Designing a Patient-Centered Clinical Workflow to Assess Cyberbully Experiences of Youths in the U.S. Healthcare System

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DESIGNING A PATIENT-CENTERED CLINICAL WORKFLOW TO ASSESS CYBERBULLY EXPERIENCES OF YOUTHS IN THE U.S. HEALTHCARE SYSTEM

by

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ABSTRACT

DESIGNING A PATIENT-CENTERED CLINICAL WORKFLOW TO ASSESS CYBERBULLY EXPERIENCES OF YOUTHS IN THE U.S. HEALTHCARE SYSTEM

Fayika Farhat Nova

Marquette University, 2022

Cyberbullying or online harassment is often defined as when someone repeatedly and intentionally harasses, mistreats, or makes fun of others aiming to scare, anger or shame them using electronic devices [296]. Youths experiencing cyberbullying report higher levels of anxiety and depression, mental distress, suicide thoughts, and substance abuse than their non-bullied peers [360, 605, 261, 354]. Even though bullying is associated with significant health problems, to date, very little youth anti-bullying efforts are initiated and directed in clinical settings. There is presently no standardized procedure or workflow across health systems for systematically assessing cyberbullying or other equally dangerous online activities among vulnerable groups like children or adolescents [599].

Therefore, I developed a series of research projects to link digital indicators of cyberbullying or online harassment to clinical practices by advocating design considerations for a patient-centered clinical assessment and workflow that addresses patients' needs and expectations to ensure quality care. Through this dissertation, I aim to answer these high-level research questions:

RQ1. How does the presence of severe online harassment on online platforms contribute to negative experiences and risky behaviors within vulnerable populations?

RQ2. How efficient is the current mechanism of screening these risky online negative experiences and behaviors, specifically related to cyberbully, within at-risk populations like adolescent in clinical settings?

RQ3. How might evidence of activities and negative harassing experiences on online platforms best be integrated into electronic health records during clinical treatment?

I first explore how harassment is presented within different social media platforms from diverse contexts and cultural norms (study 1,2, and 3); next, by analyzing actual patient data, I address current limitations in the screening process in clinical settings that fail to efficiently address core aspect of cyberbullying and their consequences within adolescent patients (study 4 and 5); finally, connecting all my findings, I recommend specific design guidelines for a refined screening tool and structured processes for implementation and integration of the screened data into patients' electronic health records (EHRs) for better patient assessment and treatment outcomes around cyberbully within adolescent patients (study 6).

I dedicate this dissertation to my parents and my husband for their continued love and support.

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CHAPTER 1 - INTRODUCTION

An increase in technological involvement has altered people's interactions online allowing them to express a variety of risky online activities, which is particularly prominent among adolescents [247].Such actions include involvement in a variety of circumstances that increase the likelihood of undesirable repercussions to oneself or others, such as emotional distress and victimization [606, 247]. A meta-analysis by [352] found that risky online behaviors are substantially linked to perpetrating cyberbullying. Some define cyberbullying or online harassment as when someone repeatedly and intentionally harasses, mistreats, or makes fun of another person aiming to scare, anger, or shame them using cell phones or other electronic media, like social media, online chat, online games, etc. [296]. Common cyberbullying behaviors include flaming, harassment, impersonation, exclusion, cyber stalking, and so on [431]. Hinduja and Patchin have reported that like traditional bullying, cyberbullying includes "being ignored, disrespected, picked on, or otherwise hassled" [294].

Despite a long history of research into online misbehavior, poor online experiences [449, 107, 495], and community moderation [125, 363], harassment and other types of abuse continue to be a persistent problem online for vulnerable populations. My previous work have discussed such harassment and classified it in terms of sexual content as well as audience concerns within populations like gender and sexually minor community [449, 446]. Newer technological features are constantly used to debase people, such as spreading rumors, stalking, or threatening, which makes cyberbullying more harmful and dangerous than traditional bullying [595], as often there is no repercussion. Increased digital exposure to a potential perpetrator of cyberbullying seems to increase the odds of victimization, in much the same way that greater exposure to a traditional aggressor can increase the odds of becoming an in-person target [386]. The more frequently a user is online, the higher their visibility and accessibility in online spaces as a potential target [211].

In the last decade, attention on how the social media landscape impacts mental health has drastically increased [198]. While these aspects of negative experiences online may have attracted attention from social computing and HCI researchers due to their increased impacts on individuals, the explorations are certainly narrowed for vulnerable populations from diverse cultural and social contexts [446]. Targets of online harassment or cyberbullying frequently report disruptions to their offline and online lives, including limited presentation flexibility, complex self-presentation strategies, and compromised safety and privacy concerns [204, 446, 39]. With the ubiquity of smartphones and constant connectedness of both teens and adults in America through online platforms [52], it is observed that many individuals have engaged in and/or been exposed to risky behaviors online, which had dire consequences [480, 146]. My previous work has investigated the impacts of online communities on this unhealthy exposure to risky behaviors, which led to many community members adopting eating disorder-related lifestyles and engaging in self-harassment[444]. This unhealthy adoption of behaviors can have severe mental health consequences. Like traditionally bullied youth, cyberbullied youth report higher levels of depression and anxiety, emotional distress, suicidal ideation and attempts, somatic complaints, poorer physical health, and externalizing problems such as increased delinquency and substance abuse than their non-bullied peers [360, 605, 261, 354]. While reporting of abuse by victims of online harassment is uncommon and often goes against social norms in many cultural contexts [449, 446, 39], children and teenagers are far less likely to disclose such incidents to anyone [573, 547]. Even though bullying is associated with significant health problems, and as per some research, bullied youth want the help of health care providers, to date, most youth anti-bullying efforts are initiated and directed primarily by the education system and not by the healthcare providers [547, 398, 87, 605].

Bullying is a major public health issue that demands the concerted and coordinated time and attention of health-care providers, policy-makers, and families [572]. Because of the extent to which social media has permeated our culture, parents and clinicians are increasingly concerned about how to protect children against vulnerabilities unique to the modern social media landscape [614]. Due to the severity of the problem and the possible long-term consequences, cyberbullying requires screening [249]. Consistent and frequent screening allows practitioners to create baselines, detect problems that require intervention, and provide information on the efficacy of the treatment [249]. According to a previous study, 7.6% of participants were unsure if they had ever experienced cyberbullying [32]. While research on cyberbullying is growing, there is no consistency among studies in how it is defined or in the domain of behavior sampled by cyberbullying measures [406]. This is critical to consider when assessing a patient for potential cyberbullying exposure because the child or adolescent may have a completely different viewpoint or understanding of cyberbullying than the provider, making it easy to miss victims. Previous literature has highlighted this potential discrepancy while reporting on cyberbullying in adolescent populations [480]. Since victims of bullying and cyberbullying typically may not want to talk about their situation, especially with adults, healthcare professionals should be equipped with information about probable indications and symptoms to be aware of [605].

While there is a rising concern about the effects of cyberbullying on victims, there are currently no standardized methods, processes, or even screening across health systems for diagnosing and treating cyberbullying or other similarly risky online behaviors among highly vulnerable groups [599, 121, 453].

In the current setting, it is challenging for healthcare professionals to implement systematic screening for socio-technical concerns among the patients due to the lack the capacity, workflows, and incentives [161, 31]. Many healthcare providers are even reluctant to screen patients for bullying involvement because they lack education and training on bullying prevention [410]. Many hospitals and healthcare practices fail to effectively incorporate social features and behaviors into patients' electronic health records (EHRs) because of such systematic flaws [68]. EHR is the foundational tool for collaborative work within the modern healthcare setting [118]. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users and can provide a broader understanding of patients at the aggregate level[218]. Because the same EHR model may not work for every medical institution, it is critical to create a systematic protocol to integrate data in patients' EHRs that seamlessly fit into the workflow pattern of that specific medical organization. However, it is not always possible due to limited effort, in-depth knowledge on the domains and quality of the data, and proper analysis of the screening protocols.

To address these issues, I designed a set of research studies that would allow me to connect the digital signals of cyberbullying or online harassment to clinical practices, as it relates to severe mental and behavioral consequences within adolescents. To do so, I first characterized how these negative experiences are presented within the current generation of social media platforms from diverse contexts and cultural norms, and then I explored and analyzed the current mechanism of assessing these socio-cultural and behavioral aspects within adolescents in clinical settings, potentially bridging my acquired knowledge of online bully-related activities with specific clinical indicators and patient data. This dissertation will seek to make contributions addressing these gaps in **knowledge** at the intersection of **social computing** and **healthcare system** by answering the following research questions:

RQ1) How does the presence of severe online harassment on online platforms contribute to negative experiences and risky behaviors within vulnerable populations?

RQ2) How efficient is the current mechanism of screening these risky online negative experiences and behaviors, specifically related to cyberbully, within at risk populations like adolescent in clinical settings?

RQ3) How might evidence of activities and negative harassing experiences on online platforms best be integrated into electronic health records during clinical treatment?

To answer these questions, I have closely worked with Parkview Behavioral Health (PBH) Institute, as they have inpatient treatment programs that offer support to adults and youth whose mental health requires short-term intervention and provide a screening survey on their bullying/cyberbullying experiences during intake. Each research study included in this dissertation has its own set of research questions that, when combined, assisted me in answering the high-level research questions I outlined earlier. The dissertation employed multiple mixed methods approaches including different statistical analysis, topic modeling, factor analysis, inductive thematic analysis, and qualitative assessment of the data collected from multiple sources (online users, health care providers, patient's EHR, current literature, etc.) and proposed curated and comprehensive screening tool and workflow that benefit both patients and providers. My recommendations can improve treatment interventions and quality of care by structurally integrating key social aspects into patients' online health records. The overall overview of the dissertation research questions, methods, and data are given below in Table 1.1.

Healthcare Settings

All provider and patient related research described in this dissertation took place in Fort Wayne, IN in collaboration with the Parkview Behavioral Health (PBH) Institute. Fort Wayne is the second largest city in Indiana and located in the Northwest region of the state, with a population of approximately 343,000 [12]. The median income in Fort Wayne is $51,454 and ap-

Research Question (RQ)	Method	Data
How does the presence of severe online harassment on online platforms contribute to negative experiences and risky behaviors within vulnerable populations?	Quantitative analysis of online survey and thematic analysis (codebook) of semi-structured interviews of victims of anonymous online harassment	291 surveys 27 interviews
	Thematic analysis of interviews, focus group discussions, unstructured online observations of Hijra populations who experience severe online harassment on social media for their gender and sexually minor identities and community values	16 interviews, 61 focus group participants
	Network analysis and quantitative (Topic modeling, content analysis)and qualitative (Codebook analysis) assessment of online con tents related to eating disorder (ED) and self-harassment on Twitter	over 32,000 public posts
How efficient is the current mechanism of screening these risky online negative experiences and behaviors, specifically related to cyberbully, within at risk populations like adolescent in clinical settings?	Retrospective chart review using deductive thematic analysis on patients' clinical notes. The data was collected using the cyberbully screening used at PBH, ICD-10 code, and adverse childhood experience (ACEs) screener tool	719 patient data
	Factor Analysis of adolescent patients and their parents' data collected through cyberbully screening tool used at PBH to measure its reliability and validity	382 patient survey, 331 parent survey
How might evidence of activities and negative harassing experiences on online platforms best be integrated into electronic health records during clinical treatment?	Qualitative analysis of interviews with healthcare providers', card sorting, and shadow observation of clinicians who interact with patients directly during treatment at PBH	6 providers interview and card sorting, 7 healthcare roles for shadow observation

Table 1.1: Overview of Dissertation RQs, Methods, & Data

proximately 15.5% of the population live at or below the poverty line [17]. The population is 72.0% Caucasian, 15.0% African American, 9.1% Hispanic, and 5.0% Asian [17]. PBH Institute provides easy access to the most robust continuum of services in northeast Indiana that impact an individual's emotional and mental well-being or recovery from substance use. The direct service area includes 15 counties with close to 1,000,000 individuals. They have both inpatient hospitalization and outpatient services for both adults and youths. Their skilled mental health teams work directly with the adolescent patients and their families/guardians to develop an individualized care plan that encourages healing and recovery. Through the Child and Adolescent Youth Services program, the patient at PBH can receive one-on-one support and education, become more aware of, and learn to appropriately express, their emotions and needs, build self-esteem and interpersonal skills, learn problem-solving skills, participate in art and recreational therapy, exercise, and other movement activities. The institute also offers family therapy and parent education sessions, as family members most often facilitate positive change in children and adolescents.

Overview

In the beginning of my dissertation in chapter 2, I first offer a comprehensive overview of the multiple online harassment-related experiences that occur on anonymous social media platforms, highlighting the major social and cultural influences on such behaviors from non-Western contexts. This study helped me to build premises on the uncontrollable exposure online that may lead to unwanted experiences perpetrated by anonymous people from victims' known social networks, resulting in mental trauma.

For my goal to build better contextual knowledge on online exposure of harassment, in chapter 3, I critically investigated how vulnerable populations, such as gender and sexually minor communities from non-Western contexts interact on social media. I explored their self-presentation strategies and contextualized the presence of community and cultural influence on their perceptions and experiences of harassment online. I particularly looked at the Hijra community from Bangladesh to understand how their identity becomes a crucial factor behind the kind of harassment they face in a daily basis and how these experiences shape their perception of online privacy, safety, and platform affordances.

Chapter 4 investigated the influence of online communities in instilling antagonistic behaviors and risky health lifestyles under the pretext of motivation or inspiration. Using a mixed methods approach, I investigated Twitter eating disorder (ED) communities in to link harmful online activities with severe health implications in vulnerable users, revealing how harassment may be both internal (on oneself) and external (on others).

Chapter 5 used direct clinical insights from patients' EHRs and connected adolescents' experiences of cyberbullying and adverse childhood experiences (ACEs) to explore and establish how the current screening mechanism of cyberbullying in clinical settings can help clinicians build better knowledge on patients' mental and behavioral health. In the absence of a formalized diagnostic process, this study also emphasized the importance of using clinical narratives as the data source and provides clinical and computational guidelines as design considerations for better EHR data integration, analysis, and interpretation of screening data.

In chapter 6, I unpacked and explored the current assessment process of adolescent patients' cyberbullying experiences in clinical settings and measured the efficacy of the screening tool that currently is being used in healthcare. The goal was to identify the potential venue of improvement that can help both providers and patients to engage more in a patient-centered supportive environment.

In chapter 7, I reflected on the data collected from the healthcare providers and combined my findings to propose a design framework that adds to the existing assessment process of screening online risky behavior and experiences, such as cyberbullying within adolescents, in clinical settings and seek to develop a comprehensive blueprint of integrating and accessing information from the screening into patient's EHR. This study classified the current challenges in the assessment processes and outlined possible design recommendations by focusing on patient-centered care and methodological inputs.

In Chapter 8, I reflected on the body of this dissertation research and reviewed the various contributions that emerged from my work. In doing so, I discussed the ramifications of my work in the social computing and healthcare domains, as well as how the outcomes of different chapters helped me to build more effective strategies for integrating digital signals of harassment into clinical practices. This chapter also offered recommendations for future studies in this area by leveraging social media data for mental health interventionists.

CHAPTER 2 - UNDERSTANDING ONLINE HARASSMENT IN ANONYMOUS SOCIAL MEDIA FROM NON-WESTERN CONTEXT

Introduction

The ability to stay anonymous directly affects how individuals behave online. Anonymous social media (ASMs) like *Ask.fm*, *Yik Yak*, *Secret*, and *Sarahah* have brought changes to the practice of communication among users by allowing them to express their thoughts and opinions anonymously, unlike many mainstream platforms. Several studies have been conducted to identify the motivations of using anonymous applications [104, 148, 334]. These studies show that some people prefer ASM for achieving protection against their socially disapproved behaviors, including online harassment [148, 334], while some may seek it to share anything on the internet without the fear of social retaliation [104]. Although most studies on anonymity and anonymous social media situate itself around western context [148, 150, 239], they often do not consider the cultural, geographical, historical, and economical differences that may influence activities like online harassment in developing context [520].

In this particular study, I have focused on the ASM experiences of Bangladeshi users. Bangladesh is a developing country that has made significant progress in ICT sector [315]. At the time of this research, ASMs like Ask.fm and Sarahah were extremely popular among the young generations in Bangladesh [577, 219]. Although previous studies on ASMs show how often these platforms promote online harassment [104, 148], no proper study has been done in Bangladesh to investigate such events from this contextual background. This creates a gap in the existing literature, where understanding on the situated experiences of sexual harassment through ASMs in a non-Western contexts is almost absent.

To comprehend the gravity of harassment related with the use of ASMs in the context of low and middle income countries (LMICs), it is necessary to consider local misogyny, patriarchy, and gender-based violence [580, 342] that often reform how people behave on social media [44, 317]. In this study, I investigate different harassment experiences that are triggered by different socio-cultural norms, users' expectations, and suspicion about harasser's identity while using ASMs in Bangladesh. This study also instigates how these users respond to such harassment, and continue to participate on ASMs. Thus, the gaps identified in these prior works led to the following over-arching research questions:

- **RQ1:** *What are the different types of harassment users experience using anonymous social media platforms in Bangladesh?*
- **RQ2:** *How do the users respond to such harassment experiences and continue participation on the platforms?*

I have conducted a mixed methods study that includes an anonymous online survey consisting of 291 respondents and an interview study with 27 participants. Although the survey and interviews mostly include participants from mid to high socioeconomic status (SES) (due to convenience and snowball sampling and also higher Internet access among urban population [69]), the experience of harassment through ASMs and its relationship with different socio-cultural practices of Bangladesh was undoubtedly severe to the victims regardless of their SES. Through inductive qualitative assessment and quantifiable survey inputs, this study identifies-

- A large portion of the ASMs users in this study, mostly women, face harassment through ASMs, which can be grouped into sexual proposition, sexually objectifying contents, romantic messages, and dating inquiries. According to the majority of the participants, the most prevalent harassment they faced through ASMs is sexual harassment
- Although the harassment happens anonymously, a majority of the times,

it is suspected or found to be done by someone victims know, which further causes emotional distress and misery among the victims

- Although these harassing experiences sometimes result into resistance, due to the lack of proper social support, and social practice of victim blaming and humiliation, it often causes technology withdrawal and non-use among users in Bangladesh

This study makes three key contributions to the existing literature by **1)** exploring the concept of harassment in ASMs from developing contextual background and further classifies it into detailed categories, **2)** investigating victim's responses to online harassment in terms of suspicion, resistance, silence and non-use that are impacted by their cultural and social norms as well as have a larger effect on their social and mental state, **3)** proposing a set of design and policy recommendations for such anonymous social media to extend the current literature on ensuring a safer online environment for women, especially in low and middle income countries.

In the following sections, I first outlined what anonymity implies in the online realm and how it enables occurrences like online harassment through ASMs. The research goes on to explain harassment in relation to various cultural values and social behaviors that exist in underdeveloped nations such as Bangladesh. Finally, the research offers the results of its extensive data analysis, which characterizes various types of harassment experiences by users from Bangladesh and explores different design and policy awareness. This work was originally published at ICTD conference in 2019 [449].

Definition of Anonymity and Anonymous Social Media

The definition of anonymity can vary from context to context. According to Gary Marx's earlier analysis, anonymity means being absolutely untraceable in every sense [333]. However, in addressing the anonymity connected with online communication today, Marx included a few more contextual variables that may characterize anonymity more broadly [391]. He suggested that online anonymity broadly involves the concepts of availability and unavailability of the person's physical existence rather than ensuring a true traceability [391]. In online discourse, people frequently value their privacy and seek to remain anonymous by concealing any traceable cue [333]. Anonymity here can be defined as *"unlinkability between the initiator and respondent, where these two entities cannot be identified as communicating with each other"* [555]. There are differences in the features and levels of anonymity provided by online applications [168]. While some applications provide options for managing the level of anonymity (like Ask.fm), some applications have the default option of anonymity implemented in them (like Sarahah, Whisper). However, hundred percent anonymity on the Internet can never be ensured due to the possibility of leaving traceable clues (user's attributes, time frame, subject matter etc.) while communicating with someone [316, 489].

Anonymity and Harassment over the Internet

With anonymity, people can discuss or share unconventional or unwanted messages with others that may receive stricter scrutiny if discussed on other traditional platforms [148]. Because of its nature, online anonymity may often lead to violence, aggression, trolling, hostile commenting, deception, and cyberbullying- acts that are illegal or harmful [333, 148, 384]. Researchers have tried to explain the increased prevalence and severity of harassment over ASMs in various ways. For example, in computer-mediated communication, anonymity has been linked to less accountability [297] and more disinhibition [328, 578]. These disinhibitions might lead to negative behaviors such as bullying and flaming [297]. Online anonymity can encourage people to behave deviant that they would not do otherwise [541] like attacking others or engaging in socially unacceptable and undesirable activities [333], as anonymity provides them a freedom from "being held accountable for inappropriate online behaviour" [106]. Such online harassment may not cause any physical damage initially, but may slowly trigger devastating psychological impacts including depression and low self-esteem among the victims, and even sometimes leads to suicide [354]. Anonymous application, Yik Yak, was banned from the market due to its massive reputation on cyberbullying that included sexual defamation [496] and yet, new ASM platform emerges time to time that provides a similar environment for communication.

Harassment Against Marginalized Populations

Harassment is often a way of exerting power over marginalized populations [602]. When a person feels compelled to make another person feel helpless by displaying superior power, they frequently resort to harassment, as evidenced in many cases of sexual harassment [385]. Such a demonstration of power is not new in the patriarchal society of Bangladesh. The cultural values and social practices in most communities of Bangladesh are discriminatory against women [641]. Women who face sexual harassment, often prefer to be passive than giving any response or reaction to the harassment [272, 627, 448], and this preference of being passive is often shaped by the contextual traditions, socio-cultural norms and unwritten expectations from women [272]. Such online harassment cause depression, guilt, embarrassment, and self-blame in the victims as well as affect the victim's family [42]. While these online harassment incidents mostly happen over media where normative practice includes non-anonymous identity (like Facebook) [42, 508], it is important to understand the severity of this issue over ASMs - where identity is not revealed, especially when such applications are often becoming popular in Bangladeshi online sphere.

Existing Western studies on ASMs and associated harassment may have provided information on the severity and consequences of using ASM platforms, but it is critical to study and comprehend such events in the context of Bangladesh, given the country's growing Internet access and the presence of severe contextual harassment.

Methods

Study Overview

The goal of this study was to explore and understand different harassment related online experiences through ASMs and unpack the nature of response and consequences that follow such events. To accomplish this, I followed a mixed method strategy combining an online anonymous survey and semi-structured interviews for this study. All but one member of this research team were born and raised in Bangladesh, and all members speak Bengali as their first language. The survey was created in Bengali using an institutional Qualtrics platform [567] and distributed by members of the research team via public posts on their online social media accounts (Facebook and Twitter). The survey was accessible to all anonymous respondents in order to gain a better understanding of how users perceive anonymity. Next, I conducted a semi-structured interview based study to deepen the understanding regarding this issue. For semi-structured interviews, I first started hiring participants from my and my team's own social network. Then using snowball sampling, more participants joined the study [281]. I kept conducting interviews until theoretical saturation was reached [257]. The participation in this study was voluntary and the participants were not given any compensation for their participation.

Anonymous Survey and Interviews

The survey had a total of 47 questions for the participants, including numeric, categorized, and open-ended questions (link of the survey: https://bit.ly/3MFpGPl). The questions were meant to gather demographic information, ASM usage patterns, and diverse ASM experiences from respondents. The survey was open to collecting responses for 2 weeks. A total of 291 people took part in the survey. Basic statistical methods were used to analyze the quantitative component of the data. The key themes were extracted from the qualitative data through inductive thematic and codebook Analysis [257].

The participants for the interviews were selected with snowball sampling method [281]. The criterion for selection was having the experience of using at least one ASM. The interviews were conducted at public meeting places (parks or restaurants) that were convenient both for the participants and the interviewer. The questions of the interviews were designed to understand the individual insights and opinions. The interviews were conducted in Bengali. The interviews were about 30 minutes long on average. The interviews were audio recorded with the consent of the participants. Later, the interviews were translated and transcribed by two Bengali speaking members of my team. A total of 27 semi-structured interviews were conducted, where 14 were women and 13 were men. Their age ranged from 22 to 32 years. The interview questions asked about the participant's motivations, target audience, positive and negative experiences, strategies, and overall feelings surrounding ASMs, which helped us get a deep understanding of the pattern of usage of ASMs in Bangladesh (Appendix A1).

