

# Flexibility and Intangibles: The Crowdfunding Needs of Stigmatized Individuals

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## ABSTRACT

HCI research on crowdfunding has primarily focused on creative or organizational endeavors. Yet a majority of crowdfunding campaigns are conducted by individuals in need, often for healthcare. To better understand and improve this common crowdfunding experience, especially for those that inhabit a vulnerable social status, we conducted 20 interviews with transmen crowdfunding for top-surgery. Design choices that optimize *site flexibility* (e.g. control of personal information; enable cross-site communication) and foreground *intangibles*, such as political values and emotional support, are priorities for individuals from a stigmatized community. Findings differed from previous crowdfunding research and contribute to limited research on transgender identities in HCI. Overall they provide unique insights into how design choices can facilitate marginalized identity management in highly public online spaces.

## Author Keywords

Crowdfunding; healthcare; transmen; vulnerable populations; privacy; identity

## ACM Classification Keywords

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

## INTRODUCTION

Transmen, or transgender individuals determined female at birth but who gender identify as male, represent a stigmatized group that may have an enhanced need for privacy that conflicts with the need for social support. This tension is highlighted in the context of crowdfunding when low-income transmen turn to public Internet platforms to raise money for top-surgery, the removal of the breast tissue and subsequent reconstruction of a masculine chest.

Neither research on crowdfunding nor transgender life is well represented in the ACM computing literature.

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CHI 2017, May 06–11, 2017, Denver, CO, USA  
© 2017 ACM. ISBN 978-1-4503-4655-9/17/05...\$15.00  
DOI: <http://dx.doi.org/10.1145/3025453.3025647>

Crowdfunding (70 articles in ACM search) has almost exclusively been investigated from the perspective of creative or organizational campaigns, often focusing on the factors that predict campaign success using computational and big-data analytics [1, 13, 14, 16]. Only a small minority of studies has investigated personal crowdfunding [18, 20], including one study that has examined medical crowdfunding [12]. However, those studies tend to emphasize the credibility and legitimacy of campaigns rather than the financial, physical, and emotional needs of users. This study aims to fill a gap in the HCI literature by exploring how members of a vulnerable population—in this case, transmen<sup>1</sup> crowdfunding for top surgery—navigate the crowdfunding process. Because healthcare is one of the most common reasons for crowdfunding [17], our aim is to provide design recommendations that optimize the user experience for any of the thousands of people turning to crowdfunding during medical and financial hardship. By exploring the experience of transmen, an exemplar vulnerable population, we hope to understand how any individual navigates public online spaces while maintaining a desired degree of privacy and agency at a difficult time.

Crowdfunding is never exclusively a financial transaction [4, 7]. HCI research has identified non-financial motives and effects of crowdfunding that operate in tandem with financial drivers. In addition to fundraising, crowdfunding is motivated by desires to gain approval, form connections, and raise awareness of an issue [6]. Using a resource exchange perspective, [8] note that crowdfunding can result in greater access to money, as well as love, information, status, goods and services. By broadly engaging one's network, crowdfunding results in a range of financial as well as non-financial advantages [19].

But reaching out to one's online network for financial or non-financial support is complicated when also trying to maintain privacy [3, 21], especially for those in the LGBTQ community [5, 11]. A small body of HCI literature on transgender issues (10 articles in ACM search) has addressed how digital affordances both enhance and

<sup>1</sup> The term transmen is used throughout this paper, however it should be noted that this is a chosen and often political identification that is not necessarily inclusive of everyone's chosen gender identification.

complicate the transgender experience. These include opportunities to remain anonymous while exploring modes of self-expression online [9], and the tension between categorical identity expression (e.g. being forced to select either a “male” or “female” gender online) and new opportunities for identity creation in social media environments [10]. In other words, trans\* and queer-identifying individuals are particularly sensitive to their need to maintain agency over identities while reaching out to others for support.

