	2 years	Y
Marianne	Female	63	21 years	Y
Clare	Female	27	3 years	Y
Rocky	Male	38	3 years	Y
Adrian ²	Female	41	4 years	Y
Maya	Female	33	5 years	Y
Chipper	Female	31	6 years	Y
Audrey	Female	53	9 years	Y
Nicole ¹	Female	28	NA	Y
Suzanne ¹	Female	35	NA	Y

Table 1. Participants in one-on-one interviews.

¹ Participant’s tattoo was a memorial to a family member who had cancer. ² Participant had not yet gotten the tattoo, awaiting medical clearance.

FINDINGS

In analyzing the themes that emerged from coding, we sought evidence that survivor tattoos facilitated support with coping after the trauma of cancer and its treatment. *Post-traumatic growth* is best described as a positive legacy of trauma, meaning transformations that take place for the traumatized individual regarding self, social, and sense-making contexts of moving forward with life post-trauma.

The three elements of post-traumatic growth are: (1) changed sense of self; (2) changed sense of relationships with others;

and (3) changed philosophy of life [49]. We structure our findings about survivor tattoo experiences across these three elements: (1) changed sense of self; (2) changed sense of relationships with others; and (3) changed philosophy of life. Finally, we note that not all experiences related to tattooing were entirely positive. We explain “tattoo regret”—feelings of regret associated with the survivor tattoo—described by two participants.

Changed sense of self

The concept of *changed sense of self* entails transformations in post-trauma self-assessment of competence and assertiveness in dealing with emotional difficulties [49]. In the context of this study, we observed that two primary changes related to this element of post-traumatic growth were facilitated by survivor tattoos: first, a renewed sense of acceptance of body image; and second, reconciling self-identity with that of “cancer survivor.”

Acceptance of body image

Cancer treatment can result in disfigurement of body parts which are also outwardly visible and leave significant permanent scars, such as removal of breasts or organs, or scars due to intravenous lines (e.g., picc lines or ports). Psychosocial needs of individuals with illness- or treatment-related disfigurement are poorly met by health care professionals [43]. In cases where participants got tattoos to cover up physical disfigurement (e.g., large wounds from infection or cover-ups for mastectomy scars), getting the tattoo was perceived as an act of “reclaiming” their bodies from the prodding of medical professionals and the endless tasks associated with treatment.

In a specific case, Maya’s tattoo artist used the term “redirection” instead of “cover-up,” because her tattoo was meant to *redirect* an onlooker’s perception of her mastectomy scar from being undesirable to beautiful body art. Maya’s tattoo transformed her feelings about her body:

I look up [after the tattoo is finished] and I'm half naked, it seems that I'm beaming, and I'm so excited, and I for once in four or five years have finally looked in the mirror and not been punched in the face...I felt like I was on top of the world [after the tattoo], and my sister was just, "To have watched you," you know, "Being horrified by your own body and then to see you be just beyond proud..." We lived at the beach at the time, and it was a world of difference when it came to make it in a bathing suit and just again it was just really empowering, the chest piece that I ended up doing. (Maya)

In a previous study, Swami [47] found that getting a tattoo correlates with an increase in positive body image, although it is not known if this increase is long-lasting. In this sense, we found that the act of getting a tattoo could improve both self-esteem and self-image, conveying an empowered feeling to the survivor.

Similarly, Chipper explained that the process of getting her tattoo was a way to build comfort and acceptance and commemorating her transition into a “new normal”, making

peace with the changes to her life and body after her diagnosis and treatment:

I guess like a 'badge of honor' is kind of a good way of putting it, and also, I guess I do similar things with jewelry as I do with tattoos where once I feel a little bit comfortable with a new kind of idea that's coming up inside myself, I tend to get to get a little pretty piece of jewelry that kind of memorializes that. (Chipper)

Reconciling self-identity with that of “cancer survivor”

As a second aspect of change in sense of self, we found that designing a tattoo was integral to how the participant self-identified, i.e., as a “cancer survivor.” Here, we distinguish between *self-identity* (how an individual views themselves) versus *social identity* (how other people make sense of an individual; [18]). The concept of self-identity manifested in participants’ design decisions, such as visibility of their tattoo to self and others, and dynamics of disclosures related to their tattoo and cancer. (We are careful to note that participants in this study embraced the phrase “cancer survivor” to varying extents. In characterizing their cancer status on the study intake form, only five participants self-identified as cancer survivors, with others preferring to use the term “in remission” or “cured.”)

Marianne asserted that anyone diagnosed with cancer should be able to say they were a survivor. Scott stated that as he was diagnosed with cancer as a small child, it is the “*only identity I have*.” For those participants who chose to get more private, less-conspicuous tattoos, the tattoo was intended as a private reminder of strength, not meant to be shared with the world.