Qualitative Data Analysis

I opted for grounded theory approach [257] to analyze the qualitative data. While using a pre-existing theoretical framework might provide a vocabulary that is more accessible to a wider audience, I emphasized more on the contextual nuances that are closely associated with the use of technology by Bangladeshi people. This has motivated me to use the strength of grounded theory to better capture the experiences of this fairly under-studied population of the global south. First, the raw data was coded by one of the team members based on some similar keywords, which were later grouped into different categories. The codebook was created through several iterations of coding, based on the collected data until I reached a theoretical saturation. The categories formed from the codes were later grouped into different themes that helped me construct the findings from this study.

Results

Demographic information and Basic Survey Insights

Among the 291 survey participants, 55% was male and 41% was female, and the rest did not share their gender. The basic demographic information about the participants is given in Table 2.1.

Gender	M (55%), F (41%), Didn't Share (4%)
Age	21-32 years (93%)
Location	Dhaka (69%), Sylhet (17%), Others (14%)
Occupation	Students (73.27%)

Table 2.1: Description of Survey Participants

Among 291 survey participants, 143 (49.14%) used Sarahah, 115 (39.66%) used Ask.fm, and the rests used Yik Yak, Secret, and Whisper. A majority of them (89.17%) learned about these ASMs over Facebook when their friends either were using those or invited them to use. The rests learned about these ASMs from email, blogs, and other online sources. More than half of the participants (58.14%) started using these ASMs because they wanted to hear from people in their known social network. 21.51% started using those for connecting with unknown people who had an interest in them and etc. Not everyone received an equal number of anonymous messages through their ASM. The number varied from 1 to 30 with an average of μ=15.5 and a standard deviation of σ=8.80. Almost half of the participants (50.34%) often shared their received messages over Facebook and other social networks.

RQ1. Different Forms of Harassment Experiences Through ASMs

Experiences from Online Survey. To address RQ1, I asked the survey participants about the kind of messages they received over their ASM apps. Among 291 participants, 72 said that they received messages or questions that were 'uncomfortable' - of them 56.5% were women and 43.5% were men. Moreover, 104 participants said that they were harassed over messages - of

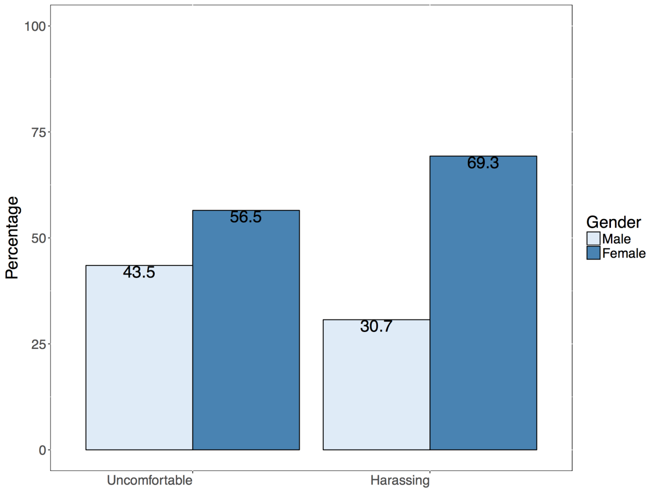


Figure 2.1: Experiences of Using ASMs Based on Gender

them 69.3% were women and 30.7% were men. These data are demonstrated in Figure 2.1. Responding to an optional open-ended question regarding the nature of such disturbing messages, 29 participants shared their experiences. Of them, 14 received messages that were so "personal" or "irrelevant" that they found those objectionable. One such participant said,

> *Someone was trying to flirt with me...they were asking me questions regarding my morale and ethics. That was totally annoying.* (male, age between 21-25 years)

Eight of them said the nature of the message was "sexual", and "offensive". For example, one of the participants (female, age between 21-25 years) mentioned that, through ASM, she was threatened to be raped and have unnatural sexual acts with the harasser. About one-third of these 29 participants did not respond to these offensive messages and ignored, while another one-third responded with angry messages. The remaining one-third either tried to guess the sender of the message, shared the message over Facebook to express their grief or uninstall the application. Besides these, a separate 23 participants said that they blocked one or more senders from their app for sending inappropriate messages.

The study showed that many of the participants tried to guess the sender of a message using various techniques. A total of 43 participants shared their techniques. 20 such participants have said that they tried to guess the sender based on the pattern of language, choice of words, use of punctuation, use of emoticons, and tone of the message. Seven participants have said that they also factored in the timing of the message and the context. Five participants have said that the content of the message allowed them to guess the sender.

While many participants reported receiving abusive messages, some of them also said how ASM actually helped them. Four participants said ASM also helped them to anonymously raise their voice to powerful entities of the society - including political parties, academic institutions, religion, etc. Eight participants said that Sarahah helped them to secretly express their romantic feelings to the person they liked. One such participant said,

> *It was difficult for me to share my feelings directly to the girl I like. So, I sent her messages. That helped.* (male, age between 21-25 years)

Finally, the findings showed most of the participants stopped using ASMs actively. Among 291 participants, 221 have either uninstalled those applications from their mobile phone and computer, or they stopped checking the messages that they receive. The rests said they use those application 'very few and far between'. I asked them the reason behind abandoning the ASMs, where among other popular reasons (faded fame of the ASM, friends stopped using etc.), 12.18% of the participants mentioned bad experiences of receiving offensive messages on ASMs as one of the reasons.

The online survey data have revealed some important aspects of ASM usage in Bangladesh. I have seen that most of the participants started using ASMs by being influenced by their friends and wanted to receive 'funny' messages from people among their known social circles. However, over the time, the platform started to become less interesting to them. What more alarming is, a good number of the participants (especially women) received disturbing messages and sexual abuses through these ASMs. These, along with some other issues, forced them to stop using ASMs. While these data thus gave me an idea about the prevalence and severity of sexual harassment on ASMs among Bangladeshi users, I also wanted to know more about the feelings of the participants, their reactions, and resistance to sexual harassment over ASMs. To get that insight, I conducted a set of semi-structured interviews described in the following section.

Experiences from Semi-structured Interviews. According to the interview data, 13 out of 14 female interviewees mentioned of being harassed through ASM. 11 out of 13 male interviewees said that at least one of their female friends, relatives, or acquaintances had been harassed over ASM. Although there were various ways the participants said harassment happened to them or to the people they knew, a few patterns emerged from their responses. For example, 19 out of 24 participants (who faced harassment or knew someone who did) mentioned about receiving messages that were purely ‘sexual’ in nature. In such messages, the sender expressed their desires to have sexual acts with the receiver. This kind of sexual harassment comes in the form of sending sexually explicit jokes, stories, or pictures. One of the participants said that, she was sexually harassed through ASM when,

> *Someone told me that he would f*ck me in a particular style (doggy), and he described the whole thing how he would f*ck me.* (female, age 22 years)

A related (and some participants identified those as ’lighter’) kind of harassment includes sending messages with romantic proposals. In some cases, the sender even proposed the receiver for a wedding. Such messages often include flirts, sexual remarks, and other flattering contents that the participants did not feel comfortable with.

> *Someone tried to flirt with me, instead of being married, by asking random questions which was lowering my social ethics or morality.* (female, age 24 years)

The third kind of sexual harassment happened when the sender sent messages that described the physical parts of the receivers in a derogatory way.

11 out of 24 received such messaged. In most of the cases, the participants suspected that those messages came from people who were in there close social circles and the sender had observed the receiver on a regular basis. This kind of messages again had two sub-categories. In the first sub-category, the sender described a certain body part of the receiver in a 'praising tone'. These kind of messages were often accompanied by a description of what the sender thought after seeing them. One such message was shared by one interviewee -

> *My friend got a text from an unknown source which talks about the shape and size of her lips, how beautiful they are and how juicy it would be to kiss.* (male, age 23 years)

In the second sub-category, the sender body-shamed the receiver by demeaning their body parts. In such cases, the sender tried to make the receiver feel bad about their body. Once such message was shared by one of the interview participants,

> *Why don't you have boobs? Didn't anyone touch you?* (female, age 22 years)

Another participant (female, age 29 years) mentioned that she was sexually harassed by the messages that talked about her big breast or used similar derogatory contents.

The fourth kind of sexual harassment that the participants received over ASMs was connected with their past or present relationship. 5 out of 24 received uncomfortable questions regarding their past relationship, which made them feel bad. They found those questions to be mean and attacking. For example, one of the participants said,

> *Someone asked me why I was in a relationship with my boyfriend and if there was a lack of boys out there... Other messages were like if I kissed my boyfriend, if I use dildo, if I was interested to give a blow job to the sender* (female, age 26 years)

Such derogatory messages not only offended the female users about their past relationships but also tried to make them feel embarrassed about current relationships. Men also received messages regarding their past and present relationships, but one major difference between those messages from the one women received was, their messages did not contain many sexually explicit words. One of the male participants said,

> *I got a message that had a story similar to my story with my ex, and I cried after reading that. (I am sure) She wrote it with all her good wishes.* (male, age 26 years)

The differences in quality and content of messages received by men and women on similar issues portray how women are often valued by their sexual appeals by the typical men in Bangladesh, and how that social construction is vividly visible over ASM as well.

User's Suspicions on Harassers and Expected Known Links. I found a common trend across all of the interview participants that they tried to guess the sender after receiving an anonymous message. In most cases, they suspected someone from their social circles to be the sender. Although theoretically the ASM profile link can reach to a stranger and the harassment might come from them, all of the participants who received harassing messages were suspicious that someone they knew had sent those messages. One of them (female, age 23 years) mentioned about sharing her personal Sarahah link only with friends on Facebook, which meant someone she knew sent her the dirty messages she received. The suspicion became stronger when the content of the message had some information that required close observation, something a person from a close social circle could only have. According to the participant,

> *I got messages that talks about my specific body parts and my dress size, how it was made, etc. So, it must be someone from my very close circle who stays around me* (female, age 24 years)

After being suspicious, the participants tried to guess the harasser using different strategies. Common phrases, mutual memories, slangs, word choices were used to devise strategies that were then used to discover the identity the anonymous sender. Some other participants tried to guess the harasser based on the content of the message. For example, one of them female, age 23 years) said, she received a message that talked about her personal insecurities that only her close people knew and so it was easy for her to guess who could send her such message. Sometimes, the harassing messages were also the result of a past animosity that the receivers could guess based on the content of the message. The receiver tried to guess the harasser based on a number of 'signals' from the language of the text, their history, and the present context. For example, one of the participants said,

> *I could identify the name who called my ex a slut. This word 'slut' can only be used by "X" - he is one of my ex's friends ... I could totally get the tone of his vengeance* (male, age 24 years)

It shows that negative associations also have a strong influence on the user experience as they associate a specific channel of strong emotions toward each other.

RQ2. Resistance to Harassment and Participation of The Victims

The study showed majority of the participants felt hurt, embarrassed, shocked, insecure, angry, and frustrated after receiving the messages that contained sexual harassment. Where harassment itself was a horrifying experience for a person, the suspicion that a known person was harassing them with dirty language and vengeance heightened the victim's tremors and revulsion. One of the participants said,

> *It is really shattering for me and I was very shocked. I couldn't get the point why they sent me a message like that?* (female, age 24 years)

Many of the participants and their friends reacted strongly to such harassment, according to the findings. One of the participants (male, age 28 years) mentioned about her friend who shared the screenshots of the harassing messages on Facebook to protest such harassment. Another participant mentioned about fighting such harassment by herself,

> *I aggressively answered 2/3 harassing messages. I did not want to sit down and accept those embarrassing messages because of some 'social shame' and fear!* (female, age between 21-25 years)

Despite the fact that some of the victims were bold enough to oppose the harassment by posting it on their existing social media (e.g., Facebook), several of them claimed that the degree of harassment only rose after they protested the harassing messages. While sharing her experience regarding this, one of the participants mentioned,

> *I got some dirty messages where sender marked me as a prostitute and asked me to publish it into the social media if I have the courage to post it. I roughly took that challenge and did post into my Facebook... Then I realized they were enjoying this as a game.* (female, age 29 years)

Because the senders were frequently disguised inside their current social media networks, their protests served primarily as a mark of achievement and a source of gossip for harassers and others. Furthermore, the victims seldom received the necessary support from society or their network of friends and family. In fact, in many cases, people around them silenced them directly or indirectly. Through the interviews, I noticed that the frustration due to the lack of social support and justice is one of the reasons why some participants did not protest harassment. One of the participants said,

> *If someone tries to protest publicly, there's a chance that she'll get harassed again. Still, some girls protest in public ... probably their family is very understanding. But everyone's family is not the same and may force her to be silent against it.* (female, age 28 years)

Not only did the participants' fear of social shame keep them from speaking up, but the country's lack of social support, justice, and legislation also worked against them.

While some of the participants embraced the practice of sharing abusive messages on Facebook to humiliate the anonymous sender and make others aware of the anguish and pain that those words had caused them, it had its own set of restrictions. Certain of the participants, for example, found the words used in some messages to be so unpleasant and sexually explicit that they hesitated and eventually opted not to post them in public. One of the participants shared her perspective on this in the following way -

> *We girls, aren't going to show those kinds of body shaming messages. Because if we share, people who will read those and will start thinking about our body rather than being supportive to us.* (female, age 24 years)

Not only the frustration of not having the support but also 'victim blaming' contributed to the silence about harassment. When the female participants reported their negative experiences with their friends, family, and acquaintances, they were frequently blamed or had seen women being blamed. One of the participants (female, age 29 years) shared such frustration saying, she was blamed for opening Sarahah at the first place, *giving* people chance to harass her. Because of such experiences, it is difficult for women in Bangladesh to confront such offensive harassment publicly and stand against it with a proper moral and social support. This also led majority of the interviewees to leave ASMs for good or delete the application. 17 out of 27 participants (10 women, 7 men) mentioned about such event where the participants had to stop using it to stay away from harassment. These types of encounters frustrated the participants and made it difficult for them to participate on ASM platforms.

Discussion

The results provide understanding on different forms of online harassment that happen through ASMs in developing context as well as specific design implications and policy recommendations for dealing with such incidents.

Concept of Harassment, User Expectation, and Suspicion via ASMs

Characterizing Harassment in ASMs. I provided insight on the degree and nature of harassment in Bangladesh through the survey and interviews, where the majority of the female participants reported being harassed through ASMs. Based on the findings, these harassment can be categorized into 4 groups: 1) sexual propositions (*having sex in doggy style*), 2) sexually objectifying contents (*big breast, juicy lips*), 3) romantic messages (*trying to flirt randomly*) and 4) dating inquiries (*kissing boyfriend or giving him blow job*). The participants, who received messages containing any sexual content or derogatory tone (*big breast, doggy style, sex, fuck, blow job, prostitute* etc.) specifically considered those as sexual harassment. This perception can be explained through the invisible socio-cultural norms of Bangladesh. In Bangladesh, public discussion on sex or any topic containing sexual contents (including sexuality and sexual health) are considered taboo and frowned upon [427, 514]. ASMs provides a safer way to break these invisible norms of society without being judged or scrutinized. These forms of harassment, that were humiliating and insulting to the women participants, can be conceptualized through power imbalance [602] and De-individuation [148] theories that I discuss below.

A critical component of harassment is power [602]. In the case of Bangladesh, this concept of power imbalance in gender is much more evident due to its contextual norms and patriarchal practices against women [641]. According to a study, as of 2017, among all the reports filed against online harassment in Bangladesh, 70% of them were against women [42]. As an ASM provides one kind of unaccountability to some extent, it is possible and easier for the people in Bangladesh to exert power over women through ASMs. This unaccountability and increased possibilities of harassment in Bangladeshi context can be further explained through the concept of "De-individuation" [148]. De-individuation is a psychological state where an individual becomes a part of an anonymous crowd and displays more anti-normative and dis-inhibited behavior due to the feeling of unaccountability [502]. Some researchers call it cyber-disinhibition when this kind of behavior happens online [653]. The anonymous platform and demonstration of power over women, influenced by the social understanding and practices impact a lot on how and why women get harassed through ASMs in Bangladesh.

User's Expectation and Suspicion about Harassers. One interesting aspect associated with harassment in the context of Bangladesh was the expectation and suspicion about the identity of the harasser by the victims of this study. The majority of the survey respondents (58.14%) and interviewers (23 out of 27) stated that their desired or expected audience on ASMs was people they already knew or had connections with on other social media platforms. This expectation or choice led them to publish their personal Ask.fm or Sarahah link with a specific selected audience inside their current social network rather than publicly. Some people tend to stay within groups, and value known and closer ties more than individual links. Hofstede has claimed that most of the "Western" culture tends to be more individualist (independent) while "Indian" culture tends to be more collectivist (interdependent) [300]. Prior work in ICTD research [215, 38, 37, 531] have explored different social phenomena through the lens of collectivism theory to understand the contextual influences on these issues. Although this study does not claim to be the first one to instigate this concept in interpreting the interaction preferences in a specific community, connecting collectivism theory to the finding certainly provides an understanding why in some communities, users in

Bangladesh expect and connect with known links through ASMs.

Although Hofstede's collectivism theory is a prominent idea in ICTD to explain the contextual effect on communication choices, there can be other explanations, one of which is homophily [402]. According to McPherson et al. [402], homophily *"is the principle that a contact between similar people occurs at a higher rate than among dissimilar people"*. This principle or inclination to connect with similar people limits how people interact with each other socially and with whom they interact. Research has been done on how homophily can also be observed in online platforms such as location surveillance network [274]. Although the concept of homophily is not unique to any specific country, it is possible to implement such concept in this ASMs study, where some Bangladeshi users have a certain expectation of being connected with a similar group of people on social media who they already know or have the previous link with. As users from Bangladesh may expect to be linked with familiar individuals even in anonymous apps and act on that expectation, it is normal for victims to infer that the harasser is someone they know. The mistrust grows when the contents, language, tone, and personal queries are revealed, which are frequently unpleasant to the receiver.

Although I agree that homophily is not especially unique to the Bangladeshi context, I believe that this viewpoint on collectivist theory may add to the prior literature in ICTD in order to better understand the users' expectations with "invisible yet known contacts" and experiences with ASMs in some communities of Bangladesh.

Reaction Towards Harassment and Future Participation on ASMs

Distress, Resilience and Secondary Victimization. Whereas harassment itself is a distressing experience, the suspicion of being harassed by someone known increased the severity of such distress among many of the survey participants and interviewees. A similar research was done by Pew Research Center [50], where it shows that, those who knew their harasser "tend to be more deeply affected by their experience and to express greater concerns for their safety". The victims of sexual harassment in this study were *shattered*, *shocked* and *extremely sad* being harassed by someone who is known to them. Previous studies on harassment suggest that, to cope up with the distressing feelings of being harassed, many of the victims seek for social support from friends, families, acquaintances or coworkers [30, 50, 230, 309]. I also observed a similar association of seeking social support by the victims of sexual harassment through this study. Although the participants shared such expectations, a majority of them shared their frustration of not being able to get social support after sharing their experiences; they rather got blamed and harassed further.

Such responses of seeking social support many times affected the way women reacted against such harassment. Majority of the data suggest women being less resilient against sexual harassment they face through ASMs in Bangladesh. Lack of social support, victim blaming, social humiliation and norms, less expectation of social justice and adverse reactions after protest lead to many women in Bangladesh being silent [427] even though they face extreme sexual harassment through ASMs. In some cases, women victims in the study did mention of raising their voices on online platforms to protest. While these protests certainly deserve appreciation and shows the bravery of those women even in this adverse situation, they often were further harassed through ASMs followup posts or faced "secondary victimization" [41] from their friends and families. Besides, whereas there are previous reports on women formally filing complaints against their online harassment [42], in case of ASMs, it is often not possible due to the lack of direct link or proof against the harassers. Such events led many of the participants to technology refusal and non-use.

Technology Withdrawal and Non-Use of Technology This study also contributes to the growing discussion within ICTD and HCI around technology withdrawal and 'non-use' of technology [83, 101]. Though many of the victims could identify or guess their harassers, for receiving less support from the society, they never protested. Those who did, got further harassed. These bitter and distressing experiences forced many of the participants to withdraw themselves from using ASMs and stop using those applications for good. This phenomenon supports the previous literature that suggests that negative experiences online increase the possibility of withdrawal from a social communication technology [83]. Due to being the primary victim of harassment through ASMs, women tend to leave the application more often than others, as per the results.

This forced non-use is particularly important to ICTD literature who emphasize on a wider use of technology in marginalized populations [462, 465]. Sexual harassment is mostly targeted toward women which often leads them to stop the using of an online platform. This way, sexual harassment is limiting woman's use of the Internet and digital technologies, and contributing toward widening the digital divide between men and women. This raises two major concerns - a) the efforts of empowering women through Internet service (online education, business, social networking) will be highly impeded, and b) online communities will lose a democratic environment with a lesser presence of women. Both of these are detrimental to the development of a community through the use of ICT. I argue that ICTD researchers should focus more on stopping sexual harassment over ICT platforms in order to ensure a balanced growth and development.

Design Implications

Various technical interventions can be designed and implemented to make anonymous platforms more usable and harassment-free for its users, especially for women. One way can be implementing an efficient algorithm (like Linear SVM [532] or LSF Framework [152]) that can detect negative or vulgar words and restrain the users to avoid writing negative messages. Different customized filters can also be added at the receiver's end to restrict specific types of messages to be received through the anonymous applications. It is also possible to incentivize positive behavior on anonymous social media through the design. For example, a 'positive user interface' can be introduced where the sender will be asked to write a few good things about the receivers and based on the receivers' feedback the sender will be honored. Such persuasive design can bring a change in perspective and bring out positivity among the users [235, 236]. Another approach can be more adversarial - limit the user activities if their posts get reported by others. If a message gets reported and reviewed as profanity or harassing, the post will be flagged or the sender will be reported [479]. Each of these technical interventions has their own limits, and implementing these in a developing context like Bangladesh will require a lot of technical efforts that may not be readily available. Scholars and researchers built some online systems that can ensure a non-harassing online environment for the users to a certain level (Squadbox [74], Hollaback [193], Protibadi [39] etc.). Although these systems exist, very less focus has been given to analyze their accessibility, efficiency and challenges in the context of global south. HCI communities should put more focus to understand and promote these platforms to ensure a comparatively safer environment in ASMs and other social media for the users, especially women.

Policy, Law and Social Awareness

An LMIC often lacks proper or efficient standard in their government, civil society, education, and law and order [259]. So, it is not very unlikely that it may fail to support the victims of online harassment, as evidenced by the survey and interviews. Because there is a lack of effective societal awareness, policy, and law against online harassment, it is easier for harassers to harass someone online without being held accountable. Although Bangladesh has ICT Act, 2006 that does address cyber harassment, it does not identify events like anonymous harassment [42]. Additionally, while social media regulations are not often explicit enough to allow law enforcement authorities to prosecute incidents of online harassment [479], there, the ability of social media sites to create their own policies adds to the ambiguity of the situation. This study of the LMICpoints out to the connected bodies of responsibilities to combat with harassment generally. A holistic set of policies connecting social media platforms, government, law enforcement agencies, and social support bodies of harassment victims can foster cooperation and collaboration among the stakeholders. While ICTD projects often provide policy recommendations (see projects of such here [298]), the policy is often a sidelined actor or comes during the assessment of a technological system. In this study of LMIC, I recommend for parallel policy updates LMICs use.

Aside from regulations, social support organizations should be formed to locate, reach out to, and help victims of online harassment. Training in how to respond to online harassment might be implemented at educational institutions and workplace. Rooting the initiatives into the cultural and religious values of the communities may help properly implement and scale up campaigns in an LMIC too.

Limitations and Future Work

While the study reveals many important aspects of sexual harassment over ASM, there are several limitations in this study, too. First of all, all of the interview participants and most of the online survey participants were from the capital, Dhaka. Also, most of them fall into the age range 22-32 years. As a result, the findings of the study should not be generalized over the whole country across people of all ages. Besides, the findings were primarily focused on women although some men also mentioned of facing harassment through ASMs in Bangladesh. Due to convenience sampling and huge data set on women victims, I decided to focus on women in this study, which also limited the findings to a certain extent. For the future work, I intend to focus on LGBTQ community and male victims to address their experiences of harassment over online social platforms. I expect that more research will be conducted in this space in future to address these limitations and to obtain a more comprehensive knowledge regarding online sexual harassment in Bangladesh. However, despite all these limitations, I believe that this study still delivers some important insights into the harassment experiences through ASMs in many closely knitted Bangladeshi communities.

