

## Designing a Social Support Platform for Adolescents Diagnosed with Cancer

### **Background**

From experiencing pain to anxiety, stress, and isolation, undergoing cancer treatment can negatively impact an individual's quality of life. This is especially true for adolescents who are more sensitive to psychosocial factors and who benefit from interventions that are developmentally appropriate (Pennant et al., 2020). As a result, it is crucial to have tailored interventions for adolescents receiving cancer treatment that address unique biopsychosocial needs of adolescent development. One such intervention, Pain Buddy, was developed to improve quality of life for pediatric cancer patients. Pain Buddy is a mobile health (mHealth) application that allows children to record their pain and symptoms experienced during cancer treatment. The app focuses on symptom management and incorporates evidence-based pain coping skills such as deep breathing, mindfulness, and visual imagery. The skills training component is designed to help develop self-efficacy in youth in pain and symptom management in the home setting. Data collected during the study period show that the Pain Buddy intervention group reported far fewer instances of moderate-severe pain in relation to the control group (Hunter et al., 2020). These findings indicate that Pain Buddy may help to reduce the severity of pain in children and adolescents undergoing cancer treatment.

While Pain Buddy has made great strides in the development of pain management strategies, the app does not currently include a social support component. Undergoing cancer treatment and experiencing pain symptoms can be very isolating for adolescents, both while they are at home and while they are hospitalized. Adolescents have indicated that having a strong social support system is crucial to helping them deal with challenges during their cancer experiences (Woodgate, 2006). An ability for adolescents to form strong social connections during their cancer treatment remains a gap and seems to be a potentially beneficial component to incorporate into Pain Buddy.

Various social media outlets have been used as a way to offer social support and connect cancer patients. Preliminary data collected by interviewing caregivers of youth with cancer in the UCI Center on Stress & Health has highlighted the need of adolescents to connect with peers going through similar experiences. They have indicated wanting a place to connect to be able to share their experiences and ask questions. Research focused on cancer-related communication suggests that cancer caregivers use their Facebook pages as a platform to communicate and support one another through the sharing of personal experiences (Gage-Bouchard et al., 2017). In addition, research focused on online health communities shows the importance of sharing experiences amongst peers. In the online communities examined, individuals shared their disease experiences and asked each other for help, and "disease veterans" shared their experiences with

newer sufferers of the disease (Willis, 2016). It is clear that online health communities and support groups have revolutionized how people are able to connect and offer each other social support. Patients can exchange peer support online and connect with others going through similar experiences, without dealing with restrictions such as location or timing (Zhang et al., 2017).

Patient participation in online support groups can have empowering processes for individuals. Sharing experiences, information, and emotional support is associated with positive outcomes such as better acceptance of their disease, feeling more informed, and increased optimism and overall social well-being (Van Uden-Kraan et al., 2008). Social support also seems to be a key factor in building resilience. Breast cancer patients with stronger social support networks also experienced a better quality of life (Zhang et al., 2017). Pennant et al. (2020) also found consistent findings when examining the role of social support for adolescents with cancer. Social support helps adolescents to better cope with their cancer diagnosis and throughout their cancer treatment (Pennant et al., 2020). The prior research suggests that social support enhances coping abilities and overall resilience during an individual's cancer treatment, which emphasizes the need to incorporate connection between participants in the Pain Buddy intervention.

## **Objective**

The overall goal of this research project is to develop an online social connection platform and integrate it into the Pain Buddy intervention. This project includes two phases, the first of which has been completed. The objective of Phase 2 of this project is to conduct formative evaluation and refinement of a beta version of the social connection platform. The feedback received from adolescent stakeholders from the larger Pain Buddy effectiveness trial will help to refine the website and ensure that it is a platform they want to use. The ORBIT Model will guide the multiple phases of this research project and can be broken down into four phases: phase 1 is the needs assessment, phase 2 is the formative evaluation, phase 3 is feasibility and efficacy testing, and phase 4 tests the effectiveness of the intervention (Czajkowski et al., 2015). It is necessary to conduct formative evaluation before an intervention study to ensure the website is user friendly and visually appealing to participants. As evidenced by the literature review, a long-term outcome of this study is that adolescent cancer patients who have more support and are connected to other patients going through similar experiences will experience a better quality of life. This research is significant for understanding the importance of social connection for adolescent cancer patients.