I was just like, I don't want to get it anywhere where people could see it because it wasn't – it's not a public thing...it's for me to be like my badge of honor, and if someone saw it then that's great, but it's not for anybody but me. (Gorgeous)

If I don't tell you it's there, you're probably not gonna know it's there, and that's exactly what I wanted, because it's my tattoo and has meaning for me. I just didn't feel the need for it to be, you know, extremely large on my body. (Robin)

The privacy of these tattoo designs contrasts with the instances we observed during online ethnography that demonstrated individuals sharing photos of their survivor tattoos online. However, the impulse to share a tattoo image went hand-in-hand with a self-identity as an advocate or more “public” survivor. For example, Adrian had begun to see herself as an advocate for fellow survivors who, like her, faced a dearth of information about breast cancer treatment specific to women of color. As a result, Adrian intended to have a more public “reveal” of her tattoo online:

When I get the tattoo, I will shout it to the rooftops. So I have a blog. I'm African American, and when I was looking for information about African Americans with breast cancer, I couldn't find any pictures. I couldn't find any visuals, and I felt like I needed that information, so as somebody who's a

born extrovert—my sister's a total introvert, but she set [the blog] up still. She put together, part of the system that she put together has a blogging feature, so I blogged everything from my naked upper all the way, you know, my before pictures all the way out, so I will probably document the whole thing and then stop the blog. (Adrian)

The above examples demonstrate changes in self-perception related specifically to body image and self-identity, as part of post-traumatic growth. In the following section, we address changes that occur socially, and the growth facilitated by participants' tattoos.

Changed sense of relationships with others

A *changed sense of relationships with others* entails two primary positive outcomes after trauma: first, an ability to make self-disclosures to find the “right” emotional support; and second, a tendency to invest in more positive and/or intimate relationships [49]. We observed two themes about the benefits of survivor tattoos that demonstrated that they facilitated this change: (1) survivor tattoos helped participants fulfill the desired role of a public survivor (i.e., *rising* to meet social gaze related to cancer and survivorship), and (2) survivor tattoos strengthened relationship-building during social acts of designing (and sometimes getting) survivor tattoos.

Fulfilling the role of a public survivor

Participants who chose more “public-facing” tattoos demonstrated a great deal of thoughtfulness about the position of the tattoo on their bodies, as well as the symbolism incorporated into its design. Laughlin [27] refers to this symbolism as the “*expressive mode*” of body modification, wherein “*the body image participates in the field of meaning that is culture*” (p.60). Cancer tattoo symbolism varied dramatically, however, even in our limited sample of 19 participants. Some of the participants chose overt cancer-related imagery (e.g., awareness ribbons); others chose more personal symbols, referring to natural objects or cultural artifacts, such as movies.

In cases where participants applied an extra, “protective” layer of meaning to their tattoo, they reduced the obvious cancer symbolism. This measure allowed participants to decide in the moment whether they wanted to discuss the tattoo’s deeper meaning. Here, disclosure usually depended on how close the participant felt to the person asking about the tattoo, or on their current mood—giving them an ongoing choice about acting as a public survivor, or not.

It's a little bit more metaphorical [and people] don't necessarily say, "Oh, that's a tattoo you got because you got cancer," it's like, "Oh, cool Star Wars tattoo." So yeah, people definitely ask me about it, and for people that are close to me I tell them a little bit more why I got it, but you know if they don't really know you it's like, "Yeah dude, Star Wars is rad." That's pretty much the end of it. (Luke)

They'll say, "Oh, [your tattoo is] so cute." I'm like, "Oh, thanks," you know, especially people that don't know about

my cancer like just strangers or whatever...there are times I question whether or not I should tell them about my cancer, and there are times that I don't know whether to do it or not. I lean 90% of the time to no. I usually don't. (Susan)

In contrast, some participants used their tattoos to openly advocate for other cancer survivors and spread awareness. In these cases, participants expressed a willingness to answer questions or share their stories. Adrian spoke about advocacy as part of sharing her tattoo story, as did Rocky:

I say this even to my friends, that it is kind of my fuck-cancer tattoo, you know, because of everything that I went through. It's a reminder for myself and to kind of show the world that it's what I went through, and this is a visible piece for people to ask about because otherwise, you know, with cancer being such an invisible disease this gets people something visible to ask about where I can talk about cancer and really promote self-awareness and things like that. (Rocky)

Sometimes, the benefits of sharing information socially benefited the participant, and not just their “tattoo audience.” About one-quarter of participants stated were still figuring out how they wanted to be identified publicly, or what they wanted to disclose. Veronica indicated that she had done some emotional processing of her cancer experience over many years of answering questions about her tattoo:

When you're thinking about [the cancer] experience, and you're answering questions, or people want to know more, it's hard, and you know you wanna not get emotional, but it's hard not to...it's not until people ask me and I tell the whole story that I'm like, "Oh, wow, that was really a crazy experience" and one that, even to this day as I talk about it I realize I'm still learning from it, so I think it was definitely – both times, it's been about reflecting, for sure. (Veronica)

Finally, Scott’s tattoo served a different purpose than the other participants; the text of his tattoo bore witness to his remarkable survival despite the medical odds of his diagnosis, and was intended to express information to the medical community. Scott is a pediatric cancer survivor who has survived 30 years after treatment for a rare and painful cancer. His tattoo encoded information about the cancer treatment center and his patient identity there. When he dies, he said, he wanted the medical world to know that he was a “human outlier data point,” so they could update their knowledge about his rare diagnosis:

My father wrote some letters to me early on to try and capture some of the decisions and rationale [my parents] were making and being somewhat of an optimist, he seized on the one data point he could find that they heard of some case of [a person with my diagnosis living] as far as 30 years, and we've kind of had that in writing all this time, and it's kind of been a magic number. (Scott)

Therefore, survivor tattoos encode information that is integral to how participants choose to be identified and communicate socially about their cancer survivorship.