Conclusion

Cyberbullying or online harassment is contextual, that is, it relies largely on the social context and the audience of participation. This is what I largely observed as well through the survey and interviews. This study suggests that, the most prevalent harassment the participants, mostly women, faced through ASMs was sexual harassment and the contents of the harassing messages broadly can be grouped into four major categories: sexual proposition, sexually objectifying contents, romantic messages and dating inquiries. The study also implies that, often users expect to be connected with known social links through ASMs that leads their suspicion of identifying the harasser as someone they know. This suspicion causes further distress and misery among them. I also noticed that, although some of the participants seek social support in order to cope up with the harassment, due to the socio-cultural norms and biases against women in Bangladesh, they were often more victimized, shamed and humiliated. These experiences led many of the participants in Bangladesh to be silent against these harassment and at one point, stop using ASMs for good. These findings extend the current literature on online harassment, technology non-use, and most important anonymity and ASMs in the context of an LMIC, where I observe the notable impact of context on the way people experience ASMs. I believe, the proposed design policies and framework to address harassment through social media, especially ASMs, can particularly benefit the ICTD community due to its wide emphasis on technology and harassment in a marginalized community.

CHAPTER 3 - EXPLORING ONLINE PARTICIPATION AND HARASSMENT EXPERIENCES WITHIN GENDER AND SEXUALLY MINOR COMMUNITIES

Introduction

There is a growing scholarly recognition of the experience and diversity of sexual and gender orientations beyond binary gender and heterosexual identities [99]. Recent work in social computing has explored the benefits, pitfalls, and design opportunities around social media for GSM identities in a mostly US context [35, 279, 538, 372]. Similarly, researchers have begun to seriously grapple with the impacts of our concepts of gender on AI-based applications such as facial recognition in a mostly-western context [339, 539]. However, while these studies move us forward significantly, they ultimately categorize gender and sexuality through a strictly Western lens [99, 36]. In order to improve and include social media platforms for everyone, we must better understand the need for and use of these platforms by stigmatized users in markedly different cultural contexts. Such a GSM community is Hijra (who are widely referred to as "third gender" [343] individuals), a group of people in south Asia who do not conform to binary notions of male or female gender but rather combine or move between them [343]. Hijra are stigmatized and excluded from the society because of their perceived gender identities [302], and experience extreme social exclusion, discrimination, harassment, and violence, with little or no access to physical, mental or social support. Instead, they turn to social media for self expression, and social support.

Social media can play an amplified role for stigmatized populations, especially those with little access to physical assistance, including LGBTQ+ communities [278, 620, 109]. For such communities, social media acts as a primary space for identity exploration and development [620, 109], a primary source of social support and justice against harassment [449, 450, 49, 48], a resource for combating stigmatization around mental health [96], and both a guide and public platform for experiences such as gender transition [278]. Prior work [190] has broken significant ground by exploring the importance of social media to members of gender and sexual minorities (GSM) in a Western, mostly US context. However,

As we continue to improve the field's understanding and treatment of gender in online platform design, it is essential to account for non-Western conceptions of gender and the needs and behavior of non-Western gender minority groups, such as Hijra, that may not necessarily align with the cultural or practical realities of Western GSM individuals. To address these concerns, me and my team engaged with Hijra populations from Bangladesh and explored how GSM from non-Western contexts participate, self-present and experience negative experiences, such as harassment, on different social media platforms, using DeVito et al.'s personal social media ecosystem framework for LGBTQ+ populations as a theoretical lens of inquiry [190]. We find:

- Hijra primarily rely on social media platforms for three reasons: (a) communication with family, (b) Hijra community participation, and (c) sex work. Depending on each of these purposes, Hijra share content to targeted online audiences, as motivated by the platform's afforded levels of presentation flexibility and visibility control.
- Technical knowledge and skill is a major factor in enabling Hijra to navigate social media platforms, with widespread lack of skill triggering online harassment and negatively impacting the way Hijra perceive platform affordances. Skill, when added to the input and influence of local authority figures (such as Hijra matriarchal leaders known as Gurumas), also motivates shifts in content across personal ecosystems and/or limitation of social media use.
- A reliance on Western cultural signifiers in designing platform features and navigation aids lessens the utility of social media for Hijra. Advanced and continually updating platform privacy features do not nec-

essarily provide a sense of safety or practical benefit to Hijra if those features and their signifiers are not culturally familiar to them.

Whereas in prior work, GSM communities like LGBTQ+ users' online self-presentation and participation were analyzed through their audiences [190], platform affordances and the usability of the space, our paper adds to this conversation by finding that for GSM in non-Western contexts, this framework does not fully work. As the platforms' intended affordances to its users are not always aligned with Hijra's understanding of the platforms, for reasons like limited platform knowledge/skill or less culturally appropriated platform design, existing framework is unable to accurately explain how Hijra self-present themselves online with regards to their audiences and spaces. Previous literature has emphasized the importance of digital literacy within vulnerable communities in terms of their social media participation [469, 467, 530]; however, such understanding is absent in the case of GSM from non-Western contexts.

Therefore, this work makes several contributions to the CSCW community: 1) This study extends and improves the current lens of social media ecosystem [190] by introducing and integrating technical knowledge and skill set in the framework based on the observations from Hijra community, 2) It contextualizes the presence of community and cultural influence within Hijra groups, which helps us to better understand how GSM from non-Western contexts perceive harassment on online platforms and come to trust certain social media for their self-presentations and participation, 3) It advocates for design practices in HCI that integrate cultural context and marginalized views in the design phase to build more accurate, more inclusive social media environments for stigmatized GSM from non-Western context, and finally 4) The study extends our current knowledge on online harassment by introducing an unique group of vulnerable populations into the context who frequently face systemic barriers to access any kind of mental or social support against online harassment. Whereas existing work in ICTD discuss such inclusion and design practices from developing context [404, 462, 597, 358], the study contributes to the conversation by including GSM populations like Hijra in HCI and CSCW. This research was originally published at CSCW conference in 2021 [446].

Hijra: A History of Social Exclusion

Hijra is an institutionalized third gender role that is neither male nor female, but contains elements of both [428]. Hijra mostly live in segregated housing communes, where unwanted intersex or trans children are raised in a safer environment [36]. Hijra identity includes traditional procedures and distinct commitments unique to this form of gender minority identity. Hijra communities are led by elder matriarchal individuals known as "nayak" or *Guruma*, at which point the new inductee is known as a "chela" or follower [84].

Government estimates say there are around 10,000 Hijra in Bangladesh, although the "Badhan Hijra Songha", a transgender-Hijra rights group, states that the figure is actually around 100,000 [621]. Even though Hijra are legally recognized in Bangladesh, they are still socially excluded [343], with the word "Hijra" commonly used to mockingly refer to undesirable digression from normative masculinity [302]. Despite formal recognition, this lingering lack of acceptance for gender identities beyond the binary results in limited employment opportunities for Hijra, many of whom turn to sex work or begging [349]. Hijra also face abnormally high rates of hate crimes involving rape, harassment and physical abuse [262]. Due to the stigmatization and exclusion Hijra experience [533], their economic backwardness [286], their unique non-Western hijra identity, and their location in South Asia, Hijra are a crucial population to represent in order to broaden our understanding of GSM social media use in a non-western context.

GSM Online Self-presentation & Impression Management

Social media plays an important role in how impression or self-presentation of a user is constructed online [174]. Facebook and other social networking sites have been a major area of research, particularly to understand what practices and behaviors users adopt during their self-presentation online [120, 329, 596]. However, particularly for GSM, this management of impression becomes more critical, as it provides them opportunities to experiment with their self presentation and identity to the the world [205, 359]. The existing work on LGBTQ+ users identifies a variety of identity management strategies that these populations adopt on social media including monitoring their online self-expression, using privacy and security controls to avoid online harassment, strategically managing their audiences and so on in Western setting [205, 167, 396].

While the vast majority of work on LGBTQ+ has been done from Western perspectives, there is some existing work that try to explore such GSM communities from a global South context. Studies like [73, 248] have focused on queer and Hijra population from India to explore their realities in terms of social, economic, political, emotional, psychological, and legal issues. Indian LGBTQ+'s adoption of email lists, message boards, and weblogs to communicate with each other online have also been explored by researchers [355, 416, 415]. However, few studies seem to have focused upon the possible use of popular social networking platforms from Global South. Literature like [191] have added to that conversation by studying how Indian LGBTQ+ individuals create multiple identity on distinct social media, such as Facebook, to protect themselves from negative experience from unwanted audiences. However, such exploration of GSM communities from developing context is understudied and can differ from how Hijra communities adapt to those online practices [396].

Digital Literacy and Skill for Navigating Online Platforms

One potentially major complicating factor around self-presentation behavior on social media platforms is lack of digital literacy or skill, as it enables users to choose effective technology practices to meet their goals [467]. As the self-presentation goals of Hijra can be complex and may require use of advanced privacy features to protect themselves from unwanted and negative comments and experiences online, lack of skill and knowledge of the platform features can be a major challenge for such stigmatized users [287]. According to previous research, privacy and security settings of social media platforms can often be difficult to navigate and imperfect in terms of user's requirement of information control [396]. For instance, [82] discusses how privacy literacy may change online behavior and perceived online safety within users; they define online privacy literacy as users' knowledge about technical aspects of online data protection, and ability to apply those strategies for own privacy regulation. [469] has identified how populations with different level of skill and particular are consistently left out from benefits of technology because they cannot access the full potentials of the technology.

Whereas these studies looked at the impact of technical skill and knowledge on populations from Western context, several studies found that it is more common within non-white users to fall behind in online privacy control behavior due to their limited skill set [468] and knowledge [467]. Such exploration of different communities around the world directs our attention towards understanding the concept of digital literacy and knowledge within GSMs from non-Western context, such as Hijra. Due to Hijra's stigmatized identity, it is absolutely essential for them to utilize different platform affordances to ensure privacy against negative experiences and control over self-presentation settings, and thus, this study tries to fill that void of knowledge by exploring Hijra communities from Bangladesh.

A Framework of Social Media Ecosystem

In prior work, researchers have conceptualized how GSM self-presentation, existing in across multi-platform ecosystem, has allowed differential presentation across different audiences and sites [190]. Specifically, Devito et al. [190] posited three specific elements of social media ecosystems that drive self-presentation behavior (and content) to appropriate outlets: audiences, affordances, and the conflation of the two with local norms, which they call "spaces".

Audience

DeVito et al. [190] found that different audience compositions per platform and, importantly, user perceptions of these audiences were a key motivator for personal social media ecosystem use and movement of content across said ecosystems [190]. LGBTQ+ users generally conceptualized their audiences as either abstract (relatively unknown) or targeted (specific people who are the potential connections users may have and want to share contents with through their social media platforms). Users imagine their audience based on factors ranging from goals and individual psychological expectations from others, allowing them to act self-protectively despite rarely having access to precise audience composition information.

Affordances

According to DeVito et al. [190], user perception of a platform and its appropriate place in one's personal social media ecosystem is heavily affected by the affordances, or possibilities for action, each platform offers to users . Stigmatized users explore and look beyond single platforms, considering the range of affordances available across their personal ecosystem when making self-presentation decisions.

Space

DeVito et al. [190] use the term "space" to describe the conflation of platform and audience by users making self-presentation decisions. Through the lens of this conflation, users form a concept of what "type" of platforms are available, what they are for, and who is welcome there. By examining the conflated spaces, it is possible to look not just at the social context intended by platform designers, but rather what a platform represents to the users themselves in comparison to other platforms within one's personal social media ecosystem.

DeVito et. al's framework of personal social media ecosystem [190] provides a solid theoretical foundation for research into Hijra self-presentation and social media platform use. I draw from this theoretical perspective to frame my research questions and also as the qualitative lens for our analysis. However, although the existing framework provides valuable perspectives on stigmatized GSM populations in online spaces, it was developed entirely in a Western context and may need extension to apply to Hijra and other stigmatize populations from developing, non-Western contexts. To better account for Hijra and other non-Western gender minorities in the design of the social media platforms they rely on for crucial services and communication, it is imperative to extend this lens beyond a Western context. As such, using DeVito et al.'s personal social media ecosystems as a guide, I ask:

- **RQ1:** *What are the audience related concerns that Hijra have in their social media ecosystem?*
- **RQ2:** *How do they manage their audiences through the affordances of different social media platforms?*
- **RQ3:** *How do audience and afforances influence Hijra to move around in different social media platforms?*

Methods

A six-month-long qualitative study was conducted with Hijra in Dhaka, Bangladesh from March-August 2019. The study took place in 6 neighborhoods of Dhaka: Lalmatia, Kakrail, Mugdapara, Gulistan, Manda, and Kamalapur. I employed multiple elicitation methods, including semi structured interviews, Focus Group Discussions (FGDs) [438] and unstructured online observations [443] of public and private (with consent) content related to Hijra. The questions for the interview and FGDs are attached in Appendix B1. To ensure a robust understanding of how Hijra interact with social media, I triangulated these multiple data sources in our analysis. All study procedures were approved by the Institutional Review Board at the lead author's academic institution.

Participants

Participant recruitment was performed through a snowball-style iterative process of networking and trust building in Hijra communities [281]. 3 preliminary semi-structured interviews was conducted with acquaintances who belong to Hijra community. From there, my team was approved to conduct our first FGD consisting of 6 Hijra in a dorm at Lalmatia, where Hijras from different districts were gathered for a cultural event. The second FGD also consisted of 6 participants, all Hijra sex workers who were visiting Dhaka for a training program arranged by a local NGO. A meeting with them was arranged with the help of *Sachetan Somajsheba Hijra Sangha*, a non-profit organization working for the welfare of Hijra community. The remaining 3 FGDs were conducted with local Hijra in a place they considered both convenient and safe.

Though the in-person activities in this study were conducted in Dhaka, I ensured representation from participants all over the country. We talked to Hijra communities from 8 divisions for the FGDs and individual interviews: Barisal(3 participants), Chittagong(4), Dhaka(37), Khulna(3), Mymensingh(3), Rajshahi(5), Rangpur(3), and Sylhet(3). In total we had 61 participants (45 from FGDs, 16 from one-one interviews). **Table 3.1** shows for additional demographic information. Almost all participants were employed doing "Hijragiri" (traditionally, the ritual of *badhai*, or blessings conferred on a newborn through dancing and singing) [526], the collection of *cholla* (tolls from jurisdictions), training to become skilled in the Ulti language [286], and sex work. Out of 61 participants, 19 were directly involved with sex work, and only 3 participants were involved with white-collar jobs. The socio-economic status of all the participants was relatively low, as Hijra community in Bangladesh conventionally consists of those from lower economic levels [320].

Data Collection

Data collection employed 5 Focus Group Discussions (FGDs), 16 one-on-one interviews, and online observations on participants' social media participation with their prior consent. Interviews and FGD data were collected in the form of field notes and audio recordings. We collected photos, screenshots, videos from our online observations. All the interviews and FGDs were conducted in Bengali, and each participant in the focus group and interview was compensated with BDT 400Tk, which is roughly around $5 and more than the minimum daily wage (BDT 50TK) in Bangladesh [5]. In all data collection activities, we focused on the social media practices of Hijra communities, with specific attention paid to audience management strategies and social media participation.

The initial data collection strategy centered around the 5 FGDs, each of which was 2.5 hours long. The 16 one-to-one interviews were conducted with the help of a Guruma who is also a Hijra activist, and helped us reach more people to talk to individually. The time and date for these interviews were chosen according to the participants' preference. Interviews averaged 40 min-

Demographics		**Percentage**
Sex By Birth	Male	93%
	Intersex	7%
Sex Assigned at Birth	Male	100%
Gender	hijra	100%
Preferred Hijra Identity	Hijra	47.6%
	Third Gender	21.3%
	Women	31.1%
Sexuality	Gay	100%
Age Range	18-25 yrs	65%
	26-33 yrs	22%
	yrs $>$ 33	13%
Highest Level of Education	No Education	38%
	Primary Education	24%
	Some High School	17%
	High School Diploma	13%
	Bachelors Degree	8%
Location	From Dhaka	87.43%

Table 3.1: Demographics of the Participants

utes each. The interview and FGD protocol consisted of 24 sets of questions, with multiple sub-questions under each of them. Answering every question was not compulsory, and the participants could skip questions if they wished. Later, the interviews were translated and transcribed by the 4th, 5th and 6th authors of this study, whose first language is Bengali.

The online observations were collected through exploring different social media platforms that Hijra mentioned in FGDs and interviews, such as Facebook and Bigo Live. While looking at the social media information provided by the participants, I also used different keywords suggested by the participants, such as *Hijra*, *Third Gender* etc., to find online groups and communities that promote anti- or supportive posts related to Hijra. Keeping ethical implications in mind, I only collected information on groups and pages through key words that were already explicitly public for everyone on social media platforms [229, 123] and were not only accessible to only a certain community of users. As suggested by [652], it is unethical for researchers to use any personal information from social media if the data or information is restricted to a certain group of people or communities. Hence, it has been ensured that the Facebook groups/pages I shared image from are public and not restricted to certain communities or populations.

Data Analysis

After data collection, the data was anonymized before analysis. To anonymize, the first and third author renamed all the FGD participants as P1, P2... etc., and for interviews, as X1, X2... etc. As our data was mostly qualitative, I used a grounded, thematic approach [648] on the collected data. For each source of data, I created codebooks following an open-coding approach to allow flexibility for new themes to emerge. I wanted to understand the rationale behind Hijra perceptions on gender identity, and online participation. The codebook was created through several iterative rounds of coding until theoretical saturation was reached [257]. The categories formed from the codes were later grouped into different themes which helped me construct the findings from this study. From the interviews, I drew deeper detail on their struggles, confusion, and frustration both in offline and online world, both confirming and expanding our initial FGD-based themes. The online observations helped me to provide visual references to the readers and connect the experiences of Hijra (that they shared through FGDs and interviews) with practical instances.

Results

The results indicate that Hijra have complex gender and identity constructions. All of the participants mentioned their gender to be "hijra" in both interviews and FGDs. However, such construction of gender gets complicated when some of the participants mentioned classifying hijra further into *Meye* hijra (for intersex) and *Chele* hijra (for trans females), which is an internal gender classification some Hijra follow and not officially addressed by any legislation. Our data also suggests that 13 out of 61 Hijra (around 21%) participants in the study preferred to identify themselves as "Third Gender" than "hijra". Additionally, 19 out of 61 participants (around 31%) mentioned their desire to be perceived as women although they do not fall under the traditional definition of cis-gender female. For a better understanding of our readers, I have created a chart (see **Figure 3.1**) that represents how Hijra classify their identity in Bangladesh.

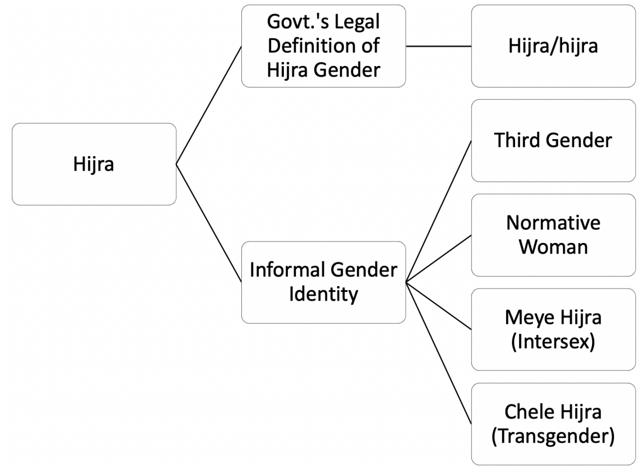


Figure 3.1: Hijra Gender & Identity Classifications

Due to such complicated identity constructions, Hijra extensively employ their personal social media ecosystems to meet a number of different goals, as motivated by perceptions of platform audience, affordances, and spaces. The study reports the results by identifying what audience related concerns Hijra have on social media, explaining their connections with platform affordances and skill, and describing the contexts in which they shift across social media ecosystem. Exploring these results will provide us better understanding on Hijra's online self-presentation and participation.

Audience Concerns and Uses of Social Media (RQ1)

RQ1 asked what audience-related concerns Hijra consider when using social media, each reflecting a core reason for using social media. Our data suggest that Hijra in Bangladesh have three types of primary audiences on social media, with conflicting sets of disclosure concerns: family, other Hijra, and cisgender men (**Figure 3.2**). Uses ranged from daily communication to online sex work. Each of these audiences not only helped the participants form their personal social media ecosystem, but also shaped their online behaviors and concerns that help them to construct their identity online.

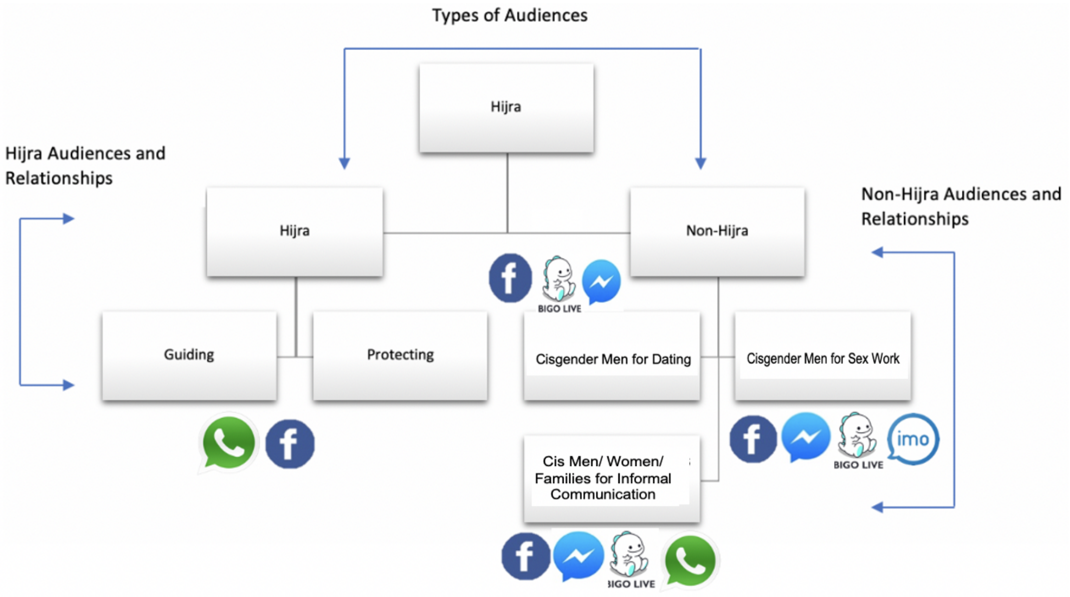


Figure 3.2: Types of Hijra Audiences & Relationships in Online Platforms

Family and Personal Connections. Our data indicates that for 37 out of 61 participants (around 60%), one of the primary audiences of interest are their existing family and friends. While family and friends are a common audience for social media content generally, the requirement that Hijra live away from their families in separate communities [302], as well as persistent stigmatization by larger society [70], heightens the importance of social media for reaching this audience. For example, interviewee X4(Age 18) mentioned:

> *I live away from my family...we are not accepted in the society...and they [mass population] even leave the place if we sit beside them in public transportation...(which is why) it is easier for me to be connected with my family and friends in Facebook*

Despite the obvious utility of Facebook for Hijra, it can also create new anxieties related to heightened concerns over managing and selectively disclosing gender identity online. The need to be connected with family via Facebook can collide with the discomfort or serious disclosure concerns of the many Hijra, who then have to hide a portion of their online participation from their families. As interviewee X11(30) mentioned:

> *One of the biggest things in my life is that my family doesn't know that I am Hijra... I have to do everything, specially in Facebook, by hiding my own identity...often it becomes very hard*

Similarly, participants like X8 and X10 also mentioned putting in extra effort to keep the platform they use for family connections walled off from the rest of their online life, such as strictly never using their *meye nam* (female names as Hijra adopt as hijra) or not adding anyone from the Hijra community. As X8(25) mentioned mentioned,

> *I use male as my gender [on social media]...[lthough] I love to think myself as a female. I have my family in my Facebook profile and they don't know about my identity...I like to keep it that way*

While such strategic outness online can maintain audience-related boundaries for Hijra, and therefore safeguard Hijra identity, participants still describe this as a "struggling" or "uncomfortable" position. This suppression of online identity, however, directly conflicts with crucial benefits of social media platforms in receiving social and instrumental support.

Hijra-Hijra Connections. Hijra also use social media to seek guidance and suggestions from their fellow Hijra. 22 out of 61 (around 36%) participants in the study said that connecting with other Hijra in this way, which enables finding appropriate communities in the physical world, is a crucial function of social media, as participant P38(40) noted in FGD4:

> *Now-a-days, we get connected with Hijra from the online communities we have in Facebook...In early days they physically had to find out the house of other Hijra...now due to the easy access to internet and Facebook pages, they can find us easily*

This ability to connect via social media groups plays an outsized role in social and especially psychological support around the trauma many Hijra experience in their daily lives. the participants were clear that their experiences include being regularly sexually harassed and potentially even raped entirely due to being perceived as vulnerable identity and lower status by the mainstream normative population. This vulnerability and the lack of support around it make online platforms crucial spaces for sharing extreme harassment experiences which originate offline or even in other online social spaces.