Given these tensions and findings to date, we explore the following questions: how do transmen as an example of a stigmatized group experience crowdfunding online for top surgery? What are the tensions between feeling safe and constrained in online self-expression? Finally, how can analysis of the crowdfunding experience inform design for the trans\* and queer community, and the medical crowdfunding community more broadly? As we explore these questions, we bring together previously disparate literatures on transgender self-expression in HCI and crowdfunding site design.

## METHODS

Potential participants were originally contacted through the popular crowdfunding site Gofundme, as the first site returned for a google search of “medical crowdfunding.” Emails sent on Gofundme were blocked by the site and so we turned to [youcaring.com](http://youcaring.com), the second google-ranked site. We searched for “trans” on [youcaring.com](http://youcaring.com) and contacted all individuals in our search results that were involved in medical crowdfunding. Of the 49 individuals contacted, only transmen or those who identified as transmasculine agreed to participate. It should also be noted that few transwomen were found in our search results. A broader search term or different search terms may have resulted in different results. Given our participant responses, however, we decided to focus on the experience of transmen in this study. Eighteen participants agreed to be interviewed. Thirty-five dollar gift cards were mailed to participants after their interviews.

The second author interviewed the 20 trans\* participants through Skype or telephone in at 45-75-minute semi-structured interview. Questions centered on privacy concerns and identity development as a result of online presentations. Twelve of the 20 participants also agreed to fill out an optional demographics survey. Of those, age ranged from 18 to 33; two were Hispanic and 10 identified as white. Six participants made less than \$25,000 a year, five made between \$25,000 and \$50,00, and one made more than \$100,000. The participants' gender identity varied by individual. We do not know why our sample was disproportionately White; this is a limitation of the data.

Interviews were iteratively analyzed: key sections were transcribed through repeated audio review and notes were taken during that process. A matrix of themes stemming from transcripts and notes was compiled to identify thematic patterns and seek disconfirming evidence [2, 15]. The authors

then met on multiple occasions to discuss themes and narrow final results. Pseudonyms are used throughout the results section.

## RESULTS

The aim of this study was to explore how stigmatized individuals navigate the crowdfunding space. In other words: what new design lessons can the HCI community learn from conversations with transmen that can enhance the crowdfunding experience for all individuals, but especially users from vulnerable populations?

### Flexibility Matters

Flexibility in deciding what, how much, and where to share information was a high priority for users. Navigating a very public space with incredibly personal information was aided here by flexible and user-friendly interface design. Most found [youcaring.com](http://youcaring.com) easy to initiate, navigate, and adapt to personal standards of disclosure, which was very important. For example, Elliot noted:

*“It had fields to put more information, but if you didn't want to put that kind of information, it wasn't like you had to fill it out in order to complete the forms, so that was nice too.”*

In other words, flexibility and accessibility when first creating a site was important for transmen to feel comfortable and helped put them at ease when first initiating campaigns.

Second, participants also appreciated flexibility in setting and receiving funds regardless of meeting campaign goals. Because money in this case is not supporting a creative endeavor or organizational aim, being assured that one would receive funds regardless of campaign success was critical. Not all sites allow users to receive funds without meeting goals. Youcaring allows users to keep all money raised, regardless of the amount, which is helpful when users face daunting healthcare costs that are often not covered by insurance.

Finally, flexibility in selecting one's audience is a priority when identity goals vary substantially by audience. The ability to tap into existing networks is complicated for those in the LGBTQ community who might not be ‘out’ in the same way to all members of their network [5], yet need to reach people for support. As Milo underscores:

*“I don't post about it that much on Facebook just because there are a lot of acquaintances of family people that I don't want to be always updating about this thing about every step of the way. Tumblr is where I talk about it most. Just because it is really easy to rant on Tumblr. Not a lot of people that I know follow me. So it feels like this safe space.”*

As one possible solution to this tension, one informant suggested a “built in feature” that would allow cross-site shares with ease. As with many other media sites, buttons to post content from YouCaring directly onto Facebook, Tumblr, Twitter and other popular social media outlets would allow interested users to quickly and selectively share content with different audiences. This function would likely ease

selective cross-media posting, benefiting users and site owners. It would also meet the flexibility needs of vulnerable populations, where *flexibility* refers to enhanced control over how information is shared.