Strengthening relationship building

Another aspect of the changed sense of relationship to others were the social aspects of designing and getting the tattoo. Participants said they often discussed their plans of getting a tattoo with friends and family prior to starting visual sketching or even locating a tattoo artist with whom they felt comfortable.

Many, although not all, of the participants brought friends or family with them while getting their tattoos for emotional support and comfort. Prior research has shown that specific reasons to get a tattoo vary by social influences around the person motivated to get a tattoo [38]. Social acceptance of tattoo culture and support in designing a tattoo is crucial to carry out the design on one's skin and body. Our participants proved no different. For instance, Audrey had cocktails with girlfriends before going to a tattoo parlor to get her breast cancer ribbon piece done. Clare's friends left her a special surprise after her tattoo session:

The best part of it was like I had a bunch of other friends who knew I was going [to get my tattoo] that day, and like we finished. I looked at it. I loved it, and [the tattoo artist said], "Oh, I have something for you," and there was a card there for me, and all of, like 6 of my other friends had actually gone in before and paid for it without me knowing...And they like left a card that said, "We're so proud of you," like sorry we couldn't be here but you know, congratulations, we love you, and I started crying, but yeah. (Clare)

The act of "celebration" at the close of cancer treatment is a social phenomenon (e.g., [20]; such celebration was common among participants when their scan results came out clean or they were done with chemotherapy). Similarly, tattooing has been previously found to fulfill a "social bonding" experience, particularly among young men [13].

The social aspect of tattoos extended to online spaces, as well. Nicole's tattoo artist put a picture of her piece on his Instagram page, saying it was "a hit" and received a lot of likes. Many participants also sought out ideas from searching Pinterest, Facebook, and on forums for cancer survivors, where a type of survivor tattoo "lexicon" for survivors has flourished, as Mifflin [33] had also noted: "*The Internet opened the door to a smorgasbord of [tattoo] designs.*" Susan observed tattoo postings on her Facebook groups, which motivated her to get a tattoo:

I saw several friends on my support groups [on Facebook], people were getting the pink ribbon of course because it's breast cancer, and I saw a lot of tattoos like "I will survive," or "I'm a survivor," and all this stuff, and I was like that's kinda cool, and I started thinking about what I wanted to get. (Susan)

Tattoos were also a type of expression that could be shared among family members, passing survival symbolism from one person to others in their support system [12, 46]. For example, Gorgeous and her fiancé displayed their matching tattoos online:

[My fiancé] came down to see me, and he surprised me with a tattoo that he got. He's 6 foot 3. He got it all along his ribcage, and it's a huge sunflower with a green lymphoma ribbon kinda going up the side...So we took a picture of our tattoos together, and that was his way of saying, "I'm in this with you." I mean, at that point we'd been together for like seven years, but you know he got this for me to show his commitment to me. (Gorgeous)

Suzanne had her husband's tattoos copied on to her body as a way to support him during cancer treatment, and as a memorial after he eventually died. Her tattoo was shared on the Facebook page of an organization she and her husband actively supported:

We had gotten in touch with an organization called Say YES to HOPE Beat Liver Tumors...when I met them in person, they took a picture of my tattoo and shared it on their Facebook pages, and they actually—one of their favorite things to do is have people draw the word, "hope," in sand whenever they are at like—we went to California with that organization and got to go to the Oscars Night of 100 Stars dinner party in 2014, and so [my husband] wrote the word, "hope," on the beach by the Pacific Ocean like that, so they've used pictures of my tattoo too. (Suzanne)

Notably, not all participants wanted to post their tattoos online. In particular, although all of the interviewees who had gotten mastectomy cover-ups were supportive of other women posting images of their tattoos online, none of them wanted to post their own images, for privacy reasons (see [33] for an in-depth discussion of mastectomy cover-up history).

In sum, the majority of participants acknowledged crucial sharing and social aspects to the design, discussion, and display of survivor tattoos. These aspects point to the process of getting a tattoo as one that facilitates the essential social element of post-traumatic growth.

Changed philosophy of life

In post-traumatic growth, the element of a *changed philosophy of life* is a process by which a trauma survivor "recognizes meaning" of their traumatic experiences to bring emotional relief ([49]; see also [29]). We observed two aspects of this change: (1) the act of regaining control, or balance, in participants' perspectives; and (2) the notion of a ritual passage onto something new. In these aspects, the act of tattooing helped to reframe the trauma as a before-and-after event, rather than a continuous personal tragedy.