Through social media groups, and individual connections, Hijra employ their personal social media ecosystem to find the right audiences from which to draw support, so they no longer have to suffer alone through traumatic, abusive experiences. For example, during FGD3, participant P26(20) said:

> *Well, we found her posting on being sexually abused that she shared in her profile...it came to our attention through multiple sharing...and our Guru Ma wanted to save her and now she's here with us (in the hijra community)*

For most, social media groups provide a place to share and be supported around experiences that they could not share physically or virtually through a sanitized profile or a general-audience social media group/page. Moreover, by allowing connection and solidarity between Hijra, platforms with Hijra audiences can allow Hijra a space to not hide their online identity, but rather receive direct, psychologically-beneficial support from their peers by fully expressing it - both the good and the bad.

Cisgender Men Connections. The final, and most potentially fraught, audience Hijra pursue is cisgender men. 36 out of 61 participants (around 59%) mentioned being purposefully connected with cisgender men (individuals who identify as men and were assigned male at birth) through different social media platforms with an expectation of developing a romantic relationship with them. In FGD3, participant P18(18) said:

> *Hijra people mainly starve for a guy's company...We add them*

> *[online]...we hang out and have fun online all the time*

Hijra largely turn to social media, as it provides them a convenient platform to access cisgender men. Building relationships with Hijra is prohibited under sociocultural, religious and political rules and customs [343], which potentially exclude them from having any sort of traditional relationships with men. Hence, social media becomes a crucial channel - potentially, the only viable channel for many Hijra, as it allows them an opportunity to have a romantic or even just flirty relationship with men, and to explore basic relationship possibilities.

Hijra also connect with cisgender men on social media platforms to find opportunities to generate income via sex work. As it is hard for Hijra to land traditional jobs due to their gender nonconformity and overall social status [70], earning money through sex work often becomes a primary livelihood. As participant P19(40) said during FGD3, social media is often the most accessible way to set up this sex work:

> *Here (in Hijra community) people can be illiterate, but they surely can use Bigo Live, Facebook and other audio/video applications like IMO, Messengers... Because, they can earn money without any toil*

This ability to find sex work is a primary motivation for many Hijra for both using social media and expanding their networks to include cis men. However, such functionality of using social media platforms to earn money through sex work did not come without any consequences for many Hijra. While disclosing their identity online provides Hijra opportunity to earn money, it also puts them at risk of compromising their privacy and hijra identity online and causes events like harassment. Despite of being aware of such disadvantages, many Hijra are forced to decide between their privacy and online identity disclosure to ensure their livelihood through sex work.

Audiences are an integral part of Hijras social media ecosystem, playing a large motivating role in terms of both identity/disclosure management across platforms as well as achieving particular goals of social meia use. This then plays a large role in setting Hijra's overall expectations from online participation.

Affordances of Social Media Platforms for Hijra (RQ2)

As it has been demonstrated above, Hijra must balance multiple audiences with very different orientations towards Hijra identity, and therefore conflicting disclosure requirements, in order to derive both social and instrumental benefits from social media use. As prior work has shown, available affordances, especially for control over audiences and visibility of content, have a large impact on both decision-making around self-presentation and identity disclosure [188] as well as platform choice within a social media ecosystem [190]. This holds true for Hijra, who must carefully consider their identity management options and the tools available to them. Distinct social media platforms offer distinct means to control audiences online, a primary concern for Hijra. According to our data, the most popular social media platforms for Hijra were Bigo Live, Facebook, Messenger, IMO, and WhatsApp. Many participants used these platforms almost daily to maintain their communication, audiences and sex work.

Presentation Flexibility. The participants in this study recounted how certain suites of affordances help fulfill their individual audience management needs. For instance, Facebook was seen as the preferred platform to maintain family communication due to the affordances provided. Compared to other platforms, Facebook affords more of what DeVito et al. call "presentation flexibility" [188] or the ability to use multiple formats and styles to present oneself to others. For example, interviewee X15(20) said,

> *I post my photo, chat with friends and families in there [Facebook]...Facebook also helps me not only to share my inner feelings with them through sharing posts but also let me do check-ins to let them know where I am or where I am going...it is so easier to update them about my life...I can also do audio or video call in*

Facebook Messenger

However, for some Hijra (13 out of 61, around 21%), Facebook has not always been an ideal platform to utilize this presentation flexibility. Despite Facebook's continuous effort to provide its users flexibility expressing their preferred identity online, it particularly fails to assist Hijra- who wish to share their hijra identity with their audiences online, including family connections. According to interviewee X13(24),

> *No, I did not give hijra as my gender online... Even though my family knows about my hijra identity and I am openly Hijra in Facebook, I have put female as my gender as an alternative option... I know I am not a female but actually in our country there are only two options of gender in Facebook- male and female... no where Hijra option is given*

Facebook's "custom" option to specify own gender, apart from male/female, by the users themselves does not work for Hijra, as (the study mentioned) the feature is confusing and unfamiliar to them. For example, from FGD5 participant P43(35) mentioned,

> *We can choose hijra (as gender)? How? I can only see male and female in the options... There was a third option probably ("custom"), but I had no idea what that meant. Does that mean hijra?*

As Hijra is not explicitly included in the gender spectrum of social media platforms, it potentially restricts and forces the members of Hijra community to construct their identity online within the dichotomy of male and female.

As the data suggests, while Facebook is a big part of Hijra connection with their families, by way of contrast, in flirty communications or sex work situations, it is more useful for Hijra to have access to a platform with far more limited presentation flexibility, so as to bound the possible interactions they can be expected to have with potential audiences or clients. For example, 28 out of 61 Hijra participants (around 46%) preferred to use IMO while building romantic rapport and engaging in sex work with cis-males due to its primary focus on chat and limited features on presentations formats. From FGD1, participant P1(18) said,

> *Through IMO, I talk to the men who are nice and interesting...I usually do audio calls through IMO and use my female voice to present myself as woman...they never realize that I am a hijra*

Another interviewee X10(35) mentioned,

> *I am engaged in sex work through IMO...I like to use it...it is simple and easy and does the work for me...I do video chat there and collect money afterwards*

IMO's core functionality of regulated one-to-one or group conversations through only audio, video, and written chat (unlike Facebook that also includes other features within the platform) helps Hijra to represent themselves in a way that benefits their goal of building a romantic rapport. As chat, and not additional functionality such as games or item listings, takes center stage on IMO, the tightly-specified form of limited presentation flexibility afforded on this platform makes it easier for Hijra keep interactions bounded to sex work and nothing else.

Audience Transparency. Privacy concerns are, of course, paramount for Hijra when making decisions as to how to fulfill their needs via social media. One of these concerns relates to what DeVito et al. call "audience transparency," or the afforded ability to be aware of who is in one's audience. Affording increased awareness of not just who is in one's audience, but also the relevant characteristics of those audience members, has proved useful to Hijra pursuing sex work in particular, as interviewee X11(30) said,

> *Actually I don't face that problem (harassment or privacy issue) in IMO... By making a call through IMO, I can understand how old are they... In IMO, who have my phone number only those people can contact with me. That's why I like to use IMO more than Facebook*

Being engaged in a profession like sex work, concerns regarding who they connect with becomes an important aspect for many Hijra online who wish to stay away from being harassed or bullied from unwanted prospective clients or others. As it is relatively easy to find someone on Facebook even without knowing their full name or information, it becomes important for many Hijra to hide their personal profile or identity from certain audiences, who can be their potential harassers in future. As many Hijra's livelihood is dependent on online sex work, they prefer to keep it as safe as possible using platforms like IMO, where clients or audiences with Hijra's personal phone number can only reach to them. However, exposure to a broader but targeted sex work client base has also been an important part of Hijra sex work online that conforms audience awareness. Some Hijra (15 out of 61, around 24%) preferred to use Bigo Live for its feature of level that helps users to broadcast their live video to a wider audience, such as foreign sex clients, with similar interests. For example interviewee X2(35) mentioned,

> *Having higher levels in Bigo Live helped me to expand my fan base and to connect more with foreigners...the higher the level, the more possibilities that people and foreigners will see my broadcasts and videos...for the kind of work I do (sex work), I prefer to be connected with clients who are foreigners...They not only pay more but most them are also nicer and more polite*

Bigo Live allows users to live-stream their favorite moments, and make friends from all around the world through live video/audio/text chat [7]. Through engaging more on the platform, some Hijra expect to be seen and discovered by foreign users who are interested in sex work and will provide big amount of money for their work. Distinct feature offered by Bigo Live has allowed Hijra to expand their popularity beyond the border and created an opportunity to be connected with expected audiences. Even though for some such exposure may be a privacy issue, for many Hijra it offers a strategic process of selecting clients or audiences to improve their professional lives.

Visibility Control and Harassment. Although distinct social media platforms have provided Hijra ways to communicate or earn money through sex work, they also have brought additional harassment, making the platform's afforded level of visibility control, which we refer as presenting themselves with selective visibility, essential concern when countering harassers. For example, many Hijra take advantage of the block feature in Facebook when the level of derogatory language used against them on their own social media platforms becomes intolerable. During FGD1, participant P1(18) mentioned:

> *For example, in Facebook or Bigo Live, when I upload a picture or video, people make comments like "Hijra" "hot/sexy", "show me your naked body" etc. I instantly block them from there*

The blocking features on Facebook and Bigo Live help Hijra maintain their social media profiles by preventing unwanted harassment. However, in some cases, the blocking feature alone is not enough to afford enough visibility control to Hijra to adequately combat harassment and bullying. Specifically, the study report that this is a problem with specific harassers who create multiple account to circumvent blocks. On this issue, interviewee X2(35) said,

> *...some people just keep calling and harass me online... when I cannot tolerate any more, I block them...The irony is some of them open new accounts and add again...one day I may find out that is the same guy that I blocked*

Here, we see a conflict between a platform's afforded high visibility control (individual, fine-grained block tools) and afforded low identity persistence (easier alternatives to the tools) in terms of audience management and harassment for Hijra. While the platforms are, indeed, trying to afford better visibility control to ensure safety, there they are sometimes simultaneously providing ways to create new/multiple accounts online for its users that bypasses the usability of the blocking feature in the first place for Hijra.

Inability to control "who" gets access to sensitive information and "how" have been a big issue for Hijra as it often turns into a matter of serious privacy and security concerns. Leaking personal photos/videos publicly, using personal information to create fake profiles and seek money from others and

হিজড়া তাড়ানো আন্দোলন
Group
হিজড়া গোষ্ঠীমুক্ত সমাজ চাই। ভিক্ষুক মুক্ত এলাকা যেভাবে ঘোষনা করা হয়েছে ,তেমনি ভাবে যে কোন এলাকাকে হিজড়ামুক্ত ঘোষনা করা হোক।তাদের...

হিজড়া আইডি নির্মূল কমিটি
Group · 137 members
এই গ্রুপে শুধুমাত্র হিজড়া আইডিদের বাঁশ প্রদান করা হবে। গ্রুপে অযথা রাজনৈতিক আলাপ কিংবা ফাউ লেখা পোস্ট করা যাবেনা। ক্যাচাল করলে তাকে...
31 members said they live in Dhaka, Bangladesh

যে ছেলেরা ফেইসবুকে মেয়ে ID(fake) চালাই ওরা হিজড়া <We hate them>
Page · 5.1K like this
যে দিন FB আইডি খোলছি সেই দিন থেকেই এই ফেইক কথাটা শুনতে অতিস্থ হয়ে পরছি। তাই এমন কাজ কেউ করবেন না।

§§ যারা মেয়েদের নাম দিয়ে fake id চালায় তারা হিজড়া §§
Page · 273 like this
আশ্চর্য জনক ছবি, তথ্য ও মজার জোকস পেতে লাইক দিন এক্ষুনি।

Figure 3.3: Anti-Hijra Groups in Facebook

spreading rumors have been common events for Hijra who were either unable to restrict the harassers or their contents. On this topic, interviewee X6(25) said,

> *...he was sharing personal photos of me and was asking for money from others in Facebook...I could guess who it was but was not sure...one of my colleagues suggested me to disable my id and report the culprit to prevent him from accessing my personal information...but the problem was I had no idea how to disable my ID or to report to Facebook about this event and the culprit*

Many Hijra lack the necessary training and technical skills to effectively employ platform tools, even to the extent that it seriously impacts their security online. While a majority of the users may be familiar with features like blocking someone or deactivating personal id to ensure visibility control online, for some Hijra, these privacy tools may not seem easily accessible, and visible, but rather excessively intricate and complicated. Being unable to utilize such complicated privacy controls has also been a concern for the participants while reporting different anti-Hijra online communities that promote hate speech against Hijra **(see Figure 3.3)**. Even though platforms like Facebook provide users security tools to report online hate speech and harassment, Hijra are seldom made aware of those tools to protect their content or shape their audiences, as participant P5(20) demonstrated in FGD1:

> *Can we report these online communities in Facebook? Really? How?... What is a "report" option? I am sorry...We are not good with technology... we don't know how to use this option online*

To the participants, tools to report online community pages are often unfamiliar, as there is no clear instruction or indication provided to them regarding their options to file complaints against harassers. Even though both block and report are privacy tools to control unwanted events and individuals online, Hijra are not aware of all these options due to their limited knowledge on the platform's affordances. Not being familiar with options like report, and not seeing any visible action against such harassing pages, individuals or contents have forced many Hijra to perceive platforms like Facebook as more hostile towards them. Such limited technical skill-set and knowledge/awareness at controlling their contents, events and individuals intensify Hijra's vulnerability online and make their social media ecosystem more complicated.

Shifting of Participation Across Social Media Ecosystem (RQ3)

Unexpected negative events and harassment can trigger Hijra to shift, limit or stop their online participation through different social media platforms. As we explore RQ3, our data suggest that Hijra adopt strategic decisions to shape their participation online that are often motivated by the platforms' affordances, Hijra skill-set and community influences conforming those negative experiences.

Migration, Limited Participation and Social Media Non-use. Hijra's experiences of being severely bullied and harassed online give Hijra good reason to identify which online spaces are less likely to be unsafe. Even though Hijra face extreme harassment online, instead of deleting their profiles from distinct social media platforms, 11 out of 61 Hijra (around 18%) prefer to shift from one platform to another in a hope to search for a space that will provide better experiences in terms of their identity. As interviewee X9(18) mentioned:

> *What I feel best about Bigo Live is it has less harassment...Facebook promotes more harassment...which is why I left Facebook and moved to Bigo Live...I still have my account in Facebook but I don't use it anymore*

As Facebook is perceived more hostile towards Hijra, Hijra looks for spaces that are supportive towards them and their identity. However, it is not uncommon for them to keep their old profiles open. Such a decision to migrate from Facebook to other social media platforms comes with it own consequences. As Facebook is the primary media for many Hijra to be connected with friends and families, such migration puts a dent in their virtual social lives forcing them to compromise their participation online. Whereas on one side, Facebook is working as an alternate for social interactions for many Hijra, stressors like additional negative experiences and privacy concerns force them to transfer or migrate their participation elsewhere.

Apart from migrating their participation, many of the Hijra (29 out of 61, around 47%) mentioned either limiting or withdrawing their participation from distinct social media platforms to protect themselves from harassment. For example, interviewee X13(24) mentioned,

> *There are many boys who come in live in Bigo Live, disguise themselves as girls and make vulgar and defaming videos...There is no way to distinguish the fake Hijra from us in Bigo Live...For them other people blame and shame Hijra like us...For these reason, I don't go in live or use Bigo Live much now*

Some Hijra mentioned withdrawing their participation from distinct social media platforms because of getting hacked and being unable to retrieve the profile. As X12(29) said:

> *My Facebook Messenger got hacked...the person who hacked it asked for money to others and leaked some of my personal pho-*

> *tos...I did not know what to do or how to stop it, so I stopped using it [Facebook Messenger]*

Limited skills to handle concerning situations like profile being hacked has also forced Hijra to withdraw their participation online. Even though the participants were familiar with the use of social media platforms like Facebook Messenger, they were not familiar enough to handle situations like these where a little bit more knowledge or skill on using the platforms was required. Such experiences were concerning for Hijra, which lead them to stop and leave the platform for good costing their proper interaction their families or clients through those platforms.

Community influences. The decision to shift to another platform in one's ecosystem also sometimes depends on the group dynamics Hijra value within their communities. As Hijra have strong bonds within their community, their decisions to move platforms or use certain platforms in certain ways often get influenced by what others from the community suggest, or the information peers or authority figures provide. Participant X6(25) (a Guruma from Comilla) mentioned:

> *I heard if you do drugs or something bad, your online ID will be hacked. But BIGO Live is safe though...I also suggest my fellow Hijra to be safe when using these online platforms*

Often, along with fellow Hijra, authoritative figures such as the Gurumas have power over what a follower should know about or use for their online participation. Even though the information provided by the Gurumas are not entirely correct or true every time, due to the influence they have over their followers, it effects the way other Hijra shape their participation in the ecosystem. Some of the participants also mentioned a tendency to adopt or reject distinct social media platforms based on their collective experiences or own internal group dynamics. As FGD1 participant P1(18) said,

> *Well, we use smartphones. We eventually know about different social media platforms...If someone in our community uses or pre-*

> *fer any specific one [social media platform] for you know…different reasons, we all get to know about it and try it out*

When a member of the community introduces a new app or platform that is beneficial (in terms of privacy, less harassing, better communication, clients etc.) for the whole group, it often influenced the participants to shift their social media participation to that new platform. As solidarity within Hijra communities is strong, it guides Hijra to adopt a new technology or social media platform.

While existence on social media becomes an issue of safety and privacy for Hijra, restricting participation online seemed more feasible for many of the participants. By limiting, withdrawing and shifting participation from one social media to other, Hijra strategically try to control such instances as much as possible with a cost of their smooth participation online.

Discussion

The study highlights important aspects of social media ecosystem of Hijra, who have their own specific audience concerns and perceptions of affordances on different social media platforms. While RQ1 and RQ2 specifically inquire into Hijra's social media ecosystem to understand with whom, how and where they build their connections and perceived affordances, RQ3 digs further to see where the system fails and thus force Hijra to migrate or shift their participation on online social media.

Gender Minorities, Hijra and Social Media Platforms

As our results suggest, Hijra break through traditional gender boundaries and cannot be reduced to merely metonymic, Western figures for an analysis of gender fluidity [348]. During the study, it was interesting to explore participants' choice of terminologies to define their identity that do not fit under the existing English language terms for other GSM communities. It is possible that many among the LGBTQ+ community from Western context are unaware of most of these local terms used to define GSM identities. In Western contexts, many LGBTQ+ communities use the term queer as an "umbrella" term that encompasses all who identify as lesbian, gay, bisexual, or transgender [656]. However, due to Hijra's unique multi-classifications of gender perceptions (that may not conform to the normative social expectations and definition of gender minority and sexuality), it is unfair to try and explain Hijra identity using English LGBTQ+ terminology [36]. It is even potentially offensive to use Westernized gender and sexuality categories for them. In the Western world, the categories that are used to define GSM are not self-evident, and raise the need of asking localized questions on what these categories mean to the people in a specific country [381]. As a consequence, this study adds to the conversation on GSM that exists in non-Western context by exploring Hijra's identity perceptions, of which some are impossible to be translated or to fit into the Western models of gender and sexual identities [412]. Additionally, this study also addresses the conundrum Hijra face of choosing between online exposure and identity protection that in turn motivates them to look beyond only audience management objectives while navigating through different online platforms. This study highlights those complexities by engaging in deeper explorations on GSM social media ecosystems and evaluating the framework more intensely from non-Western context.

Audience Management, Harassment and Reversion of Hijra

Similar to the existing framework of social media ecosystem [190], the participants described relying on perceived audiences who are an integral part of their personal social media ecosystem. Audiences such as "targeted imagined audience" based on communal ties [377] (close families and friends as well as other Hijra members of the community), or “outright” targeted audience (such as cis-males) [190] play an important role in Hijra's online ecosystem that is constructed via interplay between spaces and affordances. Due to the stigmatization Hijra face for their identity, they are in constant search of audience awareness, controlled exposure and inclusiveness by segregating identity related contents in distinct spaces. For many Hijra, having tightly-specified form of communication space with easier, less complicated features heightens their presentation flexibility towards their audiences and builds a sense of control on who they connect with and how (such as participant X2). Often, affordances in Hijra's social media ecosystem are not enough to address their audience related concerns on self-presentations and visibility control. Even though the current lens of social media ecosystem focuses on the combination of audience and affordances in audience management, for Hijra, such interplay does not always work due to their lack of understanding of the platform's affordances as well as required technical skill-set and knowledge to manage audiences.

Unable to control their self-presentation using provided privacy tools, many Hijra face unavoidable harassing experiences online, which in turn, impact the way Hijra perceive their audience management strategies. While total around 65% of the participants strategically migrated or limited their online participation from one platform to another due to these negative experiences, they kept their personal profiles open and purposefully not managed in terms of audiences. Even though Western GSM populations have a tendency to follow rigorous processes in terms of sharing content with specific audiences online [278], Hijra (e.g. participant X9) tend to have less while shifting participation for audience specific reasons without erasing or fully closing previous profile at all, which directs our observations to the likelihood of their reversion [83]. Due to Hijra's professional and personal objectives, they often need to ensure maximum exposure online; this may influence them to revert back to online spaces they left earlier. Current models of social media ecosystem needs to address such dynamic shifting of participation by GSM users who purposefully keep their audience management strategies relaxed while leaving certain social media platform.

Extending Social Media Ecosystem Framework

While our data strongly suggest that Hijra are at many times aligning their personal social media ecosystems through Personal Social Media Ecosystem framework [190], it also clearly reveals areas where this lens must be extended to better account for non-Western contexts. Our findings on Hijra's struggle with self-presentation on social media extends the existing lens of social media ecosystem by considering technical skill and knowledge as a fourth element in the framework.

A Fourth Element: Skill. The study observed a strong influence of technical knowledge/literacy or skill on Hijra's way of addressing their audience concerns and spaces. This skill/knowledge represents additional factor that potentially and significantly shapes how stigmatized GSM populations outside the US construct their concept of audience privacy and spaces and direct their participation online accordingly [445]. Past literature like [190, 188] have explored LGBTQ+ and their audience concerns through the online spaces and affordances but did not account the concept of skill that can highly impact the spectrum of social media ecosystem for Hijra. Having tons of privacy tools for the users is not enough if they are not accessible, especially for the marginalized GSM populations like Hijra. Here accessibility does not mean access to the technology, but rather denotes the concept of accessing the knowledge that is required to reap full benefits from the platforms' affordances. Our data suggests that this struggle with technological understanding and skill is not an individual problem, but rather a common experience within many Hijra communities. [531] have mentioned how in developing countries this type of struggle is not uncommon, as many people from low-income communities lack textual and digital literacy that effect their technology- operation skills. Hence, while we try to explore how stigmatized users from Western context interact with social media to construct their identity by only considering provided platforms' affordances, we may potentially exclude other stigmatized GSM communities from non-Western context whose perceived platform affordances are significantly impacted by their technical knowledge and skill-set.

Research on postcolonial computing shows that mainstream computing knowledge is often ignorant towards local understanding of technologies, which creates a space of marginalization and failure against local communities [38, 579]. Localized knowledge and understanding of technologies have been historically marginalized, suppressed and neglected [570, 579]. This type of mindset represents a heightened danger for stigmatized individuals like Hijra.Even though the usability of "disabling id" or “reporting” feature may seem straightforward to most users in Western context, due to the limited knowledge that is accessible to Hijra, participant X6 expressed frustration of not being able to identify and utilize the features during privacy concerns. Users can become unable to personalize or control the data they share online [467], as the task of exploring and mastering this protective technology is often left entirely to the adopters themselves [64, 37]. For instance, Facebook relies on the assumption that users are skilled enough to adopt platform affordances and potentially ignores marginalized populations like Hijra, who may not have the same access to the knowledge and skill. Being unable to utilize the privacy controls, many marginalized users face harassment online that effectively force them to restrict their participation on social media platforms [600, 449]. By accounting skill, we are able to directly interrogate the impact of the affordances on users’ perceptions of online spaces, self-presentation and content sharing strategies. Therefore, this study suggests to include skill as a fourth element in the social media ecosystem framework that, beyond just Hijra or other GSM populations from certain contexts, potentially controls how users perceive online spaces and interact.