### Importance of Intangibles

In addition to valuing flexibility in design and promotion, interviewee's also placed great value on the non-financial affordances of crowdfunding. To begin, another design opportunity was demonstrated in participants' sensitivity to wider social marginalization, even for those outside of their own communities. For example, multiple interviewees choose *not* to use GoFundMe because it hosted a campaign to raise funds for Darren Wilson, the police officer that in 2014 shot and killed Michael Brown, an unarmed Black teenager in Ferguson, Missouri. This finding suggests that sites that align themselves with vulnerable populations would do well to make their politics transparent in site promotion. Because LGBTQ-identified people have experienced marginalization and even violence, they may be more likely to consider politics and marginalization more broadly when selecting a crowdfunding platform.

Second, the ability for a campaign to convey emotional support was another critical intangible for users. Indeed, the most widespread benefit of crowdfunding for these informants may have been the perceived social support they received. That is, regardless of campaign success—and some campaigns were not successful (e.g. *“when you're low income you're friends are low income; my friends want to help but they just don't have the means”*)—nearly all informants expressed substantial psychological benefits that met or exceeded the financial benefits of the campaign.

Because this population is often unsupported by family and peers, the social support they received online was incredibly meaningful and often surprising. For example, according to Manny:

*“Just literally from the first day I started the campaign ‘till now I just have a totally different life view cause you know now I wake up everyday and I'm like, holy shit, a couple hundred people just came out for me super hard, like that is fucking amazing...I just never expected to have people come out for me that way.”*

For many, crowdfunding was another step in an ongoing journey of proclaiming and committing to an identity that was frequently fluid and often regarded as controversial. The act of publicly asking for money necessarily meant that informants were testing the support of their communities. In many cases, receiving public affirmation through a campaign resulted in a heightened sense of security and self-assurance. As Jackson explained:

*“I thought that it was going to be more complicated and people were going to have more invasive questions or treat me differently, or be rude, or I was going to feel uncomfortable with a lot of people knowing. But I surprised*

*when a bunch of people saw it and I was like, ‘oh this is just a thing about me.’ It became normal.”*

Similarly, Ben recognized that social media was fulfilling a role that broadcast media had traditionally played in representing minority identities. In this case, his own use of crowdfunding and social media allowed him to become part of the public discourse positively representing LGBTQ identities:

*“I think part of the problem, and why it really took me a while to figure myself out, is because there are not really examples of transpeople in movies and shows. And the ones you do have are gross dirty jokes or really negative. I know a lot of people have crazy misconceptions, but now that they know me they know that is not the case.”*

Crowdfunding site intangibles- the politics of a given site and the ability to seek, receive and even provide emotional support- were crucial components of the overall crowdfunding experience. Below we discuss opportunities for site designers to capitalize on these insights.

### DISCUSSION AND DESIGN IMPLICATIONS

Previous research on crowdfunding in HCI has emphasized organizational and creative crowdfunding experiences, despite the fact that individual medical crowdfunding is one of the most common motives for crowdfunding. Findings from interviews with transmen emphasize the need to prioritize and highlight website flexibility and platform intangibles in the design of crowdfunding systems, especially for use by individuals from vulnerable populations. These two factors were unveiled in multiple ways across the interviews.

First, a need for flexibility was highlighted in informants' appreciation of a user interface that was easy to use and provided freedom when populating fields. Site policies that insist on certain information or “accuracy” may unwittingly infringe on identity goals or privacy preferences, which are especially important for stigmatized individuals.

Informants also prioritized flexibility in setting campaign goals and receiving donations. This finding highlights a difference between the needs of organizational or creative crowdfunding campaigns and campaigns used to fund medical costs. Even small amounts of money were needed and used. Instead of signaling an unworthy cause or creative endeavor, users were clear that a lack of response often reflected limited resources within one's network. Being able to receive even minimal funds from a ‘failed’ campaign, and paying little-to-no overhead, was essential.