Regaining control or balance

Most survivors identified with the notion of regaining control through tattooing. For example, Veronica survived pediatric cancer, and reflected on how the tattoo related to her sense of control as a young adult:

And maybe [when I got the tattoo] I didn't see it that way or I wasn't pausing to think, "Okay, this is part of me taking control, you know...[but] I would definitely agree with that

in the sense that when you choose to put something on your body, it's like your choice, your control, and yeah. Maybe the subject behind it isn't all that positive or great, but it's something that you can do afterwards that's yeah, it's completely in your control. (Veronica)

On the contrary, Bruce pushed back on the idea of control; he preferred the term “balance” to describe the process of healing and coping with the arduous treatment for his cancer:

If anything, getting tattoos was giving up control. It was doing something I wouldn't do. It was doing something I can't change, so to me it was, "Look at me not being so controlled." One thing I started doing I started a year ago was I started taking tightrope walking lessons...one of the things when you're on a tightrope is you're always falling, and there's nothing you can do about that except constantly adjust, and it can look beautiful, smooth, and effortless, but it's always adjusting, and to me these tattoos are part of this larger framework of when [my doctor] says, "Do everything," I'm like, "Yeah, fuckin' do everything," like I get scarred by you guys, and I scar myself, and sometimes I don't choose it, and sometimes I do. (Bruce)

Ritual passage

Finally, the before-and-after effect of getting the tattoo was analogous to a personally relevant “punctuation point” in the experience of cancer. About half of the participants described the tattoo experience as cathartic, or at least significant. Anne explained that she was unable to talk about her feelings with her oncologist, but she viewed the act of designing her tattoo as a type of ritual that seemed to help her move past the negative aspects of diagnosis and treatment:

I mean as much as I am no longer religious, I think that ceremony and ritual has a place in modern life, and I think that, you know, those kind of rituals like funerals and weddings help people process is particular life-changing events...but you know you have a lot of time to process and think while [cancer treatment is] going on, and so I think that [getting the tattoo] could be, you know, a coping ritual to a certain extent. (Anne)

Thus, the act of getting a tattoo symbolized meaning and provided emotional benefits to participants, which they could not access in a medical setting.

Survivors and tattoo regret

We note two specific instances where participants described regret related to their tattoos, which is also discussed in prior research [30]. In one case, a participant was dissatisfied with the artwork of their tattoo, while she still liked the symbolic meaning it carried for her. She acknowledged it would be possible to have an artist “fix” the piece. In another case, during the time that had passed, the participant wished they had gotten something different:

I mean I am not exactly as proud of having a tattoo anymore...[I] kinda wish I was back to a blank slate...I was probably pretty proud at first [of my tattoo]. I still am, but at

the same time it's also—surviving cancer and chemo is something a lot of people do. At the same time, it's something a lot of people don't. I think that's laid heavier on me in more recent years. (Rich)

Rich’s feelings about his survivor tattoo, and his own survival, had changed over time, as memories do. Benson [8] stated in her history of contemporary tattoos that this notion is common. “Memory,” she wrote, “a critical property of contemporary self-identity, is externalized and fixed upon the skin” through tattoo (p. 246; see also [38]).

Our findings demonstrate how survivor tattoos facilitate post-traumatic growth through promoting changes in self-perception, changes in sense of relationships with others, and changes in philosophy of life. In the following section, we discuss implications of these findings for the HCI and health care design and research communities.

DISCUSSION

Our results point to three opportunities in the HCI and health care design and research communities. First, by incorporating tattoo information into the medical record, we describe the possibility to reframe tattoos as health information in the clinical setting, as a “window” into a survivor’s *changed self-perception*. Second, having observed the benefits of tattoo design, discussion, and display in survivors’ *changed sense of relationships with others*, we see an opportunity for a therapeutic design tool that could mimic the creative, social, and meaning-making benefits of tattoo design for cancer survivors, as well as a wider group of trauma survivors. Finally, we articulate the benefits of having engaged with our participants through discussion of their survivor tattoos, which reveal nuanced information about the participants’ *changed philosophy of life* (see Table 2 for a summary).

Incorporating tattoos into clinical information

Tattoo is about revealing, being revealed and gazing upon the revealing...One could say that to wear a tattoo is to see and be seen by controlling the gaze, as the delight in revealing the tattoo is made more exquisite by the dreadful memory of a painful inscription: pleasure in the hint of pain. ([10], p. 15)

In commentary about potential acceptance of tattoos among health care professionals, Grumet [22] suggested that mental health professionals use clients’ tattoos as a “springboard” to more personal discussion. Kleinman [25] argued for the essential role of the patient narrative in competent doctoring and care. In this sense, the “tattoo narrative” might serve as a crucial piece of the “patient narrative.” Here, we see an opportunity for designers of clinical information to assist in reframing tattoos as meaningful health information both with regards to emotional and physical health.