Community and Cultural Influence on Combating Harassment. While we establish technical skill or knowledge as a primary element within social media ecosystem for Hijra in non-Western context, we also observe community and cultural influence on these low skilled users that potentially construct their online practices as well. Hijra, with limited knowledge on platforms features, are often dependent on the information flow passed to them from their closely knitted community. Previous literature on information seeking states that users with limited resources seek and make sense of any information they receive when they have high-level self-presentation goals, but may not know exactly how to achieve them [256, 523, 189]. Connections like friends and families step in such cases and inform the users of their social media platforms' affordances, including lax privacy settings [189].However, for Hijra, such exogenous information come from other Hijra members of the community or sometimes from authoritative figures like Guruma. Their influences as sources of information on platform affordances impact the way Hijra's ecosystem are built or perceived. As many Hijra get engaged with unsolicited work to earn money through distinct social media ecosystem, to protect themselves from unwanted harassment and invasion of personal privacy, Hijra are at constant look for adopting new social media platforms that will bring the more clients and better privacy. This adoption of new platforms often happens earlier with Gurumas who wish to ensure their followers safety online before they engage in it. Taking influence of authoritative figure and community influence on limited skill-set into consideration help us to explore Hijra's perception, or in a broader sense GSM perception, on building their social media ecosystem more accurately.

Apart from community influence, cultural influence on skill-set has also been an important factor for Hijra in Bangladesh. While many social media platforms offer its users extensive options of privacy settings, they are not always culturally appropriate and signified and thus, become unnecessary and useless. For example, even though participant P5 was struggling through intense online harassment for being Hijra online, it never occurred to them to "report" against someone or pages/groups, as the feature is not culturally signified to this low-skilled population. While previous research states that social media can reinforce personalized content curating behaviors within users that range from hiding posts to blocking other users [651], there some Hijra primarily online rely on the feature "block" than any other censorship tool to restrict harassment or unwanted connections. However, such feature of blocking users became impractical by the existence of fake profiles online. As Hijra often add unknown people to their existing online profiles to build connections, experiences of being deceived by the fake profiles make it harder for Hijra to trust the space. Whereas Hijra acknowledge harassing contents created against them are done by homophobic users in Bangladesh, they also count the space responsible for hosting such negative contents. Such distrust on a specific space influence Hijra to leave or shift their participation to another platform that is less harassing towards them or needs less technological understanding to control. This indicates an inadequacy within the platform design system that fails to serve GSM populations from a culturally different context.

Implications for Design Practices

The findings add to the broader conversation on building more inclusive technologies for GSM populations by identifying specific design practices that need to be adopted by the designers during platform development. Be it for gender construction or privacy controls during online self-presentation, GSM users like Hijra from non-Western contexts struggle with platform designers' current design practices that are mostly informed by the Western notions of affordances [530, 434, 38]. The study highlights two of the most crucial implications for design practices in the context of non-Western GSM users that may help designers to develop more inclusive social media platforms.

Complicated Gender Constructions. First, as the current design of most of the online platforms incorporate less granular gender choices for

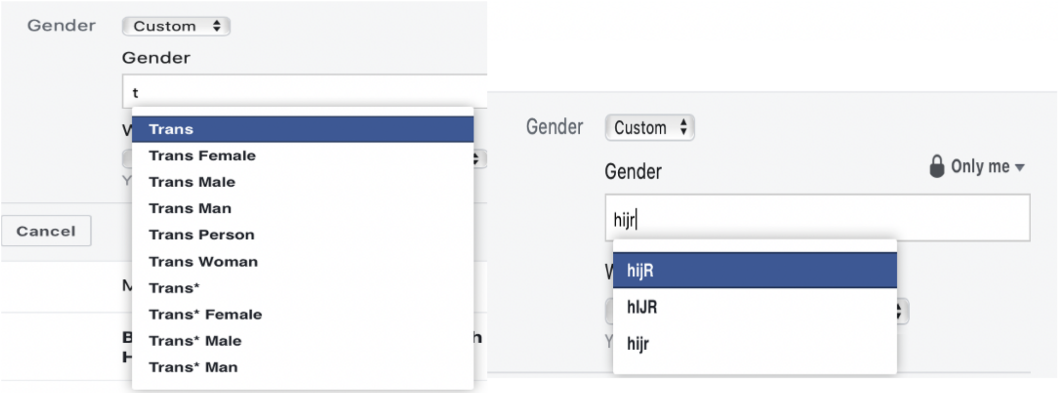


Figure 3.4: Classifications of Gender in Facebook

their users that only include male, female and custom/others options, extra step to customize gender while not having hijra as a direct option similar to male/female categorization confuse Hijra, making their identity constructions on social media further challenging. On the gender issue, previous study mentioned that Facebook's gender classifications exists somewhere in-between a rigid binary and fluid spectrum [102]. Even after Facebook has incorporated new ways to increase gender flexibility for its users, in their structural level, it still has continued to fit non-binary genders into binary classifications to serve stakeholders while also shaping the perceived needs and preferences of both users and advertisement clients [102, 103, 539]. These prior studies back our arguments on the existing shortcomings of gender classification design practices of platforms like Facebook that need to be reevaluated and restructured from a non-Western perspective for communities such as Hijra. While Facebook prides to support GSM populations by providing 56 gender options (under custom) in the interface that pop up when a user attempts to type in their preferred gender term [21, 102], the study shows that for Hijra, it fails to support in similar manner. A user needs to type in the whole term "hijra"/"Hijra"/"Meye Hijra"/"Chele Hijra" to select their gender, whereas for other GSM users, such as trans populations, typing in only a letter brings up possible suggestions related to that gender **(see Figure 3.4)**. This confirms how platform designers' understanding of gender is limited within a pre-set

Westernized gender classifications and force GSM users from non-Western context to follow extra complicated steps to construct their identity online. Thus, to set the focus more on non-Western GSM context, the study joins the discussion and encourages designers to think holistically about how these marginalized users prefer to define their gender online and provide more accessible and culturally appropriated options to them.

Privacy Affordances. Second, even though platform designers include many privacy controls setting for their users while developing platforms, such as features like reporting or blockng individuals/disabling personal id, it was evident within our findings that such mechanism often do not work for Hijra from individual level. The study finds, Hijra have strong community aspect within themselves; as such, their perceived platform affordances is significantly influenced by their group dynamics and largely dependent on the sharing of information within communities. Thus, incorporating and introducing group level privacy tools, such as collective block list, may benefit Hijra, as it can facilitate individual effort to combat online harassment with group support as well as can create a more manageable and user-friendly experience for them. Conceptualizations of online privacy remain mostly at the individual level in Western context [89, 153, 234], and while research like [576, 182, 322] validates group privacy concerns as parts of design practices from a Western non-marginalized non-GSM context, the study strengthens these design implications by situating them in non-Western contexts for GSM. Of course, this must be weighed against technical understanding of the GSM users, as these design practices will end up adding more complexities to the existing privacy mechanism if the designers incorporate them within design practices without providing proper guidelines to their users who may lack access to the needed knowledge of using these tools. Therefore, platform designers need to think more expansively about how they can address this inaccessibility of knowledge and skill by the GSM users while also adding privacy flexibility to them from non-Western context, as it significantly impact their self-presentation online.

Limitations and Future Work

This study has some distinct limitations. Even though we wanted to ensure author accountability for the findings reported in this study by member checking our results with participants, due to the participants' extremely busy schedule and being severely affected by COVID-19 in Bangladesh, we could not meet the participants to discuss the reported results. Even though we accept it as an unfortunate limitation to the study design, we have tried our best to do extensive background research on Hijra community and carefully checked all the claims we made in the paper to ensure accountability. Additionally, while this study primarily focused on Hijra's self-presentation and online practices through social media ecosystem framework, it was outside the scope of this study to examine external circumstances such as local laws and changing political circumstances which can also effect Hijra's social status both offline and online. Future work could explore these structural factors while also investigating the possible intracommunity differences between trans and intersex Hijra individuals through an ecological lens [190], potentially yielding a more complete picture of Hijra, or in general GSM self-presentation in non-Western contexts.

Conclusion

Social interaction across multiple online platforms is a challenging issue for members of GSM due to the stigmatizations they face in daily basis for their identity, which increases the complexity of their self-presentation decisions. In this paper, through investigating personal social media ecosystem model, I have explored how GSM from non-western context, such as Hijra, construct their online participation around harassment and self-present focusing audiences, affordances and spaces in mind. This paper has also extended the model by incorporating user skill and knowledge as a fourth crucial element in the ecosystem that significantly impacts Hijra's perceptions on online space and online practices, such as audience and privacy management or platform migrations. The contributions of this study on community and cultural influence on Hijra's online participation have inspired me towards implications for design practices that take account of more accessible and culturally appropriated gender categorizations for Hijra as well as group level privacy controls to facilitate these populations during online harassment. These suggestions on design practices can provide guidance to the researchers and designers in further efforts to understand and support GSM in achieving their self-presentation goals, and lay the groundwork for future in-depth work on these populations in an increasingly diversifying social media space.

CHAPTER 4 - INFERRING ONLINE COMMUNITY BASED INFLUENCES ON RISKY HEALTH BEHAVIORS AND SELF-HARASSMENT

Introduction

Online platforms have significant impacts on users' mental and behavioral health [232, 75]. Various communities within social media platforms, such as Twitter, allow individuals with chronic health conditions to share data, provide and receive help, raise awareness, challenge stigma, document their experiences, and advocate for themselves [94, 126]. While participation in these communities can positively impact users, there is potential for harm as well. For example, there are many online pro-Eating Disorder (ED) communities that actively promote ED activities and behaviors as a legitimate lifestyle choice rather than an expression of a serious mental illness [423, 456] or deviant behavior, such as cyberbullying and online harassment [478]. These pro-ED communities can negatively affect people with and without EDs, via promoting unrealistic standards of thinness, encouraging disordered eating behaviors, and sharing harmful tips on how to develop and maintain an unhealthy weight (known as "thinspiration" or "thinspo") [478, 114, 117, 583].

Over the past decade, the HCI community has dedicated considerable research to this mental health issue, focusing on deriving understanding and knowledge from public social media data. Research topics using this public data include the identifying and understanding eating disordered behaviors and activities online [624, 452, 478, 482], predicting risks of ED activities [143], and discovering the in situ evolution of social norms and practices within online platforms as they relate to ED behaviors [145, 227]. However, research focused on node-level influence and nuanced community structure within platform-specific ED community networks is limited. Identifying who manages or affects these online communities is crucial because it gives additional and deeper information about the networks' internal dynamics and how this sphere of influence takes shape dependent on node-level involvement.

Therefore, to address this gap in existing literature regarding influence within online communities of ED networks, we report the findings of both qualitative and quantitative network analysis. The dataset was constructed with over approximately 32,000 data points collected through Twitter's official premium API between May 1st-May 31st, 2020, using specific ED-related hashtags (#thinspo, #proana, #edtwt). Using quantitative measures such as centrality matrix, rank correlation, community detection algorithms (Louvain [581] and Girvan-Newman [187]) on this dataset, we identified which central nodes are influencing the ED communities and how the community is structured around them. Using combined computational topic modeling (i.e., LDA [501] and NMF [138] topic modeling algorithms) and qualitative thematic analysis, we also analyzed the text entities of the data set (user tweets) to identify emerging and popular contents and topics within the ED network. The findings show:

- The ED community on Twitter is a homophilic network where many interactions between nodes are done through retweeting certain influential nodes. This pattern indicates an information dissemination characteristic of the community in which majority nodes in the network are exposed to unhealthy ED contents through retweeting specific central nodes

- The community detection algorithms confirm the existence of defined communities and sub-communities within the Twitter ED network that are primarily led by these central nodes. However, depending on the structure of the network (whole vs. sub-graph), the shape of this leadership can be sparse

- Along with existing popular contents, we observe emergence of new contents, such as meanspo-related tweets, which highlight the importance of receiving extremely harsh or negative "encouragement" online for some individuals with EDs. The analysis on the central nodes confirms that these popular contents are also common and significant within these influential nodes

- We also identified emerging ED-related linguistic indicators based on topic modeling for online ED community, which included important primary and secondary themes, such as community building, community curating, desired ED lifestyle, and emergence of novel community platforms. Such results indicate that community sense within ED individuals in Twitter is very strong, and it often became the central topic of discussions and participation via tweets

This research makes three key contributions to the HCI literature: 1) It contextualizes the presence of ED influence in online communities through node-level participation and engagement; 2) it provides a granular understanding of prominent topics and contents within ED community online using multiple topic modeling algorithms and extends the current knowledge on online ED contents; and 3) It contextualize emerging ED-related linguistic indicators (e.g., meanspo) with known ED activities that are centered around self-harassment and online censorship. This research has been published at GROUP conference in 2022 [444].

Information Dissemination of Pro-ED Communities

Studies have demonstrated that the structure of online communities influences [164, 367] and can be influenced by [228, 560] the information that enters and is diffused through them. This spread of influence plays a major role in the spreading of information, some of which may affect offline behavior as well [45]. Research on social networks primarily focuses on how social structure and relationships promote or influence health and health related behavior [382]. It's not unusual for a small group of influential and active community members to provide the majority of online content [40].

Previous research has investigated the contents of pro-ED communities on online platforms, such as blogs and related social networks [116, 233, 374, 550, 145, 478] using mixed methods approaches, such as codebook analysis and topic modeling, to identify the support structures these communities offer to their members through posts [116, 233], the search pattern and linguistic variations for pro-ED contents [374, 145], censorship around ED participation [142], and the ethical implications of pro-ED materials in online groups [550]. Twitter is a very well-known and well-used social media platform within ED communities, as it provides a sense of community identity and mutual social support online [624], as well as a unique setting for pro-ED content to be publicly exchanged through "follow," "retweet," "reply," and "mention" features [624, 57]. Although there has been extensive work on identifying signs of ED from user-generated content on Twitter, few have investigated the community membership and structure of these heterogeneous networks in depth [145]. As an attempt to fill the gap in community understanding of ED network, [624] focused on users' participation in Twitter ED communities, and based on interactions between individuals, presented the existence of homophily among eating-disorder communities on social media. Another study [417] used quantitative measures such as Gephi and network centrality matrix to identify community structures and influential users within a Reddit pro-ED forum. Others have described the structure and evolution of communication in online eating disorder communities using clustering techniques to identify ED-related issues that were discussed in online conversations and to depict interpersonal connections in the network [625].

While the findings of these research are insightful, they largely focus on community connections without focusing on the peer influence within these ED networks and its impact on how harmful information is spread.

Impacts of Online Interactions on Risky Health Behaviors

When discussing the scope of peer influence within online communities, one must consider the pervasiveness of social media platforms within daily life in the U.S. [66]. Extant literature has examined a wide range of both positive and negative effects of life online. For example, individuals are able to connect and maintain relationships with friends, family members, and colleagues [546, 607] and develop new ones [291, 151]. However, the use of social media and other forms of computer-mediated communication is associated with negative impacts as well, including harmful interpersonal interactions (e.g., harassment [107, 323], cyberbullying [563, 480], doxing [566, 200], trolling), non-consensual and/or age-inappropriate exposure to explicit sexual content or behaviors (e.g., sexual solicitation [633], sharing of nude images [480, 169]), development or exacerbation of addiction issues (e.g., internet addiction [632], online gambling [245]), and issues arising from an erosion of privacy related to personal content online [390, 565].

With the ubiquity of smartphones and constant connectedness of both teens and adults in America [52], it is expected that many individuals have engaged in and/or been exposed to risk behaviors online. For example, the majority of adolescents report either being cyberbullied or witnessing cyberbullying [480, 146].Research suggests that adolescents experience negative emotional effects after single incidences of exposure to certain online risks and behaviors (i.e., cyberbullying, sexual solicitation, explicit content) [400]. Research has verified that youth as young as 11 and 12 years old report negative impacts of interactions online, including exposure to eating disorder activities [480]. In the last decade, research has diversified beyond the more explored depression [175, 196, 367] and anxiety [413, 558] to include non-suicidal self-injury [299, 356], eating disorders [478, 477, 482, 145, 624], suicidalidy [357, 441], bipolar [393, 166], and schizophrenia [214, 623] to understand and make inferences about technology and hospitalizations as well as treatment. Additionally, a few have looked at gender and culture as they relate to online activities [482, 177, 379, 485].

Most of the social media work outlined above focuses on using public data. While this is useful in helping define the phenomenon, it does not allow for understanding individual-level influences, characteristics, and desires. Pater et al. conducted a mixed methods case study including a review of the social media activity of eating disorder patients during the 18 months prior to their first hospitalization [477]. They found that patients were avid consumers of online ED content, but not producers. This research raised questions about who the influences within the ED networks are and what type of content are they sharing. The research presented in this paper is grounded in these important questions:

- **RQ1:** *What does the community structure look like for ED networks on Twitter and who are influencing these online ED communities?*
- **RQ2:** *What types of ED contents (hashtags, media, links) are popular and shared within these ED networks on Twitter?*
- **RQ3:** *What emerging ED-related linguistic indicators can we identify from the ED communities on Twitter?*

Methods

In this section, we provide a detailed description of the Twitter dataset along with the data collection methods, preprocessing techniques, and the approach for the qualitative analysis. We subsequently describe the community and topic detection algorithms used in this study to identify communities as well as the prominent topics within the dataset. We also established a codebook for the analysis of both the hashtags associated with the posts as well as the posts themselves. Each post included a combination of a piece of media (video, image, gif), post text, and hashtags.

Study Data

We used Twitter's official API to collect over 32,000 public posts in the pro-ED space between May 1st and May 31st, 2020. As Twitter's free API only sends back tweets for last 7 days, we used premium full archive API to gather targeted tweets [20]. The data gathering occurred in three stages. First, we obtained posts counts using primary tag #thinspo, which is known to be highly related to eating disorder content [478, 145]. The resulting sample of approximately 14,000 tweets provided a list of top tags connected to the #thinspo community within Twitter. Within those tags, we decided to include two other primary tags, #proana and #edtwt, as they had the highest counts within this initial data collection. Table 4.1 provides an overview of the final data set created from the three ED-related tags. Finally, we created a candidate set of posts from these raw sets that we confirmed to be related to pro-ED behavior.

Number of Total Tweets	32530
Number of Unique Users	5658
Total Retweets	19165
Actual Tweets	13365
Total Tweets with Links	8262
Mean Tweets Per User	6.67
Variance of number of posts per day per user	12.42

Table 4.1: Statistics of Twitter Data of the Study Cohort

Prior to topic modeling, we pre-processed the tweets using methods like Tokenization, Normalization, and Stemming [543]. The final data set included over 32,000 pieces of data from 5658 users, including over 19,000 retweets (tagged as RT) and 1141 unique tags. Qualitative observation showed that these tags were strongly associated with the pro-ED community on Twitter. The variables in the data set collected from Twitter were:

- **Timeline:** The timeline of the tweet posted (integer)
- **ID:** Unique ID of the user (integer)

- **Name:** Name of the user (string data type)
- **Screen name:** Unique screen name of the user (string data type)
- **Reply count:** How many replies each tweet received (integer)
- **Retweet count:** How many retweets each tweet received (integer)
- **Like count:** How many likes each tweet received (integer)
- **Total Status:** How many total statuses that user has shared at the time of posting each tweet (integer)
- **Friends Count:** How many users the user follows at the time of posting (integer)
- **Followers Count:** How many total followers the user has at the time of posting (integer)
- **Tweets:** The individual tweets that included texts, the hashtags and media links (string)

Algorithms Used for Community Detection

In this work, we chose two algorithms, Girvan-Newman [187] and Louvain [581] to find sets of nodes in a graph that have higher density of community connections within themselves in a set than between multiple sets. These algorithms are known to produce reliable results, and work efficiently in online networks.

The Girvan-Newman algorithm determines the communities by continuously removing the edges from the original networks which are not relevant to that particular user [582]. This algorithm mainly focuses on the concept called “edge betweenness” which is used for determining the communities in huge and also complex networks. We can describe Girvan-Newman algorithm in the following way [187]:

1) Calculate edge betweenness for every edge in the graph

2) Remove the edge with highest edge betweenness

3) Calculate edge betweenness for remaining edges

4) Repeat steps 2-4 until all edges are removed

Because of its simplicity and ease of implementation on network structure, this algorithm has been successfully applied to a variety of networks [582]. However, because of its computational complexity, which is O(m2n) for a network with n nodes and m edges, it can only be used in networks with a few thousand nodes [582]. We used python implementation of edge_betweenness for GN algorithm.

The Louvain algorithm is one of the fastest existing algorithms because of its low time complexity and sequential access feature performance [346]. This algorithm is more efficient than other algorithms and detects communities in big networks by maximizing modularity [112, 455, 509]. The approach is agglomerative, which means that nodes are initially assigned to a community of size one and then successively aggregated with the nearby community that yields the highest gain in modularity (if it exists) [581]. The communities discovered in the first step become nodes in a new network, with edge weights defined by the number of connections between them [581]. The algorithm therefore constructs a hierarchical representation of the network and proceeds until no more modularity gains can be identified [581]. The final clustering that results from this procedure is used to define the community structure. We used python package community and module best_partition for Louvain algorithm.

Topic Modeling Procedure

To perform unsupervised topic modeling on the data extracted from Twitter ED Network, we used Latent Dirichlet Allocation (LDA) [501] and the Non-Negative Matrix Factorization (NMF) [138] models. The LDA approach was chosen because it is straightforward and widely utilized in a range of fields for topic modeling text corpora, which may be utilized as a sort of text summary of a huge number of documents [501]. NMF is distinct from previous dimensionality reduction methods in that it uncovers hidden low-dimensional patterns inherent in high-dimensional data and provides a nonnegative, part-based representation of data, allowing for more meaningful interpretations of mined data [138].

Before applying the algorithms, text processing techniques were implemented to clean the data. We filtered out tokens that were present in less than 15 documents (absolute number) or more than 0.5 documents (fraction of total corpus size, not absolute number). After the above two steps, we kept only the first 100,000 most frequent tokens. The process is then followed by the vectorization of the data to document-term frequency matrix. In case of LDA, the model is trained over a corpus, which in this case is the collection of words in the documents of the textual data. For NMF, the created document-term frequency is factorized as per the algorithm before printing of the obtained topics. The number of topics were decided based on repeated experimentation [501] and after some trial and error, we discovered that constructing models with ten topics offered enough coherent themes to adequately evaluate the data. The final output for both LDA and NMF contained the top 20 key phrases and associated tweets for each relevant subject, as well as their contribution. According to the findings, NMF outperformed LDA in selecting themes from the dataset based on their coherence score (mentioned later in results).

Codebook Analysis

The tweets in the dataset included at least one of these components: hashtags, text, and attached media (i.e., image, video, gif). A total of 75,676 hashtags were attached to the 32,530 posts in the data set, of which 1141 were unique. We used an inductive approach to analyze the tags and identified common as well as emerging hashtag categories within the dataset.

We also used an inductive approach to analyze 710 random posts within the dataset to see what the media, linked with the tweets, look like, what types of links they are, and what information they provide. Based on the link types, general themes were created and further refined into coding taxonomy. We created media archetypes [478] based on the types of information the media links provided. We also conducted qualitative assessment of the topics generated from LDA and NMF to group together similar themes and categories that were reflected through shared tweets within the ED network.

Ethical Considerations

We collected this data without user knowledge or consent – an accepted practice when dealing with public data. Thus, this research may misrepresent the behaviors, challenges, or identities of the study population, and the methods do not allow us to clarify potential misrepresentations. Additionally, the social media activity in the analysis is unable to capture the many complexities and nuances of human behavior. To ensure anonymity of the users in the dataset, we have replaced all actual usernames with pseudonyms. We have also used representative media and text examples and/or edited any direct quotes to ensure that the user-generated content reported in this paper cannot be searched and connected to the account that posted it.

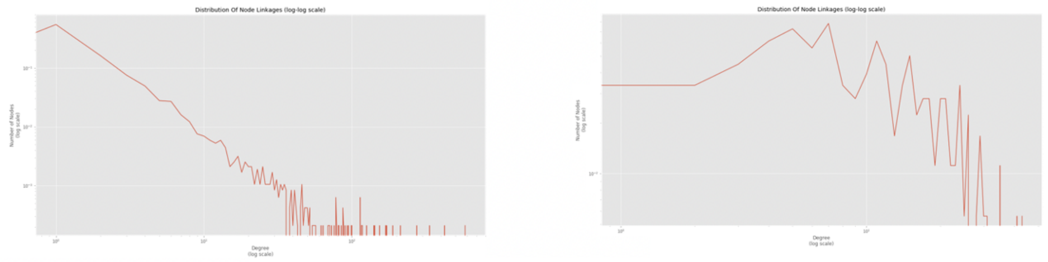
Results

The aim of this paper was to explore the presence of ED influence in online communities through node-level participation and engagement, while also examining prominent topics and contents that emerge through quantitative and qualitative analysis.