## **Methods**

### *Preliminary Data: Phase 1 Needs Assessment*

Phase 1 of this project used a qualitative approach to assess the social support needs of adolescents undergoing cancer treatment. During the 2021 summer, in-depth interviews were conducted with four adolescents between the ages of 14-17 years. The interviews were focused on gaining an understanding of their social media use, social support needs, and level of interest in online health communities. All of the adolescents interviewed during phase 1 expressed

interest in connecting with peers who were also undergoing cancer treatment. Consistently identified features of a platform included: the ability to discuss their experiences during cancer treatment, chat with each other using online messaging, and socially connect based on their interests. With an understanding of the participants' interests and social support needs, we began working with California Institute for Telecommunications and Information Technology (Calit2) to develop a beta website that is able to socially engage and connect adolescent cancer patients. During phase 2 of this project, I am going to conduct formative evaluation of the beta version of the Pain Buddy social connection website.

### *Participants*

Participants for this study will be recruited from the pool of individuals who have already participated in or are current participants of the Pain Buddy study. The inclusion criteria for participants consists of the patient: being between the ages of 12-17 years old, being within 16 weeks of a first-time cancer diagnosis, currently undergoing outpatient cancer treatment, previously having experienced a pain score of 30 or greater on the visual analog scale in the past month, being able to speak, read, and write in English, and having internet access on their mobile device.

I will recruit and interview a total of 20 participants by the spring, as a subset of the larger study. It is feasible to conduct a study with this sample size, based on the high consent rate of approximately 80% from Pain Buddy. On average we recruit 3 participants a month to be part of Pain Buddy, so this will continue to increase the pool from which we can draw from for this project.

### *Thematic Analysis*

Semi-structured interviews will be held either in person or through video conferencing with participants who give their consent to participate in this study. During the interview, the participant will navigate through the website and then I will ask for their feedback. Open-ended questions focused on the usability, likeability, and relevance of the website will be asked during the interview process. Interviews will be audio recorded, and then transcribed. The qualitative data collected from interviews will be analyzed to identify connections between all of the transcribed interview notes (Noble & Mitchell, 2016). This will involve coding each line of the interview notes in order to highlight key phrases and themes. The thematic analysis will allow me to gain an understanding of whether adolescents like the design and features of the social connection website, would want to use it, and would find it useful.

### *Iterative Approach*

An iterative approach will be taken to refine the beta platform. Interviews will be conducted in three iterations. I will hold 6-7 interviews per iteration or until we receive consistent feedback from participants and reach thematic saturation. After each iteration of interviews, we will make changes to the website based on the feedback we receive from

participants. Once the feedback is integrated into the website, I will conduct another iteration of interviews and repeat this process until all 20 participants have been interviewed.

## Budget

Even though this is part of the larger Pain Buddy study, there is currently no funding towards this specific aim. For this reason, I am respectfully requesting \$1,000 for study materials that will allow me to successfully complete my research project.

Budget Item	Amount	Rationale for Request
Participant compensation: 20 \$25 gift cards	\$500	Compensating the study participants after the interviews
Qualitative software: 10 hours of NVivo transcriptions	\$200	Software to assist with transcribing the interview audio recordings
Website development: purchasing a server, a domain name, and a Canva Pro subscription	\$200	Ensures we can integrate the participants' feedback into the website after each iteration of interviews
Presentation materials: poster supplies	\$100	To be able to create a poster to display my findings at the UROP symposium

## Responsibilities

I will be responsible for recruiting participants to be part of this research project as well as collecting and analyzing data. This will consist of conducting the interviews, transcribing audio recordings, and coding interview data. I will have regular weekly meetings with my faculty mentor to discuss the progress of the project. I will also have monthly meetings with the California Institute for Telecommunications and Information Technology (Calit2) team to discuss changes that should be made to the beta website.