This design opportunity leverages, in particular, the element of post-traumatic growth related to changes in self-perception. Specifically, Tedeschi and Calhoun [49] characterize this change as one that can lead to strength, and

self-assurance, particularly in facing further emotional difficulties in life. However, discussions and health care provider support on such personal and emotional growth is not common in oncology medical settings. By including survivor tattoos in the clinical record and recognizing them as a potentially valuable artifact for communication on the cancer experience, health care professionals can use them to elicit survivors' feelings about their current treatment or recovery, physical disfigurement, past trauma, as well as investigate their fears about future ill health or emotional setbacks. This provides opportunity to direct survivors to adequate professional support to foster positive growth.

For example, designers could incorporate tattoos and their personal meanings into clinical artifacts such as medical history intake forms; the patient could opt to tell their health care provider about any health information encoded in tattoos. By asking for information such as tattoo with prompts such as placement (location on the body), symbolism, and visual appearance (perhaps even with a sketch or a photograph), a patient could feel validated to discuss a tattoo and its meaning.

By reframing of tattoos as a type of health information, health care providers can become more open to understanding the relevance of tattoos in helping patients discuss their feelings. A participant in this study (Luke) explicitly made this connection between his feelings and his tattoo, calling it “*a conduit for being able to talk about my emotions.*” At present, this “conduit” was not being effectively used in Luke’s clinical interactions, but he hinted at the rich information conveyed by his tattoo nonetheless, a “window” into the state of his *changed self-perception* and therefore, his post-traumatic growth.

Designing a tool for visual expression

In this study, we found that participants’ work to design, discuss, and (often) display survivor tattoos helped to facilitate growth post-cancer trauma, particularly in terms of a *changed sense of relationships with others*. Cancer—as with all illnesses—is a social experience [55]. Cancer often becomes a socially destructive force in the lives of survivors, as shown in our study. Responding to this force, survivors should seek expressions that can help others understand their cancer history, their desired identity, and the significance of an event like cancer in their lives.

Participants described the act of designing their survivor tattoos as a social one—shared through discussion with individuals in their support network, or shared with peers in online forums. This type of visual language is an important aspect of the survivor/support lexicon, and should be embraced by social computing researchers. Thus, we see an opportunity for designers or researchers to offer a tool for survivors of cancer (or other illnesses or trauma) to virtually design a tattoo or other visual metaphor for their feelings. Such digital metaphors can then be outwardly shared either through online platforms or among closer social ties. Although this approach could be seen as related to art therapy, the tool we suggest here would facilitate a more collaborative and social experience than traditional art therapy [23], which is traditionally conducted one-on-one with therapist and patient, to evoke emotion through imagery as a way to process those emotions.

Participants repeatedly pointed to social influences in their lives that intertwined with bodily sensations and emotions, leading to the aggregate visual and symbolic elements of their final tattoo designs. A digital or computer-based tool to

Post-Traumatic Growth Element Themes in Survivor Tattoos	Design Opportunity	Expected Impact
Changed self-perception <i>Improved body image</i> <i>Survivor self-identity assimilation</i>	<u>For clinical informatics design:</u> Incorporating information about tattoos into the medical record, to legitimate the knowledge about self, health, and past trauma encoded therein	Supports discussion between a patient and health care provider about past trauma and progress related to post-trauma growth, as well as discussion about fears for future emotional difficulties
Changed sense of relationships with others <i>Determining “public” survivor identity</i> <i>Social aspect of tattoo design</i>	<u>For HCI designers:</u> Offering a digital tool to replicate the social aspects of survivor tattoo design, facilitating discussion among trauma survivor’s support network	Enables individuals who do not necessarily want a tattoo to engage in the social articulation and reflection of trauma, and helps them “practice” self-disclosure for growth
Changed philosophy of life <i>Regaining control or balance</i> <i>Tattoo as ritual</i>	<u>For health and HCI researchers:</u> Embracing artifacts of participants’ own design for projects that elicit information about past events, particularly those involving trauma	Acknowledges the creativity and agency of traumatized individuals, and assists the researcher in avoiding re-traumatizing participants in research

Table 2. Design opportunities for HCI and health designers and researchers

give survivors of trauma this kind of access to expression of their feelings in coping—an authoring tool for visual art—would ideally include two functions:

- (1) Ability to mix and match visual elements of a “tattoo” or visual design, regardless of artistic ability; and
- (2) A mechanism to share visual designs and collaborate with caregivers, friends, and peers in evolving the design over time (or to pass along to a tattoo artist, should the impulse to apply artwork to the body arise).

These types of “symbolic engagements” have been previously suggested as a way to nurture post-traumatic growth in a social context [11]. Similarly, this type of digital tool would enable survivors—of cancer, or other illnesses and trauma—an expressive outlet that still facilitates post-traumatic growth elements, without the commitment of getting a tattoo while retaining the benefits of facilitating a collaborative, expressive design act—a process we observed that facilitated a *changed sense of relationships with others*.