Influence within ED Network

My initial analysis of the dataset shows that, of the approximately 32,000 tweets, around 13,000 are actual tweets (including mentions) and 19,000 are retweets. In order to study some of the characteristics of the central nodes, we formed a network of mentions where, if User A mentioned User B, we connected A to B using an edge. I also formed a network of retweets where we connected each user to the other user(s) that they have retweeted. As most re-tweeting cascades are fairly shallow [5], all retweeters of a tweet can be regarded as direct retweeters approximately [44]. Whereas the retweet network (FG) is comprised with total 4,747 unique nodes (denoted as U_r) having total 10,686 edges between them (denoted as E_r), the direct mention graph is created with only 39 unique nodes (denoted as U_m) and 23 edges (denoted as E_m) between them. This primarily indicates that majority users within ED network are more prone to retweets than creating/sharing actual contents (including mentions).

User Influence. To detect influential users in the network dynamics, I considered retweets as a proxy to represent an endorsement to the tweet content shared by the user. For analysis purposes, along with the graph with 4,747 unique nodes (for graph FG), I also looked at a subset of this network by filtering nodes having 20 or more connections. The resulting network is represented as SG = $\langle V_{sg}, E_{sg} \rangle$, where V_{sg} are the set of nodes represented from U_r having 20 or more nodes with E_{sg} edges between them. After filtering, the final graph SG was consisted of much smaller network with a total of 179 nodes and 1061 edges. Figure 4.1 illustrates the degree distributions of both graphs where the tails of the distributions follow a power law.



a. Degree Distribution for Full Graph

b. Degree Distribution for Sub-graph

Figure 4.1: Degree Distributions of Nodes from Full Graph & Sub Graph

The study conducted an analysis of centrality matrix to identify the most important nodes within the network. There are many different centrality measures in use [90], and for this paper, we specifically looked into degree centrality (DC), betweenness centrality (BC), eigenvector centrality (EC), and closeness centrality (CC), both for FG and SG graphs, to identify who are the major nodes within this ED network. The DC scores from both network graphs create a very different list of central nodes. The majority of the prominent nodes for both graphs are different users, and for cases when they are same, their rank is different (Table 4.2). These ranks are created based on how many times these nodes have retweeted or been retweeted by others in the network. As the basic difference between FG and SG is how the nodes are defined in terms of their connectedness, this suggests that the top ranked nodes from FG are mostly retweeting or getting retweeted by others who have less than 20 degrees of connection of their own, and thus, being downgraded in the sub-graph when those nodes are being excluded. Also, Table 4.2 indicates central nodes from FG are being retweeted more in the network as opposed to retweeting others.

Rank	Top Users from FG	Degree of Connections,n	Retweeted Others	Got Retweeted	Top Users from SG	Degree of Connections, n	Retweeted Others	Got Retweeted
1	TikTokDiets	583	583	0	Thinspo02468	43	0	43
2	Bonespo4eva	424	420	4	thyn_babiee	41	32	9
3	thynspoo_k	335	335	0	ciqarxttxs	35	11	21
4	thin_hunnie	275	263	12	Bonespo4eva	35	33	2
5	famishedbarbie	213	204	9	restricted_vegiie	31	3	28
6	gottabth1n	189	189	0	hungri_q	30	0	30
7	Nahglossy	172	167	5	anamia_teeeennn	29	18	11
8	EDliife01	170	169	1	lacielosesweight	29	5	24
9	Skinnidaily	169	169	0	skanksubweight	29	13	16
10	bitch_n_binge	154	148	6	Eun-ice92	28	11	17

Table 4.2: Rank & Degree of Connections of Central Nodes

Additionally, we also report the average correlations among the centrality measures with error rate $er=$ 95%, and $\alpha = 0.05$ (Table 4.3). For this paper, we opted for Spearman's rank correlation coefficient (ρ) and Kendall's Tau (τ) [170] to analyze the correlations. The upper section of the table highlights the rank coefficient values for each of the centrality matrices within FG where we observe highest correlation values between DC and BC for both Spearman's coefficient (ρ) and Kendall's (τ), then EC in the middle

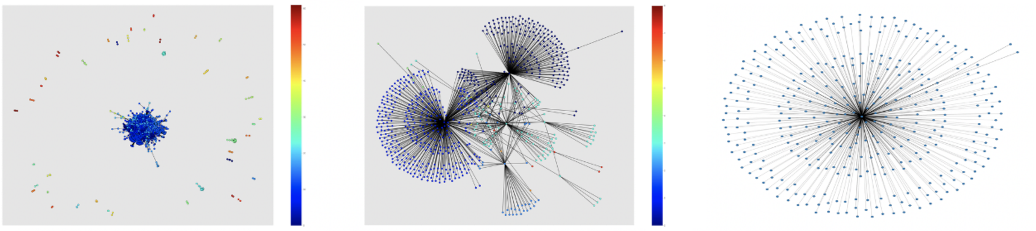
FG								
	Spearman Correlation Coefficient, ρ				**Kendall's Correlation Coefficient, τ**			
Matrix	Degree	Eigenvector	Betweenness	Closeness	Degree	Eigenvector	Betweenness	Closeness
Degree	**-**	**0.758**	**0.879**	**0.661**	**-**	**0.6**	**0.733**	0.467
Eigenvector	**0.758**	**-**	**0.661**	**0.830**	**0.6**	**-**	**0.511**	**0.689**
Betweenness	**0.879**	**0.661**	**-**	0.624	**0.733**	**0.511**	**-**	0.467
Closeness	**0.661**	**0.830**	0.624	**-**	0.467	**0.689**	0.467	**-**
SG								
Matrix	Degree	Eigenvector	Betweenness	Closeness	Degree	Eigenvector	Betweenness	Closeness
Degree	**-**	**0.720**	**0.757**	0.369	**-**	**0.535**	**0.535**	0.303
Eigenvector	**0.720**	**-**	0.552	**0.842**	**0.535**	**-**	0.422	**0.689**
Betweenness	**0.757**	0.552	**-**	0.442	**0.535**	0.422	**-**	0.289
Closeness	0.369	**0.842**	0.442	**-**	0.303	**0.689**	0.289	**-**

Table 4.3: Spearman & Kendall's Correlation Coefficient for Full & Sub Graph

and then CC. If the measures are not highly correlated, they indicate distinctive measures likely to be associated with different outcomes. The significant values are marked with bold in the Table 4.3. In almost all cases, the deviations of rank correlation coefficients are almost invisible for both Spearman's rank correlation coefficient (ρ) and Kendall's (τ). Based on the values from the table, it can be interpreted that, for the overall network, there is a strong relation between a node's degree of connection and its probability of being the information bridge within the network. The higher a node is being retweeted, the higher chances that that node will act as a bridge between nodes to spread information. For sub-graph SG, nodes with higher degree of connections not only work as bridges within the network, but also tend to be connected with other stronger nodes with similar influence as the correlation between DC and EC have been also found significantly strong along with their BC values. It means popular re-tweeters within structured network often seek information from other active re-tweeters. This sounds reasonable, as we can easily understand why information could propagate through Twitter by re-tweeting based on this [43].

Sparse Community Influence by Top Users. To understand the structure of the Twitter ED network, along with nodes' centrality matrices, we also studied how these central nodes are situated within ED community structure. To do that, we first looked at the clustering coefficient in the graphs we created. In graph theory, a clustering coefficient is a measure of how closely nodes in a network cluster together [22]. For the ED retweet network, the global clustering value of the whole graph was around 0.0365 and of the sub-graph was around 0.132. The lower clustering value of the *FG* graph shows how sparsely the neighbors are connected in the network; however for the sub-graph, it seems much more connected. To have much more nuanced understanding of the community structure for ED network, we also applied Louvain and Girvan Newman algorithms on the dataset to visualize the existence of communities within this network.

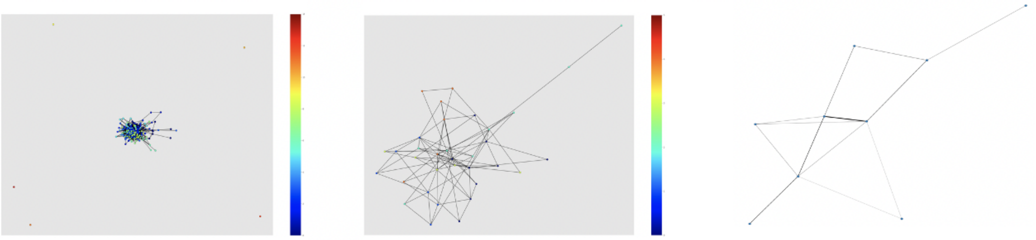
Through Louvain and GN community detection algorithms, we identify existence of multiple communities within ED network. Using Louvain community detection algorithms, we found existence of total 61 communities (Figure 4.2a) within *FG* network graph and total 14 in the sub-network graph *SG* (Figure 4.2b). Girvan algorithm resulted much smaller communities and indicates existence of total 14 communities in *FG* and total 6 communities in *SG* network graph. For conveniences to address these communities, we provided unique ids for each of the communities. The modularity



Communities in graph *FG*
(a)

Sub-communities in Community FGC7
(b)

Biggest sub-community (FGSC2) in Community FGC7
(c)



Communities in sub-graph *SG*
(d)

Sub-communities in Community SGC4
(e)

Biggest sub-community (SGSC1) in Community SGC4
(f)

Figure 4.2: ED Communities & Sub-communities on Twitter Using Louvain Algorithm on Full Graph

scores for both of these algorithms indicate that the Louvain algorithm outperforms the method of GN (for Louvain, modularity score $Q=0.54860$, for GN, modularity score $Q=0.45090$). Whereas the Louvain algorithm was able to detect more communities within ED network with much more structure, the Girvan-Newman algorithm created one bigger community with majority of the nodes in it (for *FG*, n= 4545 and for *SG*, n=174). Even though the majority of the communities created by the Louvain algorithm only include 5 or less than 5 nodes as community members (around 65%), the rest of the 35% communities include decent amout of nodes ranging from 10-507 nodes. In Table 4.4 (Left section) listed the top 3 communities using both Louvain and Girvan-Newman algorithm with the highest number of nodes in it. While visualizing each of these communities through graph network, we observed existence of multiple distinct cluster of nodes forming sub-communities (Figure 4.2). To further explore the structure of the communities, we ran the community detection algorithms on each of these communities again and found the existence of sub-communities within them. For example, communities FGC11 and SGC4 (the biggest communities from *FG* and *SG*), respectively had 8 (Figure 4.2b, 4.2e) and 6 sub-communities based on Louvain algorithm. Similarly, communities FGC2 and SGC1 respectively had 5 and 2 sub-communities based on GN algorithm. The top 3 sub-communities and their node numbers are provided in Table 4.4 (right section).

Louvain Algorithm							
Community ID	Members, n	Community ID	Members, n	Sub-Community ID	Members, n	Sub-Community ID	Members, n
ID FGC2	450	ID SGC3	32	ID FGSC1	227	ID SGSC1	9
ID FGC7	507	ID SGC4	34	ID FGSC2	359	ID SGSC2	6
ID FGC11	725	ID SGC8	29	ID FGSC4	89	ID SGSC3	8
Girvan-Newman Algorithm							
ID FGC2	4545	ID SGC1	174	ID FGSC2	4519	ID SGSC1	169
ID FGC12	40	ID SGC2	1	ID FGSC12	19	ID SGSC2	5
ID FGC7	32	ID SGC3	1	ID FGSC7	7	-	

Table 4.4: Top 3 Communities and Sub-communities for Full & Sub Graph

As the community detection algorithms confirms the existence of defined communities and sub-communities within ED network, we wanted to identify the influential nodes within these smaller clusters. The analysis on the sub-communities of FG shows that for each of these communities, the central node is someone who has the highest scores in all of the centrality matrices and is consistent with the original central node list from Table 4.2.

As we also noticed major differences in the centrality scores between the central node and the following nodes, it can be assumed that in sub-communities, the majority of nodes are dependent on one specific node (the central node) for community connection and information flow through retweets. However, the analysis on the sub-graph's sub-communities provided different results.Unlike FG, the central nodes for each of these sub-communities were diverse, inconsistent, and often did not belong to the original top 10 lists. This indicates that for smaller and much more structured networks on Twitter, influence is not as static as the overall graph, but rather is dynamic and sparse within communities.

Validating Contents within ED Community Online

As we investigated the concept of influence within ED network through analysis of prominent nodes, we also explored what prominent contents, such as hashtags and media, were shared within the communities.

Assessment of Hashtags. While the inductive analysis provided us understanding on established ED hashtags that are prominent within this network, we could also identify the prevalence of nuanced and newly emerging hashtags with unique linguistic meanings. A total of 75,676 hashtags were attached to the 32,000+ posts in the dataset, of which 1,141 were unique. On average, there were 4 tags attached to each post (SD = 2.0; range 1-14). Apart from the three primary hashtags that we started working with, hashtags like #meanspo, #ed, #sweetspo, #bonespo, #anorexia, and #bulimia were some of the most used hashtags by the users in the ED network (Figure 4.3).

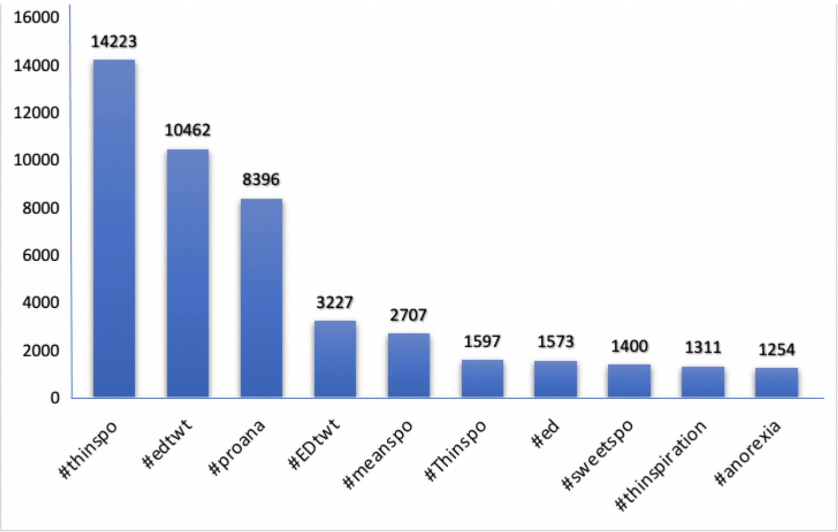


Figure 4.3: Top 10 hashtags Shared within Twitter ED Communities

Along with my research team, I created a small classification codebook for the hashtags; APPENDIX C1 highlights and defines the primary hashtag categories based on the dataset. While the majority of these categories have been consistently perceived through previous literature, we did observe new emerging categories of hashtags, such as meanspo and trends/viral platforms, that have not been properly introduced and discussed previously. Even though category Viral Platforms and Trends only encompasses 0.2% of the total hashtags observed within the dataset, it signifies emergence of new social media platforms within the Twitter ecosystem through hashtagging. Whereas some of these platforms are not new (e.g., Instagram, Tumblr), platforms like Tiktok, Douyin, and OnlyFans are comparatively new, have been trending/viral within younger generations, and are making an impact within ED network as well.

A New Component of Harassment: #Meanspo. Of the total hashtags within the dataset, 4.54% were related to the emerging pro-ED trend of Meanspo, including 2837 instances of the specific hashtag #meanspo. Short for “mean inspiration”, meanspo consists of overly critical and insulting statements hurled at those who are “not thin enough,” (either oneself or others) intended to inspire them to stop eating, purge, and lose weight. Even though previous literature has discussed positive and negative thinspirational posts in pro-ED online communities [478], specific focus on the meanspo hashtag has never been explored. This paper categorizes the negative inspirations through #meanspo to create better insights not only on the negative support/inspiration shared in ED Twitter, but also on the toxic environment that creeps behind general/trivial terms like negative inspiration. Of note, although other tweets may have included content that was mean or harsh in nature, we only categorized tweets where users directly tagged the post with some form of "meanspo."

Meanspo presented in a variety of ways in the dataset. Similar to other negative support previously documented [478], one class of meanspo focused on support through *disapproval or negative contexts* where a user tries to "motivate" oneself or others through disapproving of their eating habits or ED lifestyle. These posts were all connected through the hashtag "meanspo," often with additional ED-specific hashtags as well. Examples of this type of post include:

- Restrict..or you are going to regret it
- If you really wanted to be skinni would you eat that?
- Just bcz they don't call you fat on ur face mean you are skinny..try harder

Another form of meanspo tagged tweets were more *antagonistic or aggressive* in nature. These included extreme bullying and harassing tweets and were often expressed by fat shaming and name calling of oneself and others. Examples of this language include:

- I'm a worthless fat pig and nothing can stop me until I die
- Stop lying to yourself whore! You fucking loser, you're never going to lose weight!

- You think you can eat that and loose weight you disgusting fucking fat piece of shit?

Finally, there were people directly *soliciting meanspo* to be directed at them or joining a group that would support this type of negative pro-ED support. Users would actively seek to join/create/add groups or group chats that were specifically focused on sharing/providing harsh meanspo. Often times, users are specifically seeking an ED "coach" or "buddy" who uses meanspo to motivate. Examples include:

- Anyone interested in a meanspo gc? Looking to send/receive with like minded people
- where are the proannna coaches or meanspo lovers? looking for a new texting buddy?
- I desperately need a meanspo gc where we can talk shit abt each other
- I am in need of a meanspo bae

These categorizations of meanspo tag highlight the use of negative reinforcement as a driving force for people to comply with the difficulties of their ED journey. While the analysis of hashtags suggests new emerging activities through introducing new tags within ED community, exploration of such tags more deeply opens up discussions on bullying or self-harassment that are integrated within the ED network as part of motivation/inspiration.

Media Analysis. We also looked at different media attached to the posts within ED network. The analysis of the media posted on these social platforms identified certain ED-related archetypes. For this study purpose, out of around 8,000 media, we randomly selected 710 (around 9%) and manually coded them to categorize media archetypes. We separated the media links into posts that included text in addition to the media link (n=510) and posts with no additional text other than hashtags (n=200). The initial analysis showed that, within the first category, around 47.6% of the posts were

Media Type	General Posts (n=510)	Posts with No Text (n=200)
Photo	47.6 %	46.7%
Video	20.2%	17.4%
Gifs	1.0%	0.0%
Unavailable/Suspended	31.2%	35.9%

Table 4.5: Details on Media Type

photos, 20.2% were videos, 1% were gifs, and the rest of the media were either suspended, unavailable, or access limited (Table 4.5). We observed similar presentation of media within the second category as well. The media archetypes include, but are not limited to, Thinspiration, Celebrity Idealization, Trends and Viral Platforms, Updates on ED Journey, ED-Related Memes, Resource and Information Sharing, and Unrelated Images. While all media did not fall into one of these foci, these are representative of a majority of posts within the dataset. Below we discuss few of them.

General Thinspiration: Media in this category offer inspiration to both themselves (individual) as well as others within the network. Thinspiration or "thinspo" are media that encourage individuals to be as thin as possible, such as images of severely skinny body parts that are intended to encourage others to strive for the "ideal" body type. Figure 4.4 is an example of the type of thinspiration posted by users to promote thin body image Twitter. This category also includes "bonespiration" or "bonespo," characterized by the ability to see as many of your bones through your skin as possible. Some of the media shared within this category also include goth- or grunge-inspired ED contents, where the focus is on different body parts with dark or black clothing, aesthetic, or dominant appearance of the image.

Celebrity Idealization: Media under this category includes photos and videos of celebrity individuals whose bodies and thinness are idealized. Celebrities like Kendall Jenner, Ariana Grande, and various K-pop stars, such as Itzy Lia, fall under this category (Figure 4.4). Media related to these celebrities are used as pro-ana and ED lifestyle motivation and are often worshipped for

Figure 4.4: Thinspo & Celebrity Idealization

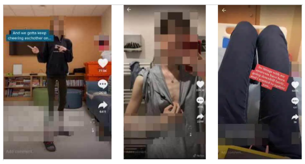


Figure 4.5: TikTok Videos on ED Lifestyle

having perfect figure and bone structure.

Connections to Other Social Platforms: Media under this category promote similar types of thinspiration by users, with the additional criteria that they were initially posted on other viral platforms such as Tiktok and Douyin (Figure 4.5). TikTok and Douyin are popular social media platforms (Tiktok is the international version of the Chinese app Douyin) upon which millions of users make a variety of short-form videos. Posts within this category were initially created for Tiktok/Douyin users and then later shared in Twitter. Many of these media include individuals (not necessarily the user herself) posing in front of camera, dancing or modeling, while showing off their perfectly trimmed and skinny body. Figure 4.5 demonstrates some of the snapshots of the videos shared as part of the Tiktok/Douyin trend/thinspiration.

Updates on the ED Journey: Media in this category focus on the journey and updates associated with weight loss. Figure 4.6 provide example of these type of images, including current personal before-and-after shots. Some users highlighted this journey through screenshots from different mobile apps that store information on calorie intake, water intake, amount of weight loss, exercise timeline, and more.

Figure 4.6: ED Journey Updates

Figure 4.7: Resource & Information Sharing on ED lifestyle

Resource/Information Sharing: This category includes media sharing resources and information related to the ED lifestyle, like pictures of foods suggested and/or consumed by users (often with calorie counts) as part of diet regime, type of exercises for losing weight (again, sometimes with calorie counts), and information on TV shows, movies, or books related to ED (Figure 4.7).

Validation by Central Nodes within ED Network. I wanted to validate this analysis of contents through the sharing pattern of the prominent nodes within the ED network through the assessment of hashtags used and media analysis.

Central Node	**Prominent Use of Hashtags (%)**	**Prevalent Type of Content Shared**
TikTokDiets	#Thinspo/#thinspiration (100%)	**Unavailable: Could not check**
Bonespo4eva	#thinspo (80%), #edtwt (80%), #meanspo (58%), #edmeme (10%)	ED memes, thinspo, Tiktok, resources
thin_hunnie	#thinspo (73%), #proana (50%), #meanspo (58%)	**Unavailable: Could not check**
thynspoo_k	#thinspo (100%), #skinny (90%)	thinspo, update, Tiktok
famishedbarbie	#edtwt (58%), #thinspo (40%), #proana (35%), #anorexia (32%), #meanspo (6)	**Unavailable: Could not check**
Nahglossy	#thinspo (100%), #meanspo (18%)	**Unavailable: Could not check**
Thinspo02468	#thinspo (76%), #ana (41%), #meanspo (14%)	thinpo, Tiktok
restricted_vegiie	#thinspo (80%), #bodygoal (24%), #meanspo (7%)	ED memes, thinspo
hungri_q	#thinspo (57%), #proana (34), #meanspo (10%)	thinspo, grunge, not me
anamia_teeeennn	#thinspo (59%), #edtwt (68%), #proana (34%)	thinspo, resources, food, ED meme, Tiktok
EDliife01	#thinspo (43%), #proana (29%), #meanspo (14%)	Thinspo, Tiktok, Resource
Skinnidaily	#edtwt (66%), #bslyw (39%), #thinspo (32%)	thinspo
bitch_n_bingee	#edtwt (74%), #thinspo (42%), #proana (42%))	thinspo, resources
skanksubweight	#meanspo (50%), #thinspo (21%), #edtwt (14%)	thinspo, resources

Table 4.6: Content Shared by Central Nodes: Hashtags (%) & Content Archetype

First, my team and I compared the total number of individual hashtags with the total hashtags shared by these nodes (see Table 4.6). While the frequency of hashtags related to #thinspiration, #edtwitter, and #ana/#proana was very high within these nodes (as expected, as they were our base hashtags), we also observed additional prominent hashtags, such as #edmeme, #bodygoal, #skinny, #meanspo. We also noticed that there is a consistency between major nodes and their media sharing pattern in the ED network (see Table 4.6). Similar to the overall finding, the majority of their shared media were based on Thinspiration, Resource Sharing, Tiktok and Douyin Thinspiration, ED-Related Memes, and so on. These results reconfirm the inductive analysis of the contents shared within the ED network and provide evidences that there can be a possible influence of the central nodes on deciding what contents get mostly shared and become popular.

Identifying Emerging ED-Related Linguistic Indicators

Along with content analysis, we also analyzed prominent topics discussed within the ED network. After data pre-processing, we obtained 32,530 tweets to feed into the topic modeling analysis where we used both LDA and NMF algorithms. These tweets contained 228,357 tokens with a vocabulary size of 9,316. The mean length of the tweets was 5.5 and the max length was 18.

Analysis of Topics. When specifying a topic model, several parameters, such as the number of topics, K, must be defined. To determine an adequate number of topics, we ran several candidate models with varying numbers of topics and for k=10 topics, we received highest coherence and perplexity scores for both LDA (CS=0.34876, $perplexity$= -5.843) and NMF (CS=0.38826) models.