## Timeline

### *Fall Quarter*

- Submit an IRB amendment to be able to show participants the beta version of the website and get their feedback: ~6 weeks for approval

### *Winter Quarter*

- Iteration 1: ~3 weeks
  - Conduct semi-structured qualitative interviews with 6-7 participants until we reach thematic saturation
  - Transcribe the interview audio recordings
  - Code and analyze transcribed interview data
  - Integrate the participants' feedback into the website

- Iteration 2: ~3 weeks
  - Conduct semi-structured qualitative interviews with 6-7 participants until we reach thematic saturation
  - Transcribe the interview audio recordings
  - Code and analyze transcribed interview data
  - Integrate the participants' feedback into the website
- Iteration 3: ~3 weeks
  - Conduct semi-structured qualitative interviews with 6-7 participants until we reach thematic saturation
  - Transcribe the interview audio recordings
  - Code and analyze transcribed interview data
  - Integrate the participants' feedback into the website

#### *Spring Quarter*

- Complete the data analysis of the interviews
- Finish writing my research thesis paper
- Present my findings at the UROP symposium in May

#### *Future steps of the project:*

The social connection platform will be integrated into the overall Pain Buddy intervention where participants will be able to use the website and connect with one another. Psychosocial outcomes will be examined in adolescents to understand the significance of social support.

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## **Appendix: Interview Guide**

Below are sample questions that we will ask participants during the semi-structured interview process:

### Social Support Needs

1. Tell me about some kinds of social support you've used during treatment.
2. Some people get support through social media or text messaging. What are your thoughts on getting social support online?
3. Would you like to connect more with people your age who are also going through treatment?
  - a. Why or why not?
  - b. Specifically, what are your thoughts on being able to connect with teens also using Pain Buddy?

### Website Look and Design

1. What do you think about the look of the website?
  - a. Colors, font, and graphics etc
2. What are your thoughts on the layout of the website?
  - a. What do you like / dislike?
  - b. What would you change?

### Usability

1. How usable did you find the website?
  - a. What made it easy or hard to use?
  - b. What do you like / dislike?
2. What did you think about navigating through each of the sections of the website?
3. How does it compare to other social media platforms you use?
  - a. What would you change?

### Features

1. What are your thoughts on the features included in this platform?
2. What changes would you like to see made to the website?
  - a. What would you change or take away?
3. What features would you like to see added to the website?

### Connection

1. What are your thoughts on the map and search feature?
  - a. What do you like / dislike about it?
  - b. What would you add or change?
2. What's your preferred method of contacting people?
  - a. Phone, email, social media

3. Would you like to be able to chat with people directly on the website?
  - a. Do you prefer individual chatting or group chatting?

### Profile

1. Tell me your thoughts on creating your profile.
  - a. What do you like / dislike about the profile?
2. What additional information would you like us to include in the profile section?
3. Are there any questions you'd like us to remove from the profile?
4. Are there additional interests that you'd like to see included?
5. What are your thoughts on having the ability to remain anonymous?

### Relevance

1. Tell me your thoughts on how useful you think this website is.
  - a. Do you think this website would be helpful for you?
  - b. How can we make it more useful?
2. Would you want to use this website?
  - a. If yes, what makes you want to use this website to connect with other teens?
  - b. If no, what makes you not want to use this?
3. What about the website makes you want to use it or not want to use it?

### Other

1. On a scale from 1 to 5, how much do you agree with the following statements? (1 being strongly disagree and 5 being strongly agree)
  - a. I like how this website looks.
  - b. I think this website is easy to use.
  - c. I would like to use this website frequently.
  - d. I would feel comfortable interacting with people through this website.
  - e. I think this website would be helpful for me.
2. Is there anything else you'd like to tell us about the website?
  - a. Any comments or suggestions you have that we haven't discussed?