Engaging participants through their own artifacts

The body, as a communicative text, may readily be modified in order to manage emotions that might be otherwise pushed behind the scenes of social life or expressed through destructive attitudes. ([4], p. 193)

Engaging potential research participants through the meaningful artifacts of their survivor tattoos proved helpful in centering the participants’ lived experiences and, in particular, eliciting the progression of their *changed philosophy of life*, the third element of post-traumatic growth. In this study, we asked about existing artifacts of the participants’ *own* design, versus artifacts introduced by researchers to elicit participant data (e.g., [54]). This approach had the particular advantage in grounding participants as experts in makers of their own “rituals.”

In recruiting for this study, several research participants expressed surprise that someone in academia wanted to know about their tattoos. Bruce, who was recruited into the study by an acquaintance of the author, initially puzzled about the scope of the interview, but stated afterward that he could see why his tattoos would be of interest to researchers working to improve cancer survivorship. He stated that talking about his tattoos had broached much of his changing emotions about having survived a difficult cancer treatment.

Finally, Nicole expressed her gratitude after taking part in the interview study as sharing about her journey through the tattoo had emotional significance for her, in that the research design itself authenticated strong feelings she had processed by designing a memorial tattoo for her grandmother:

[My tattoos] really do like mean a lot to me...yesterday I'm like, Dad, there's this [researcher]...I filled out her survey for my cancer tattoos, and she might wanna do an interview about them, and he's like, "Uh huh, yeah." I'm like no, seriously, Dad, like I told you these tattoos will mean something someday, so like I could see like a little smile on

his face, so I think that really like kinda like made both of our days, so thank you. (Nicole)

LIMITATIONS

The size of the interview sample, as well as its limited scope of inquiry, are intended to produce information about a specific phenomenon in the cancer survivor community (e.g., survivor tattoos), and are not intended to generalize to all members of the cancer survivor community.

CONCLUSION

There are as many ways to cope with cancer as there are cancer survivors. The range of behaviors related to cancer survivor tattoos is similarly varied. Survivor tattoos can be very private—a secret totem for the survivor to keep up their spirits or for a sense of protection. But survivor tattoos can also be a public signal, shared both offline and online in social situations, giving the survivor a chance to tell their story or advocate for cancer awareness. By interviewing survivors with tattoos, we were able to identify all three elements of post-traumatic growth, which were fostered and facilitated by the acts of designing, discussing, and displaying cancer survivor tattoos.

In this study, we discuss three opportunities for HCI and health designers and researchers to enhance the benefits of post-trauma growth mechanisms supported by the “work” involved with survivor tattoos. First, by incorporating tattoos into the clinical record, designers can help legitimate the information encoded in survivor tattoos that convey aspects of *changed self-perception* after trauma. Second, digital tools to encourage trauma survivors to collaboratively design visual expressions of feelings and memories can facilitate the necessary *changed sense of relationships with others*, which is essential to post-traumatic growth. Finally, researchers should embrace creative means of engaging with artifacts designed by research participants, which can be used to elicit *changed philosophy of life* after trauma. These three design implications give HCI and health designers and researchers greater sensitivity in working with survivors of trauma, while enhancing trauma survivors’ engagement with essential elements on post-traumatic growth.

ACKNOWLEDGEMENTS

We thank our participants for their insights and enthusiasm. The first author also wishes to thank her oncologist for his encouragement in carrying out this study.

REFERENCES

1. Josh Adams. 2012. Cleaning up the dirty work: Professionalization and the management of stigma in the cosmetic surgery and tattoo industries. *Deviant Behavior* 33, 3: 149-167.
2. Nazanin Andalibi, Pinar Öztürk, and Andrea Forte. 2017. Sensitive Self-disclosures, Responses, and Social Support on Instagram: The Case of #Depression. In *Proceedings of the Computer-Supported Cooperative Work and Social Computing (CSCW '17)*,