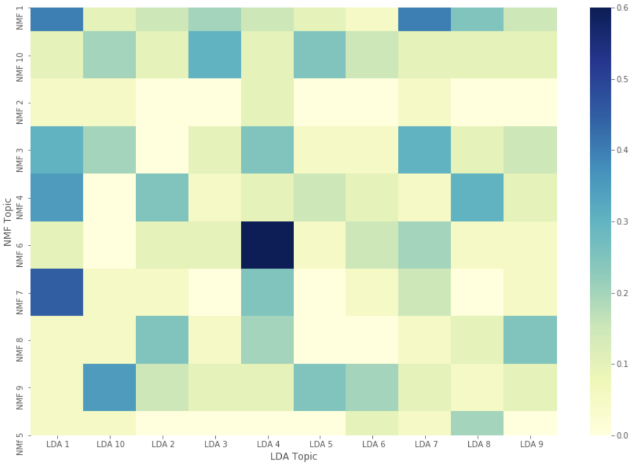


Figure 4.8: Topic Reliability between LDA & NMF

As the models created top keywords and most relevant tweets under each topic, we manually analyzed them and came up with 10 primary themes from each topic, both for LDA and NMF. Additionally, for each of these primary themes, we also identified multiple secondary themes that further explains the primary themes with more detail. I have added the primary and secondary themes for both models in APPENDIX C2 and C3. To measure the reliability of the models, we implemented an approach following the intuition of comparing two models for their similarities in resulting keywords under each topic. The results of the comparison is given in Figure 4.8, where the column numbers represent LDA topics and the row numbers represent NMF topics. The rate of convergences between different topics for both models range between 0-60%.

Topic Categories	LDA Topics	NMF Topics
ED inspiration and motivation (2)	-Specific ED Inspiration -Thought processes during active ED -General presentation of ED	-Support/Motivation during active ED -ED focused aspirations
Weight/Fitness	-Weight loss setting/status -Fitness/diet	-Weight loss
Community Building and Maintence	-Community building/Maintenance	-Community building -Community-based characteristics and curating -Popularity of major community member
Engaging the Community	-Engagement with sub-communities -Best Practices and plans -ED experiences and values	-Disorder-specific engagement -Targeted engagements and presentations of ED journey
Reflections and desires	-Personal reflection on body image	-Desired ED lifestyle -ED-specific reflection

Table 4.7: Topic Categories Created from LDA & NMF

Qualitative Assessment of Topics. The topic categories resulting from the qualitative analysis of the LDA and NMF topic models highlight standard content within these communities (Table 4.7). The topics with similar themes were grouped into 5 categories: ED Inspiration and Motivation, Weight/Fitness, Community Building and Maintenance, Engaging the Community, and Reflections and Desires. Below we unpack several of these topics. ED Inspiration and Motivation: This topic resulted the traditional forms of inspiration and motivation both in positive and negative tone. However, the aforementioned "meanspo" goes beyond the typical negative toned support. The idea of using negative reinforcement as a form of support in pro-ED behaviors is not novel, yet the emergence of communities forming around a particularly direct, antagonistic, and sometimes severe harassment as a form of support online is an aspect that has not been published on at the time of this writing. Within this category, we also saw posters connect traditional subcommunities (#proana, #thinspo, #edtwt) with both gender (#malespo) and ethnicity (#pocthinspo). Within the media content of these posts, users shared traditional hallmarks of ED media (focusing on specific body parts, sharing diets, the curation of idealized celebrities), yet additionally made them gender- or ethnicity-specific.

Community Building and Maintenance: Topics within this category centered around how members actively or passively carried out these activities. A prominent aspect of this data is the amount of moderation. We also saw examples of gatekeeping within the community by members that were actively opposed to integration of the TikTok/Douyin community within the ED Twitter space. This theme also included examples of community members actively seeking others to build specific group chats or find support for a variety of things including meanspo, accountability in diet/exercise, and sharing of best practices.

Reflections and Desires: This category includes themes related to explicit desire associated with various aspects of an ED (e.g., ideal body, ability to restrict, the way others perceive them) as well as emotions associated with specific aspects, reflections on where they are in their ED journey, and the challenges/rewards of the ED journey. These tweets reflected a full spectrum of emotional and mental states of users and ranged from more negative (sadness, frustration, defeat, and self-hate) to more positive (pride, happiness, and optimism). However, in general, this was more skewed to the negative, especially posts where users indicated their desperation/longing (want, wish, kill) for certain ED lifestyle and body traits (skinny, thigh gap).

Discussion

Influential Users and Exposure to Unhealthy Lifestyle

Interactivity among online communities can impact people's attitude and intentions towards how their perception on health related behaviors get influenced [324]. This study highlights two important implications within ED network: first, majority nodes in FG only retweet the central nodes in ED network and don't interact with each other that much (thus, have less number of degrees) and second, the central nodes from the FG are the main content creators of the ED network. We explain these implications in details below.

Homophily and Social Influence on Risky Health Behaviors. As this study aims to identify influential individuals who promote risky health behavior and lifestyle in online ED network, we observe certain disparities between the ranks of popular nodes (from overall and sub-graph) created due to the diverse retweeting behaviors within users. According to the social network structure theory, the degree of connectivity of a node in a Twitter network can be a measure of a user's popularity and, as a result, social influence [383, 194]. While certain nodes had a higher degree of connections within the ED network for being frequently retweeted by others, the sub-graph created from this network had much more inter-group interaction where the central nodes not only got retweeted, but also retweeted other stronger nodes (with higher degree of connections) in the network. These pattern of communication is not uncommon within structured online health communities where ties between nodes are stronger, as opposed to unstructured network [494]. This type of network structure is supported by the idea of homophily, which asserts that users in a social system are more likely to bond with those who are "similar" to them than with those who are "dissimilar" [292, 178]. While we observe homogeneous ties within the ED network where people retweet nodes with similar interest, it was more evident and frequent within the sub-graph network. This principle or inclination to connect with similar people limits how they interact with each other socially and with whom they interact within online communities.

While mutual friendships between nodes are typically analyzed to examine connections within homogenous networks, it may also be one-directional, with general nodes within a network seeking guidance or information from specific notable nodes in the network [521]. Communication structure (who communicates with whom) is key for the study of peer influence on health behaviors [486, 426]. Twitter network of diabetes and diets [213] highlights how certain users behave as diabetes advocates, spreading information and serving as opinion leaders, affecting others' attitudes and behavior in the network [636, 494]. Individuals in the network may not actively participate by providing their own content, but still are able to perceive the value and potentially shape ideas and norms by being influenced through these central nodes [284]. As the ED network on Twitter includes multiple communities and sub-communities, such social influence can be perceived through community-level interaction between central nodes and general nodes where often central nodes are in control of those sub-communities. While influence within sub-communities led by multiple nodes are hard to control, being able to identify these prominent nodes from overall graph can help us to implement some level of regulation against sharing risky ED contents.

Exposure and Unhealthy Adoption of ED Lifestyle. Findings on influential nodes within the ED network support the findings from the content analysis that show popular contents within the ED network are also shared by the important users in the network. Whereas previous literature explored popular contents within ED networks [478, 145], this study connects those contents with node-level participation. As a majority of the interactions within the network are happening through retweeting central nodes, this higher exposure influences higher adoption of unhealthy behaviors within users through the forms of inspiration and motivations.

Previous research suggests that homophilous relationships within a community can enhance the dissemination of behavior amongst individuals [178, 141], and being a prominent figure in such a social network adds a lot of value to information dissemination among other users [486]. For example, influential nodes within the network, such as celebrities, dietitians, advocates of special diets and weight reduction programs, frequently promote popular social media material on food, nutrition, and diet [510, 383]. Similarly, individuals who work as bridges between multiple nodes and groups, such as the prominent nodes with higher betweeness centrality, also help this diffusion of information within networks, thus enabling unhealthy behaviors within users. This increased exposure to negative social influence and harmful information from important nodes raises the likelihood of greater levels of unhealthy adoption, particularly among general users with health concerns, who are more likely to adopt health-related behaviors from their social network. Research demonstrates that being exposed to information that promotes the thin ideal encourages self-objectification in individuals [252, 347], which can lead to an unhealthy lifestyle and serious eating disorders.

Antagonistic Motivation for ED Success

The data shows users within the ED network adopt unhealthy eating behavior through communications, which includes antagonistic motivation. Many of the tweets shared within this community go beyond the colloquial meaning of negative motivation [478] and include extremely aggressive or harsh comments, such as meanspo (inward/outward) or abusive insults.

Act of Harassment As Group Norm and Motivation While such antagonistic communications are masked as motivation/inspiration to support the ED community, often they blur the fine line between motivation and harassment. Online harassment is an issue of public concern and discussion, particularly for vulnerable populations, in the context of persistent problems like cyberbullying [449, 446, 61, 171], hate speech [195], and the idolisation of self-harm [145, 479].While harassment is frequently defined as an exterior act directed at another person [634, 637], it may also be internalized, with a person harassing themselves through self-injurious behaviors [254, 479], which reflected online is known as digital self-harm or self-harassment/cyberbullying

[479, 470].

According to Pater and Mynatt, harassment within ED networks can include online speech and conduct that leads to, supports, or reinforces non-suicidal, yet purposeful, injury or damage of an individual's physical well-being [474]. As observed within the study, a large number of tweets contained extremely negative contents influencing others or oneself towards intentional harm on their physical well being (e.g., "you eat that and you will never loose weight you disgusting fucking fat piece of shit"). Even though these tweets are often masked as support/feedback, they are extremely aggressive in nature and can cause serious mental and physical health consequences. Prior work has indicated that social media sites such as Reddit, Twitter, and others can provide users a false sense of anonymity, lowering social inhibition and encouraging them to be more aggressive in this sort of communication [518]. As a result, some people may perceive their online conduct as harmless or as a right to free speech or concerned engagement, but might be misinterpreted as online harassment. Such conduct is referred by some studies as cyber-disinhibition or the toxic online disinhibition effect [654], which embodies displays of impolite or vulgar language, harsh remarks, "hate speech," and even threats that would be highly unusual in a face-to-face context (e.g. [619]).

Often such toxic online behaviors by prominent nodes become group norms. As the Twitter ED network has strong evidence of communities and sub-communities that exacerbate harmful ED lifestyle behaviors within users through antagonistic motivations, it is possible for the members of those communities to take on group identity and follow the group norms that are set up by the community leaders. Such conformity can work as an uncontrollable external condition that may both directly and indirectly affect user decisions of seeking/providing extremely antagonistic tweets as motivations, and may socialize them into a normalized culture of antagonistic behavior or harassment.

Meanspo - Pushing the Boundaries of Negative Feedback. A unique phenomenon that we witnessed in the dataset was the target of meanspo specifically requesting this form of harassment and the community discussion of creating these groups to "support" each other and others across the community. Based on the definition provided by Pater and Mynatt, this form of digital self-harm [474] goes beyond the canonical descriptions of self-harm related to self-cyberbullying [470] which are not as aggressive or antagonistic as the examples of meanspo within the dataset. Previous HCI research has documented the use of negative, pro-disease content to support community members [478, 624, 227, 144]. Pater et al. highlighted examples of negative reinforcement like "You don't deserve to eat. You really don't. Look at you. You're fat. You're [sic] bones are being crushed under all of this fat" [478]. However, meanpso goes beyond this level of negative reinforcement, integrating more caustic, cruel, and antagonistic characteristics. The use of personal insults that border on emotional abuse are likely to have an impact on the clinical manifestations of eating disorders, as negative eating expectancies have been implicated in the development of bulimic behaviors [537]. This finding is consistent with previous research indicating that interest in negative feedback contributed to increased body dissatisfaction [132, 181], as well as findings suggesting that maladaptive Facebook usage (i.e., the tendency to seek out negative feedback and/or engage in social comparisons) may predict greater eating pathology [308].

This psychological phenomenon share similarities with the colloquial concept of "negging," which is a form of emotional manipulation where negative feedback or reverse psychology is employed to undermine a person's confidence and thus, increase the need of the manipulator's approval [437]. The unsolicited engagement with meanspo content could potentially be an extension of negging within this community. Future work exploring the dependence of community members on meanspo as a critical feature of the pro-disease support could provide meaningful insights into how this form of insult you under the guise of "constructive criticism" [491] functionally and psychologically connects with the concept of meanspo.

Censorship within ED Communities

This study found that 32.5% of the dataset that was randomly selected for qualitative coding had been censored by either the platform or the individual. Censorship within ED networks is a phenomenon that has garnered interest in the HCI community [144, 145, 142, 624, 479]. Self-expression of eating disordered behaviors and activities are ripe for censorship because they are viewed as a form of self-harassment within many online platforms [479]. The guiding policies of social engagement (e.g., Terms of Service, Community Standards) slightly differ across platforms with regards to how eating disorders are characterized: harassment, harm, self-harm, self-injury, abuse, and even explicitly calling out eating disorders. Like the characterization of the activity, the type of censorship also varies from restricting accounts to removing content to working with law enforcement and other third parties.

Online characterizations of pro-ED communities online have documented the internal community norms and values [270, 114, 117, 479, 478], many of which run afowl of overarching platform community norms [479] or smaller sub-communities [226]. In-community gatekeeping to maintain the pro-ED community norms was present in the dataset. The cross-posting of content from one platform to another is common practice in the ED community [227, 478]. However, one particular platform - TikTok - was not appreciated by all community members in this dataset. Posts explicitly dissuaded users from reposting TikTok videos *and* sharing the types of content that are frequently shared on TikTok. This points to a set of social norms that would be difficult to perceive for those on the periphery, but ingrained for those at the core of the community [364].

Censorship also had impacts on the research process. As noted in the results, the censorship of the content significantly limited the qualitative assessment. For posts that contained no text other than the hashtags, the ability to access the post to assess the media is critical. For the subset of this type of post, approximately 36% of the posts were no longer published for a variety of reasons: suspended accounts, deleted accounts, and content that was taken down by the platform or the individual. Past research has shown the importance of assessing the media of ED content, as it can often paint a more nuanced or different story than the text itself [478]. There are examples of censorship where content is preserved and the reasons for censoring are made public as a way teaching the community what is acceptable and what is not [483].

For vulnerable populations building community online, group support/ intercommunication is critical [446, 79]. The sharing of activities and behaviors associated with disease or your health status online can be considered beneficial [244, 647]. More research is needed to understand the impact of censoring online activity of an individual's current mental health state.

Translating Findings into Clinical Practice

Within the social computing, much of work in online health spaces focuses on identification, characterization and brief proof-of-concept lab or in-the-wild studies. Translating findings into clinical practice is far less common. The findings from this research could have critical importance into the healthcare practice. Providers have said that they believe social networks have a negative impact on patients and that engaging patients on their social media activity in the clinical setting should be explored [475]. Creating feedback loops for providers to translate the research findings into a package, tool, or information that is usable for providers would be a positive next step in the meaningful integration into clinical workflows and practice. For example, patterns of influence (content or individuals) could help providers target therapeutic approaches, understand triggers and responses, and keep them abreast of the technical affordances/trends that could have implicit or explicit impacts on their patients. Connecting the technical with the clinical will take more than just surface-level integration, but true embedded partnerships that will allow for a more meaningful and deeper engagement that will facilitate the translation across domains.

Limitations and Future Work

There were several limitations to this study. First, the authors are not a part of the ED community on Twitter. As outsiders, it is possible to miss latent signals or misinterpreted aspects of the activities that are qualitatively coded by the authors. To ensure that this study addressed this limitation, I consulted with the clinical partners at Parkview Health whenever we had questions about the ED activities being coded. Second, I used the NMF and LDA algorithms for the analysis which are unstructured. I could have looked at this through the lens of structured algorithm. A point of future work could be to analyze such a dataset with a structured and unstructured algorithm and explore the clinically-relevant differences between the two approaches. Third, the terms we used were general in nature. Additionally, as I did see traces of gender and ethnic diversity in the dataset through posts using #menwithED and #POCthinspo, exploring the differences in the presentation of ED online related to gender and ethnicity is another area of research for futher exploration. Finally, this analysis only took place with Twitter data that was collected over a 30 day period. Looking at data over a longer duration of time could highlight insights that might be seasonal or not constrained to a 30 day time period. Extending the contributions this study makes, future work is needed to understand the interplay of node-level activities *across* platforms, such as Twitter, TikTok, Instagra, Douyin, and YouTube, as observed within the data.

Conclusion

This study provides details on the current ED network on Twitter based on dataset collected from a specific timeline using both qualitative and quantitative measures. As impacts of social media can be dangerous and harmful for ED patients, this study tries to understand how ED influences are shaped on Twitter from network structure as well as from content adoption. Details from this study will not only help researchers and clinicians to identify possible sources of influences for ED patients through social media participation, but also will help policy makers to structure preventive and appropriate methods to limit promotion of such unhealthy lifestyle online. Insights from the analysis on node-level influence identify the importance of understanding the nuanced community structure within online ED networks, as the roles of the central nodes and their influence over other nodes vary depending on how these smaller communities and sub-communities are formed. Additionally, insights from the content analysis can help researchers and clinicians to identify particular online channels and technological affordances that foster adverse effects on their patients, as well as discover what common and emerging behaviors and environmental factors are contained within these platforms in relation to eating. The contributions of this study also illustrate the importance of additional studies in the social computing area that not only investigates the effects of social media on population-level ED patients, but also speculates on them at the person level. Studying these impacts is a crucial component in linking HCI research to clinical practice in this area, and eventually learning how to clinically treat digital self-harm in the future.

CHAPTER 5: USING CYBERBULLY SCREENING AND CLINICAL NARRATIVES TO UNCOVER ADVERSE CHILDHOOD EXPERIENCES (ACES) WITHIN ADOLESCENTS

Introduction

Adverse childhood events (ACEs) are potentially traumatic experiences that have serious implications on the victims [276]. The concept of ACEs is comprised of several components of childhood maltreatment that includes different forms of abuse, violence, neglect, and incarceration within family to name a few [140]. In the United States (US), approximately 50% of children under 18 years of age have been exposed to at least one ACE event/experience, and approximately 33% have been exposed to multiple ACEs [525]. Given their widespread prevalence and impact, ACEs have major public health implications [47] with increased risk of cognitive, social, and emotional impairments in children [307].

There is a growing academic and public interest in understanding ACEs. While the SIGCHI community has not engaged with the concept of ACEs as a whole, it has researched components like sexual harassment/abuse [48, 449], mental health concerns [466], and drug dependence [275, 306]. Yet, there is still a gap in knowledge on how other external implicit or explicit risk factors interact with ACEs and contribute to victims' outcomes [409]. Additionally, there has been surprisingly limited clinical research on how experiences of traditional bullying and/or cyberbullying may be linked with these prevalent events and the additional consequences that are generated from this connection. Cyber/bullying is a serious and complex issue that also has been identified as a growing public health concern due to its severe negative effects (e.g., depression, anxiety, suicidal ideation etc.) on children and adolescents (Centers for Disease Control and Prevention [CDC], 2019) [75, 224]. Previous research on adverse childhood experiences and cyber/bullying (as experts have began to question the futility of distinguishing between bullying and cyberbullying because of their high correlation with each other [353], we have referred traditional bullying and/or cyberbullying as cyber/bullying throughout rest of the paper) showed that experience of early ACEs and cyber/bullying can significantly impact children's mental growth and state [165]. Some experts have argued that cyber/bullying in itself constitutes an ACE, given its negative impact on children's mental and behavioral health [232, 75]. While cyber/bullying has been an extensive research domain in SIGCHI [562, 154], it has mostly been operationalized through surveys and public data analysis, with only a few studies applying direct clinical insights [186, 511].

Clinical insights built from individual patient data, such as electronic health records (EHRs), can provide researchers more in-depth knowledge on patients' with ACEs and cyber/bullying experiences because of interconnectedness of the detailed clinical notes, demographic information, or diagnoses included in the system [100]. While EHRs are primarily designed for improving healthcare efficiency from an operational standpoint, researchers have also found secondary use for these data in clinical informatics applications, such as prediction of certain health related activities [512], specific health conditions [341, 67], or clinical outcomes [265]. SIGCHI researchers have long been interested in the challenges that arise when managing patient-related information in highly collaborative hospital systems, such as the EHR [493]. While EHR aids health workers (e.g., medical specialists, therapists, nurses) in making collaborative decisions on patient's health, it may also inherit internal biases [615] in analyzing observational health data without careful consideration to their context- a theme often explored in SIGCHI [283, 285].

Therefore, the aim of the current study is to contribute to the scarce research examining the association and consequences of the experiences of ACEs within youth populations who have been cyber/bullied using their EHR data in clinical settings. I, with my research team, conducted a retrospective chart review on a total of 719 patient encounters from Parkview

Health's inpatient youth behavioral health hospital. In 2018, this unit updated their standard-of-care to include a cyber/bullying survey for all patients at intake and discharge. We collected their diagnoses, demographics, specific survey question results and the clinical narrative/notes from EHR for analysis. The data was collected on patients admitted between June 2018-January 2019. The specific findings are:

- Integration of structured and unstructured data in EHRs to assess impacts of ACEs without the use of a screener is challenging due to the lack of a properly established mechanism or method in place. Mismatch between survey inputs and EHR potentially complicate proper assessment of ACEs and create problems for clinical decision-making.
- Non-ACE indicators like encounters with the Department of Child Services (DCS) and adoption were frequently linked with other indicators of ACEs, such as drug abuse, emotional, physical and sexual abuse, neglect and incarceration. Prevalence of such non-ACE indicators suggest reevaluating the definition of ACEs for younger patients.
- The use of discrete variables, such as presence of cyber/bullying, gender, and clinical diagnoses, as lenses to analyze unstructured clinical notes reported considerably distinct results on the prevalence of ACEs within patients. Specially, the differences in gender assigned at birth on the rates of experiencing and reporting ACEs, particularly relating to sexual, physical abuse, and suicidal ideation/attempt, were prominent within the results.

This research makes three key contributions to the social computing and healthcare literature: 1) Using direct clinical insights from patients' EHRs, this study sheds light on the adverse impacts of ACEs, specifically within cyber/bullied patients, to build better knowledge and health implications that may go unnoticed otherwise, 2) This study provides qualitative evidence on discrete lenses (e.g., gender/clinical diagnosis) that may be used as a part of ACEs assessment for better collaborative decision making on patients' health, 3) In the absence of a formalized diagnostic process, this study emphasizes the importance of using clinical narratives as data source and provides clinical and computational guidelines as design considerations for better EHR data integration, analysis, and interpretation. This research has been published at CSCW conference in 2022 [447].

ACEs: Definition and Risk Factors

Adverse childhood experiences, or ACEs, are potentially traumatic events that occur in childhood (0-17 years) [24]. There are ten recognized ACEs indicators that fall into three categories – abuse, neglect, and household dysfunction [140]. Ten ACEs, as identified by the original CDC-Kaiser ACE study [3], include physical, sexual, and emotional abuse, physical and emotional neglect, and household dysfunction such as substance use problems, mental health problems, domestic violence, and instability due to separation/divorce and incarceration [140]. ACEs have been linked to chronic health issues in adulthood like depression [149], obesity [545], suicide [202], drug and

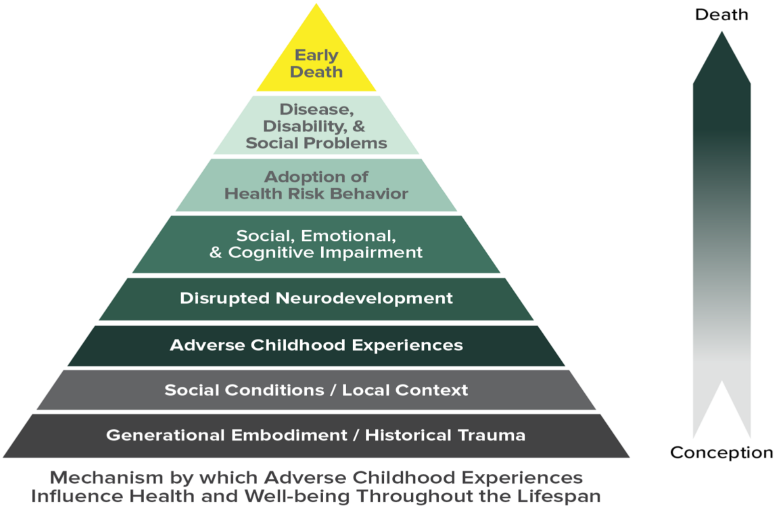


Figure 5.1: ACEs Conceptual Framework [Feliti]

alcohol abuse [403, 203] and other mental health disorders [608]. In their seminal study, Feliti et al., provided a conceptual framework, outlining the mechanism by which ACEs influence health and well-being throughout the entire lifespan (see Figure 5.1) [221].