Finally, desires for greater networking flexibility highlighted another design opportunity. The use of buttons that link site content directly from campaign sites to Facebook, Twitter, Tumblr, or other mainstream social media outlets could help users readily promote campaigns with specific, different social media audiences. Such an option would undoubtedly benefit all crowdfunders, but would be especially beneficial

for those with heightened privacy needs. Although transmen must navigate the same tension between privacy and self-promotion as many other crowdfunders [e.g. 7], previous work and evidence from these interviews suggests that those in the LGBTQ community are particularly aware of this tension and, like other stigmatized individuals that are susceptible to attack, benefit from enhanced control over online presentations [5, 11]. Being able to efficiently share content between the crowdfunding site and select social media outlets would better help users navigate this often complicated social landscape.

The other reoccurring theme was the ability of a site to convey intangibles. For example, informants were attuned to discrimination in all its forms—often recognizing, for example, that despite their hardships, these White mainly transmasculine identifying participants often had an easier time getting through life than transwomen or trans people of color. Such values were reflected in the sites they chose to host their campaigns. As another example of the importance of intangibles, informants were deeply invested in the psychological benefits of receiving positive feedback via a campaign. Crowdfunding necessarily required that these transmen publicize their stigmatized identities. As a result, many were awestruck by even small donations or encouraging words that they received. This support in the face of potential bigotry was very powerful and often an unexpected benefit that became the heart of the crowdfunding experience.

Given the importance of intangibles for this community, HCI researchers and designers should explore ways to highlight the social and political experience of crowdfunders. For example, cross-site comments from supporters could be made public beyond the crowdfunding site, if agreed upon by both user and commenter and made permissible by privacy settings. Having supportive comments on YouCaring that automatically update on Facebook, Tumblr, Twitter, etc, could further enhance the positive psychological benefits of crowdfunding for users, as well as raise visibility of the campaign. Furthermore, increased public affirmation of members of the trans\* community could be useful for other LGBTQ people and allies who benefit from public portrayals of trans\* people. As Ben noted, given the dearth of trans figures in corporate media, broadcasting everyday trans experiences through social media, including crowdfunding, can help increase visibility and, as a result, increase social acceptance of self and others.

As another way to foreground intangibles, it could also be an effective marketing approach for site runners to highlight values that might align a site with marginalized groups. This may increase adherents and draw certain users (of course, this could alienate other users, and thus would hinge on the politics and values at each corporation). But, as these findings underscore, politics are not removed from the marketplace. These insights might even suggest an opportunity to design a new crowdfunding site framed

around social justice issues, highlighting the needs of individuals from marginalized communities (as an international example: [www.watsi.org](http://www.watsi.org)). A site that foregrounds its politics, regardless of what those politics are, could conceivably tap into existing communities, thus signaling potential supporters and better enabling users to reach beyond personal social networks in an online space that is explicitly accepting.

## CONCLUSION

Our aim with this paper is to explore how a stigmatized group—transmen—navigate the highly public space of crowdfunding, and in doing so broaden the HCI discourse on queer and trans\* identities online. In reality, any individual facing unmanageable medical costs and grappling with health and financial problems is likely to be in a vulnerable state. Transmen underscore those vulnerabilities, as they and other members of the LGBTQ community often experience a heightened need for agency over identity representation and protection from stigmatization [3, 11]. Yet, as [3] note, seeking support online necessarily means disclosing hardships. In other words, publicly proclaiming the need for financial support, especially in response to a medical procedure, would likely be difficult for most people. Insights gleaned from these interviews may help crowdfunding site owners and designers consider ways to best assist individuals in their crowdfunding experience, and generally support the needs of those who may have some ambivalence about promoting their campaign even as they reach out to large public networks. Suggesting opportunities for optimizing flexibility and highlighting intangibles in crowdfunding site design are just two approaches that may not only improve the crowdfunding experience, but may be relevant for other sites that serve similarly vulnerable populations.

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