- 1485-1500. DOI:
<https://doi.org/10.1145/2998181.2998243>
3. Myrna L. Armstrong, Alden E. Roberts, Donna C. Owen, and Jerome R. Koch. 2004. Toward building a composite of college student influences with body art. *Issues in Comprehensive Pediatric Nursing* 27, 4: 277-295.
 4. Michael Atkinson. 2002. Pretty in ink: Conformity, resistance, and negotiation in women's tattooing. *Sex Roles* 47, 5: 219-235.
 5. Michael Atkinson. 2003. *Tattooed: The sociogenesis of a body art*. University of Toronto Press.
 6. D.J. Barker and M. J. Barker. 2002. The body as art. *Journal of Cosmetic Dermatology* 1, 2: 88-93.
 7. Susan E. Bell. 2006. Living with breast cancer in text and image: Making art to make sense. *Qualitative Research in Psychology* 3, 1: 31-44.
 8. Susan Benson. 2000. Inscriptions of the self: Reflections on tattooing and piercing in contemporary Euro-America. In *Written on the body: The tattoo in European and American history*, Jane Caplan (ed.), Princeton University Press.
 9. Joanna Berzowska and Paul Yarin. 2005. Memory rich garments: body-based displays. In *ACM SIGGRAPH 2005 Electronic Art and Animation Catalog*, 168-171.
 10. Marc Blanchard. 1991. Post-bourgeois tattoo: reflections on skin writing in late capitalist societies. *Visual Anthropology Review* 7, 2: 11-21.
 11. Alice V. Brown and Jaz Hee-Jeong Choi. 2017. Towards Care-based Design: Trusted Others in Nurturing Posttraumatic Growth outside of Therapy. In *Proceedings of the 8th International Conference on Communities and Technologies (C&T '17)*, 56-63. DOI: <https://doi.org/10.1145/3083671.3083703>
 12. Melissa Burden. 2011. Unlikely inked: Breast cancer survivors say matching butterfly tattoos help show support, bring them closer. *Flint Journal*. (11 July, 2010). Retrieved September 11, 2017 from http://www.mlive.com/news/flint/index.ssf/2010/07/unlikely_inked_breast_cancer_s.html
 13. Kathryn Coe, Mary P. Harmon, Blair Verner, and Andrew Tonn. 1993. Tattoos and male alliances. *Human Nature* 4, 2: 199-204.
 14. Dwane H Dean. 2011. Young adult perception of visible tattoos on a white-collar service provider. *Young Consumers* 12, 3: 254-264.
 15. Margo DeMello. 2000. *Bodies of inscription: A cultural history of the modern tattoo community*. Duke University Press.
 16. Daantje Derks, Agneta H. Fischer, and Arjan ER Bos. 2008. The role of emotion in computer-mediated communication: A review. *Computers in Human Behavior* 24, 3: 766-785.
 17. Dirk Dhossche, Kenneth S. Snell, and Samantha Larder. 2000. A case-control study of tattoos in young suicide victims as a possible marker of risk. *Journal of Affective Disorders* 59, 2: 165-168.
 18. Judith Donath. 2014. *The Social Machine: Designs for Living Online*. MIT Press.
 19. Henrik Eriksson, Mats Christiansen, Jessica Holmgren, Annica Engström, and Martin Salzmänn-Erikson. 2014. Nursing under the skin: a netnographic study of metaphors and meanings in nursing tattoos. *Nursing Inquiry* 21, 4: 318-326.
 20. Jordan Eschler, Zakariya Dehlawi, and Wanda Pratt. 2015. Self-characterized Illness Phase and Information Needs of Participants in an Online Cancer Forum. In *Proceedings of the International Conference on Web and Social Media (ICWSM '15)*.
 21. Jordan Eschler and Wanda Pratt. 2017. "I'm so glad I met you": Designing dynamic collaborative support for young adult cancer survivors. In *Proceedings of the Computer-Supported Cooperative Work and Social Computing (CSCW '17)*, 1763-1774. DOI: <https://doi.org/10.1145/2998181.2998326>
 22. Gerald W. Grumet. 1983. Psychodynamic implications of tattoos. *American Journal of Orthopsychiatry* 53, 3: 482-492.
 23. Ellen Urbani Hildebrand. 1999. Coping with Cancer Through Image Manipulation. In *Medical art therapy with adults*, Cathy A. Malchiodi, (ed.). Jessica Kingsley Publishers.
 24. Hsin-Liu Cindy Kao, Paul Johns, Asta Roseway, and Mary Czerwinski. 2016. Tattio: fabrication of aesthetic and functional temporary tattoos. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems*, 3699-3702.
 25. Arthur Kleinman. 2008. The art of medicine: Caregiving: the odyssey of becoming more human. *The Lancet* 373, 9660: 22-23.
 26. Jerome R. Koch, Alden E. Roberts, Myrna L. Armstrong, and Donna C. Owen. 2010. Body art, deviance, and American college students. *The Social Science Journal* 47, 1: 151-161.
 27. Charles D. Laughlin. 1997. Body, brain, and behavior: The neuroanthropology of the body image. *Anthropology of Consciousness* 8, 2-3: 49-68.
 28. Anne E. Laumann and Amy J. Derick. 2006. Tattoos and body piercings in the United States: a national data set. *Journal of the American Academy of Dermatology* 55, 3: 413-421.

29. Miles Little, Kim Paul, Christopher FC Jordens, and Emma-Jane Sayers. 2002. Survivorship and discourses of identity. *Psycho-Oncology* 11, 2: 170-178.
30. Eric Madfis and Tammi Arford. 2013. The dilemmas of embodied symbolic representation: Regret in contemporary American tattoo narratives. *The Social Science Journal* 50, 4: 547-556.
31. Lenore Manderson and Lesley Stirling. 2007. The absent breast: speaking of the mastectomized body. *Feminism & Psychology* 17, 1: 75-92.
32. Lydia Manikonda and Munmun De Choudhury. 2017. Modeling and Understanding Visual Attributes of Mental Health Disclosures in Social Media. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17)*, 170-181. DOI: <https://doi.org/10.1145/3025453.3025932>
33. Margot Mifflin. 2013. *Bodies of subversion*. Powerhouse Books.
34. Vaughn S. Millner and Bernard H. Eichold. 2001. Body piercing and tattooing perspectives. *Clinical Nursing Research* 10, 4: 424-441.
35. Craig Nathanson, Delroy L. Paulhus, and Kevin M. Williams. 2006. Personality and misconduct correlates of body modification and other cultural deviance markers. *Journal of Research in Personality* 40, 5: 779-802.
36. National Cancer Institute. 2017. Cancer Statistics. Webpage. (March 22, 2017). Retrieved September 13, 2017 from <https://www.cancer.gov/about-cancer/understanding/statistics>
37. Patti Neighmond. 2017. Teen Wants A Tattoo? Pediatricians Say Here's How To Do It Safely. NPR online. (18 September 2017). Retrieved September 18, 2017 from <http://www.npr.org/sections/health-shots/2017/09/18/551212312/teen-wants-a-tattoo-pediatricians-say-heres-how-to-do-it-safely>
38. Atte Oksanen and Jussi Turtiainen. 2005. A life told in ink: Tattoo narratives and the problem of the self in late modern society. *Auto/biography* 13, 2: 111-130.
39. Jessica A. Pater, Oliver L. Haimson, Nazanin Andalibi, and Elizabeth D. Mynatt. 2016. "Hunger hurts but starving works": characterizing the presentation of eating disorders online. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW '16)*, 1185-1200. DOI: <https://doi.org/10.1145/2818048.2820030>
40. Alan Radley and Susan E. Bell. 2011. Another way of knowing: Art, disease and illness experience. *Health (London)* 15: 219-222.
41. Jonathan W. Roberti and Eric A. Storch. 2005. Psychosocial adjustment of college students with tattoos and piercings. *Journal of College Counseling* 8, 1: 14-19.
42. Timothy A. Roberts and Sheryl A. Ryan. 2002. Tattooing and high-risk behavior in adolescents. *Pediatrics* 110, 6: 1058-1063.
43. Nichola Rumsey, Alex Clarke, Paul White, Menna Wyn-Williams, and Wendy Garlick. 2004. Altered body image: appearance-related concerns of people with visible disfigurement. *Journal of Advanced Nursing* 48, 5: 443-453.
44. H. Alan Scott. 2016. How Instagram Helps Young People Cope with Cancer. *Vice*.
45. Ashley Wilder Smith, Keith M. Bellizzi, Theresa HM Keegan, Brad Zebrack, Vivien W. Chen, Anne Victoria Neale, Ann S. Hamilton, Margaret Shnorhavorian, and Charles F. Lynch. 2013. Health-related quality of life of adolescent and young adult patients with cancer in the United States: the Adolescent and Young Adult Health Outcomes and Patient Experience study. *Journal of Clinical Oncology* 31, 17: 2136-2145.
46. Laura Starnier. 2017. We Chose To Be Ink Sisters After Life Made Us Pink Sisters. *IHadCancer.com*. (13 February, 2017). Retrieved September 11, 2017 from <https://www.ihadcancer.com/h3-blog/02-13-2017/we-chose-to-be-ink-sisters-after-life-made-us-pink-sisters>
47. Viren Swami. 2011. Marked for life? A prospective study of tattoos on appearance anxiety and dissatisfaction, perceptions of uniqueness, and self-esteem. *Body Image* 8, 3: 237-244.
48. TeamIHadCancer. 2015. 10 Beautiful Cancer Survivor Tattoos. Webpage. (7 October, 2015). Retrieved September 11, 2017 from <https://www.ihadcancer.com/h3-blog/10-07-2015/10-beautiful-cancer-survivor-tattoos>
49. Richard G. Tedeschi and Lawrence G. Calhoun. 1996. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress* 9, 3: 455-471.
50. Marika Tiggemann and Louise A. Hopkins. 2011. Tattoos and piercings: Bodily expressions of uniqueness?. *Body Image* 8, 3: 245-250.
51. M. Tzanakis, G. Alexias, and M. Savvakis. 2013. From the "Suffering" to the "Contributing" Body: Breast Cancer, Mastectomy and Images of the "Amputated" Self in Greek Women Narrations. Unpublished manuscript.
52. Ozum Uçok. 2007. The fashioned survivor: Institutionalized representations of women with breast cancer. *Communication* 4, 1: 67-78.
53. Seçil Uğur. 2013. *Wearing embodied emotions: A practice based design research on wearable technology*. Milan, Italy: Springer.
54. Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in

- dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13), 2617-2626. DOI: <https://doi.org/10.1145/2468356.2479560>
55. Echo L. Warner, Erin E. Kent, Kelly M. Trevino, Helen M. Parsons, Bradley J. Zebrack, and Anne C. Kirchoff. 2016. Social well-being among adolescents and young adults with cancer: A systematic review. *Cancer* 122, 7: 1029-1037.
56. Silke Wohlrab, Jutta Stahl, and Peter M. Kappeler. 2007. Modifying the body: Motivations for getting tattooed and pierced. *Body image* 4, 1: 87-95.
57. S. Yousuf Zafar. 2016. Financial toxicity of cancer care: It's time to intervene. *JNCI: Journal of the National Cancer Institute* 108, 5. <https://doi.org/10.1093/jnci/djv370>