While ACEs are traumatic incidents for all adolescents, some are at higher risk of being victims and suffering more severely than others [15]. For example, in an extended study on ACEs of the original CDC-Kaiser ACEs study, additional factors or community level stressors, such as cyber/bullying, adverse neighborhood experience, and living in foster care have shown high association with impacts of ACEs within individuals [15]. Researchers from SIGCHI have begun working with the Child Welfare System to investigate ways to improve the lives of children who have been separated from their families, including developing unbiased algorithm systems or frameworks [493, 536]. Previous studies showed, for factors like being in foster care and involvement with child protection or welfare involvement, children experience alarming number of ACEs as compared to their peers who did not face such life events [77, 127, 54]. Factors like race and ethnicity can also impact the severity of such events on youths [197]. For example, the consequences of ACEs may be more severe in Hispanic communities, as previous research found larger associations between ACEs and chronic disease among Hispanic relative to non-Hispanic adolescents [207]. Non-Hispanic black children and youth are also more likely than non-Hispanic white and Hispanic peers to have had three or more negative experiences (17 percent, compared to 10 and 11 percent, respectively, in 2016) [2].

Socio-economical status, and educational background also seem to impact ACEs within individuals, as children in poverty and children near-poverty are more than twice as likely than their more affluent peers to have had three or more other adverse experiences [2]. Some studies identified the gender differences in exposure to different types of ACEs, particularly sexual abuse, as females were substantially more likely than males to report this event [139, 394, 276]. The majority of these studies, however, relied on publicly available or community-based data rather than actual medical records. The integration of behavioral health interventions into pediatric and adult medical practices can have beneficial health effects, potentially mediating the impacts of the ACEs on future health outcomes [58].

Association Between ACEs and Cyber/bullying

There exists a positive relationship between childhood maltreatment and increased cyber/bullying [210] - both with the intended targets and the bullies themselves [33]. While not an explicit adverse childhood event, cyber/bullying is a form of emotional abuse or trauma [210]. Like victims of ACEs, youths with cyber/bullying experiences report higher levels of depression and anxiety, emotional distress, suicidal ideation and attempts, somatic complaints, poorer physical health, and externalising problems such as increased delinquency and substance abuse than their non-bullied peers [360, 609, 439]. Previous research on ACEs and cyber/bullying has shown that early ACEs, whether mild or substantial, as well as cyber/bullying, can have a significant impact on children's mental development and state [201, 165]. It is also well documented that exposure to ACEs increases the risk for cyber/bullying victimization at school [517, 158].

While children who are exposed to ACEs and cyber/bullying may develop internalizing (anxiety and depression) and externalizing (delinquency and peer aggression) symptoms, not all children develop these symptoms similarly [237, 638]. In a recent study, Folayan et al., investigated the correlation of ACEs, cyber/bullying victimization and resilience in Nigerian children. They found significant correlations ($p<0.001$) between ACEs and cyber/bullying victimization and self-esteem issues [238]. Another study has examined cyber/bullying involvement and ACEs as factors associated with school disengagement based on a dataset from 2016–2017 National Survey of

Children's Health where they showed cyber/bullying and experiencing adverse events increase school disengagement within adolescents [75]. Others have found that individuals with multiple ACEs are more likely to engage in or become victims of violence, including fighting, cyber/bullying, and other forms of self-harm [631]. While convergence of ACEs with concerns like cyber/bullying exists, assessment of the experiences of ACEs victims, who are also cyber/bullied, is extremely limited, both in socio-technical and clinical contexts.

Assessment of ACEs & Data Complexity

While there is a significant connection between ACEs and cyber/bullying incidents, very little attention is paid to the explorations of combined effects of these events on youths. While CSCW community has not engaged with the concept of ACEs as a whole, it has addressed fragments or specific aspects of ACEs like sexual abuse/harassment [466], parent separation [337], drug dependence [306, 275], along with cyber/bullying related concerns within youths [562]. These CSCW research on socio-technical challenges aligned with healthcare and computational domains have provided substantial information on individual needs (i.e. patients) and have significant impacts in health informatics through system design implications and guidelines [136, 392, 318, 492].

There are several tools that assess ACEs- all focused on the same core tenants. Some tools are more clinically focused while others are used by public health or research [95]. These tools all use a similar approach to identifying aspects of childhood maltreatment, differ in who takes the survey (e.g., child report [221], parents and/or child [128], even teachers [111], healthcare providers [293]). For example, the Center for Youth Wellness and Benioff Children's Hospital Oakland (BCHO) developed a final Pediatric ACE and other Determinants of Health Questionnaire [350]. OCHIN (a nonprofit health care innovation center) has integrated a new suite of tools that allow providers to screen patients for ACEs and toxic stress directly from their EHR platform, helping them to better serve their patients [389]. The researchers have also put efforts to create effective predictive and detection models of cyber/bullying experiences within individuals that have considerable scientific merit [314, 622]. The community has explored aspects like detection [429, 351, 155], characterization [571], aspects of cyber/bullying disclosure [60], even the review of legal aspects [574]. Al et al. [43] and Nandhini et al. [430] have separately developed SVM and Naïve Bayes approaches for detecting cyber/bullying on respectively Twitter-based networks using a set of specific Twitter-derived characteristics and MySpace network using their dataset. Similarly, Isa et al. [313, 282] proposed using SVM and Naïve Bayes for cyber/bullying detections using data from kaggle. Cyber/bullying, while not the focal point of the research, has also been observed and evaluated with respect to general technology use of youth and the potential negative issues/dangers related to technology use [481]. All of these studies used either survey data or publicly available data, limiting what can be inferred from a clinical perspective.

An EHR is a digital version of a patient's paper chart [11]. EHRs are patient-centered, real-time records that make information available to authorized users promptly and securely [218, 650]. While an EHR system often incorporates a patient's medical and treatment history, it is designed to go beyond traditional clinical data collected in a provider's office to give a more comprehensive perspective of a patient's care [424, 649]. It enables healthcare professionals to diagnose patients more accurately, lower medical errors, and deliver safer care [26]. Although EHR has made it simpler for physicians to manage patient records, allowing patients to access their own medical records through a patient portal (as an information technology platform) or mobile application has also increased the quality of their interaction with healthcare professionals [185, 388, 617, 62]. Patients can now interact with their healthcare providers, access their records, download information from them, share clinical data (such as lab results, clinical summaries, and medication lists), and explore educational resources [585, 585].

Yet, despite all that, studies have also identified many potential drawbacks to EHRs. Clinicians frequently express dissatisfaction with EHRs because they do not support their information and cognitive workflow needs [336]. EHR interface designs usually produce challenging user experiences because they are inefficient and confusing [646, 159]. Problematic EHR navigation, for instance, switching between interfaces, can have cognitive effects [522]. For example, a verity of patient information can be made available through the restricted lens provided by an EHR display, which can create a significant EHR usability bottleneck [549, 206]. In addition to physician dissatisfaction, concerns about ethical, security, and privacy management of data have also been expressed due to patients' access to their medical records [62]. Previous study showed, accessibility to EHR can make patients more anxious and stressed, as the contents of EHRs frequently includes alarming diagnostic possibilities, and sensitive information [587]. According to Wass et al. (2019) [626], some patients have difficulty understanding medical jargon and acronyms, while other studies have raised the concern of malpractice and legal risks in the event that data security is compromised [587, 62]. While improving the flow of information among patients and healthcare professionals would help in enhancing the quality of care and reducing errors, leveraging such information systems in the fast-paced and information-intensive environment of hospitals is difficult [424]. Researchers explain how EHR systems are overly structured and created with rigid rules that drive data uniformity (e.g., drop-down options, text entry constraints) that may lead to information problems caused by the design of the EHR [59].

EHRs play an important role in the ICD-10 coding process. ICD-10 (International Classification of Diseases, Tenth Revision) [454] are specific hospital codes for diagnoses and recording of cyber/bullying as well as abuse, neglect and other elements of ACEs [293] in patient EHR. EHRs also provide the ability to take survey/questionnaire responses to be scanned into the EHR as a media file or they can be put into a flowsheet, which allows for more streamlined secondary use for research purposes [629]. These data formats can be classified as structured (demographics, height, weight, laboratory tests, medications etc.) and unstructured (clinical notes, surgical records, discharge summaries, medical images etc.) [591]. Standard statistical or machine learning approaches may be used to analyze structured data types with little effort because the data already has a fixed structure [591]. The unstructured narratives and other non-discrete data fields are less explored, due to data being more unorganized and in raw format. Narrative analysis of clinical notes has been used to detect latent signals of many health issues from the EHR [635, 378, 642], even demographic data [220]. Yet, the ability to use such data for collaborative decision making in healthcare to deliver the best and most informed treatment to patients suffering from ACEs and cyber/bullying is currently restricted.

CSCW fosters the goal of exploring technical, social, material, and theoretical challenges that affect groups, organizations, communities, and networks [1]. SIGCHI community has long been interested in the challenges and complexities that arise when handling patient-related information in highly collaborative hospital teams and systems [493]. Due to the highly collaborative and distributed nature of hospital work [80], interdisciplinary patient-care team members rely on each other to deliver accurate and reliable information [424]. This collaboration can be multidisciplinary, in which case primary physicians, nurses, therapists, and specialists collaborate with each other while consulting patients from their own perspectives, or it can be interdisciplinary, in which case healthcare professionals collaborate while working in an interdisciplinary manner to build on each other's expertise and skills to achieve mutually defined goals [618]. EHR also gives patients and doctors a place to collaborate because it makes it easier for both stakeholders to access medical records, discuss about treatment options, and raise standards of care [610]. As a result, creating an integrated and better organized EHR for effectiveness and quality has recently received increased attention [303].

Formal clinical decision support systems have been considered as a promising way to provide medical practitioners with computational information about a patient's condition in order to aid them in making better decisions in various health domains [369] (e.g., cancer diagnosis [133], or diabetic retinopathy detection [85]).Previous research has highlighted the necessity of knowing clinician needs as well as a number of socio-environmental elements that aid in the deployment of effective collaborative decision support systems in clinical settings [369]. However, even if such systems have the potential to improve the quality and efficiency of health care [425], implementation in reality is difficult due to a lack of user-centered designs [76, 340] and a lack of clarity on how data should be fed and analyzed in the system [369].

Therefore, this study tries to address this gap in research and provides qualitative evidence on discrete lenses (e.g., gender/clinical diagnosis) that may be used as a part of ACEs assessment for better collaborative decision making on patients' health in the absence of a formalized diagnostic process in acute clinical settings. We specifically ask the following questions:

- **RQ1:** *What are the most prevalent latent ACEs within patients' electronic health records, particularly those who have been cyber/bullied?*
- **RQ2:** *How does social aspect like gender or clinical constructs like diagnosis, influence the presentation of ACEs within the electronic health records of cyber/bullied patients?*
- **RQ3:** *What clinical and computational design guidelines can make assessing ACEs and other adverse experiences actionable within the clinical settings?*

Methods

This research is part of a larger study focused on understanding the impacts of cyber/bully within the Parkview Behavioral Health's in-patient youth behavioral health hospital population. The clinical team (several of which are authors) implemented a change to their standard of care during the in-processing of new patients on the unit, screening their experiences with cyber/bullying with an in-patient patient survey (APPENDIX D1). Information collected through this survey is used in a variety of ways including guiding collaborative decision making regarding treatment and post-discharge care at Parkview. The research team is embedded in the healthcare system, but is its own autonomous unit. For the purposes of this research, the only questions used from this in-patient survey instrument are those that indicate if the patient had been previously cyber/bullied and if cyber/bullying was a contributing factor to the patient's current admission (Yes/No questions).

In order to understand how adverse childhood events are connected with patients who are bullied or cyberbullied, we conducted a retrospective chart review on the youth patient panel at Parkview's behavioral health hospital. In addition to the survey questions mentioned above, we also collected EHR data related to patient's diagnoses, demographics, and their encounter narrative notes for analysis. The Parkview Institute Review Board reviewed the retrospective chart review protocol and found it to be exempt from human subjects review.

Data was collected on a total of 719 patients who were admitted between June 2018 and January 2019. The average age of patients was 14.2 (SD=7.4) years with the youngest being 5 years and the oldest 18 years old. The average duration of stay in the inpatient facility was 4.9 days (see Table 5.1). The average number of clinical diagnoses for per patient was 3.36 (SD=1.6, range 1-11).

Gender	
Female	61.9%
Male	38.1%
Age	
5-9	8.1%
10-14	36.7%
15-18	55.2%
Avg.	14.2
Length of Stay	
Range	0.5 - 23 days
Avg.	4.9 days

Race	
White/Caucasian	72.2%
Black/African American	12.0%
Hispanic/Latino	3.8%
Other	0.8%
Unknown	6.2%
Declined	5.0%

Table 5.1: Patient Demographics Derived from EHR

Qualitative Assessment of Clinical Notes

The clinical notes collected for admission and discharge are stored as unstructured data in free text forms within the central database and were collected as part of the chart review. A deductive thematic analysis was conducted by two of the authors using the ACEs screener tool [140] for thematic categories. The elements of ACEs were derived from the notes and used as codes for this analysis. When a clinical note mentioned physical, emotional, domestic and/or sexual abuse perpetrated against a female care giver, this was coded as maternal violence. Additionally, physical and emotional neglect were collapsed into a singular "neglect" category. While divorce and engagement with a Department of Child Services or Child Protective Services (both coded as DCS) and adoption are not technically ACEs, the two clinical partners in this research (with over 56 years of experience combined) felt it was an important category to code based on their subject matter expertise and experience from working in this unit. We coded them as "informal" ACEs in this study. All chart notes presented in this paper are derivatives of the original, removing all identifying information and some contexts that could potentially lead to unmasking or identification of the patient.

Two of the authors met weekly to discuss the boundaries of the codes and consensus coded 50 records. An example of defining the boundaries of definitions is the divorce code. Through discussions it was decided that it only applied when the clinical note directly mentioned divorce or used a permeation of the term "step parent" as not to bias the analysis against non-conjugal familial arrangements. Once consensus was derived and definitions were established, the two authors coded the same 50 records. The overall Kappa for this coding was 0.914. Table 5.2 highlights the agreement for each of the categories. The dataset was then divided and coded. As records were flagged for discussion, the coders would work though finding consensus. Any coding issues were also bought up at the regular larger group meetings to seek input from the larger team.

ACE Category	**Cohen's Alpha**	**Level of Agreement**
Abuse	0.96	Almost Perfect
Neglect	1.00	Perfect
Substance Abuse	0.95	Almost Perfect
Jail	0.86	Almost Perfect
Divorce	0.82	Almost Perfect
Mental Health	0.73	Substantial
DCS	0.94	Almost Perfect
Adoption	0.94	Almost Perfect

Table 5.2: Inter-rater Reliability by Category

As explored through the review of previous research, qualitative coding of unstructured EHR narratives is rare in the SIGCHI community. The example below is a small fraction of the clinical note for P38. This note was coded as divorce, sexual abuse, physical abuse, maternal violence, emotional abuse, jail, and DCS.

> *Patient is a 15 year old female admitted due to suicidal ideation after a conflict with step-father. Patient's mom initially refused to enter the assessment room and when she did, she was asked to leave as she and patient continued to yell and scream at each other. Mom was questioned about patient's report that her step-dad was aggressive and mom responded, "It's our business you don't need to know." DCS was contacted and are also aware of patient's past sexual abuse by bio dad's friend and physical abuse by bio-dad. Patient was interviewed. Patient is tearful throughout*

> *session when talking about her step-father and says she was admitted for making suicidal comments when he was pinning her down and fighting him. He is abusive and controlling to both patient and her mother. Things worsened when patient's older brother went to jail about 3 months ago, because her brother was a protective factor. He is verbally abusive, calls patient various derogatory names and constantly tells her how worthless and "stupid" she is and that her biological father does not want her. Her mom does little to defend patient and patient thinks she will not leave him because "she's scared to leave because he will hurt her."*

Extracting Indicators of Cyber/bullying

As previously stated, there are several ways in which cyber/bullying were noted within the patient records.

- An ICD-10 code within the patient's EHR that indicated cyber/bullying which included Victim of cyber/bullying, Victim of teen psychosocial violence, Victim of teen psychosocial violence (suspected), Intimidation through social media (suspected), Victim of teen psychosocial violence (confirmed), and Intimidation through social media (confirmed).
- The cyber/bullying survey indicated that the patient had been cyber/bullied
- Cyber/bullying was mentioned in the list of reasons for admission
- The unstructured narratives mentioned cyber/bullying

Based on these indicators, we further refined the dataset for patients where cyber/bullying was or was not present as this is an important factor based on the literature linking ACEs and cyber/bullying as previously highlighted.

Methodological Considerations

Clinical chart review is an intensive process aimed at obtaining retrospective data to provide context to and answer clinically-oriented questions [534]. The methodological rigor of chart reviews has been proven throughout the clinical research space [253, 534] and recommendations on how to enhance this rigor have further strengthened this methodology [612] by addressing the well-documented limitations [464]. Because of the highlighted complexities of the EHR including data governance issues, the outcome of clinical chart reviews can often lead to more contextual and complete knowledge generation than what is provided through queries to the databases [507].

Due to the sensitive nature of the data in the EHR narratives, we will not report out direct or parenthetical quotes from the EHR. The results will be reported in aggregate, with exemplars of scenarios found in the unstructured note to provide more context.

Limitations

There are several limitations associated with this research. First, the narratives that we analyzed are not direct patient accounts. They are filtered through the healthcare provider who is documenting the conversations that were had with the patient. This process inherently means that there is context that is lost in that translation. However, that does not mean that there is a lack of value in the analysis of the clinical notes to understand the global presence of a certain phenomenon within a patient panel. Additionally, there was no set of specific screener/questionnaires used by the providers to assess ACEs within patients. While deductive approach was used to identify ACEs from the narrative, due to probable data loss and lack of general assessment for ACEs, the results presented in this research are most likely under-representative of the patient panel assessed. In addition, for the scope of this study, we only looked at the data when cyber/bullying involvement in hospital admission was reported solely through patient narratives. Future research should include data from additional patient narratives that suggested the same through different data sources, such as inpatient survey. In the healthcare domain, computationally identifying temporality from clinical text to determine the order of events (when the ACEs first started/occurred) [331], the cause of the adverse event, and co-reference within the text is still a challenge [553]. Therefore, the design guidelines proposed in this study need to be evaluated and validated using real-world data to explore how well they perform.

Ethical Considerations

There are several ethical considerations of this research. Due to the nature of this data, we put several guardrails in place. First, we limited the demographic data (i.e. name, zip code, address, etc.) collected as to mitigate the potential negative effects if a data spill were to take place. Additionally, all notes were de-identified prior to analysis for the same purpose. The nature of the clinical notes often dealt with very graphic details related to abuse, neglect, and general maltreatment of the youth patient. The research team both de-identified and coded the data. Due to this exposure, several safety provisions were enacted for the team. First, the coding authors were QPR [16] and ASIST [4] trained. The training teaches participants how to identify and communicate with those who are under emotional strain, such as those who have suicidal ideation or have attempted suicides. While not directly engaging participants in this research, it was beneficial to the coders who were reviewing the clinical notes. Second, the coders met regularly during the process to discuss aspects of the clinical notes that they were struggling with or having a hard time moving beyond. This form of self-care is a well-documented approach for researchers who are emotionally or psychologically affected by emotionally demanding research [357]. Finally, we brought in a trained psychiatric social worker to meet with the team several times during the data analysis process.

Results

The aim of this paper was to explore the prevalence of ACEs within patients, especially those who indicated they were being affected by cyber/bullying and/or if it contributed towards their inpatient hospital admission. Out of total 719 patients, 32.9% reported that cyber/bullying contributed to their in-patient stay via the inpatient cyber/bullying survey with 23.7% not responding to this question.

However, this report on contribution towards hospital admission was inconsistent between survey and patient narratives in EHR. For example, of the patients with a positive hit for cyber/bullying, only 30.4% of them were consistent in reporting of such events both in survey and EHR notes, while 24.5% indicated such events only in survey and 45.1% were indicated only in discharge/intake notes in patients' EHR. Cyber/bullying reporting was considerably more thorough and extensive in patient narratives documented within EHR than in surveys, and it contributed the majority of the data we required to conduct the data analysis. A factor within this inconsistency is the acute nature of this encounter - the purpose of the admission is to stabilize and assess for referrals to other specialty or long-term providers. Depending on the severity of the patients and their duration of stay, reporting cyber/bullying may or may not have been fully assessed and thus not documented in the EHR.

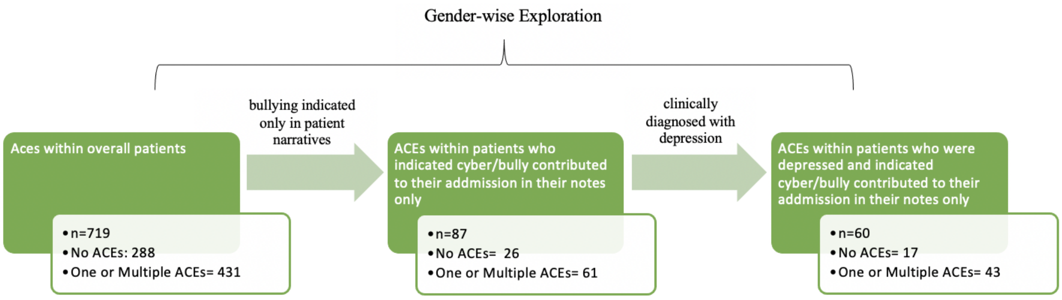


Figure 5.2: Overview of the Result Structure

The results section is structured as below: first, I explored the most common and prominent ACEs within all patients (n=719) and outlined the themes around those adverse events. Next, I narrowed my lens and focused only on cyber/bullied patients to investigate the prevalence of adverse experiences within them. For the scope of this paper, I focused on patients who indicated instances of cyber/bullying only in patient narratives (n=87), as they comprised the majority of the patients' information. I also integrated gender and clinical diagnosis (n=60) as lens to investigate ACEs within cyber/bullied patients. I used binary gender spectrum (female/male) as lens.Figure 5.2 outlines the result structure.

Assessing ACEs from Clinical Notes

Indicators of ACEs were assessed through the qualitative coding of the unstructured narratives in the EHR. Figure 5.3 depicts the prevalence of various ACE indicators with gender breakdown in patients based on their charts where text was found to be related to a specific ACE category. All these values are in percentages (%). Substance abuse was the most prevalent ACEs within the patients (24.9%) with majority being female patients (60.9%). There were five types of specific abuse present in the dataset (Figure 5.3. All these values are in percentages (%).), including 18 records that were coded as general/not defined. As the patients reported having one or more ACE

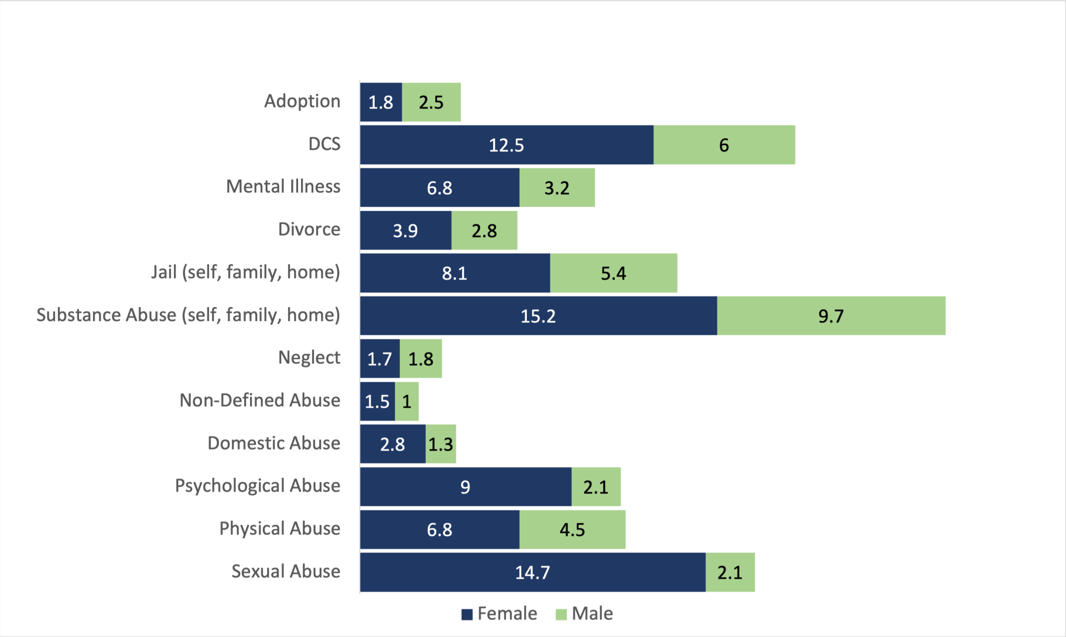
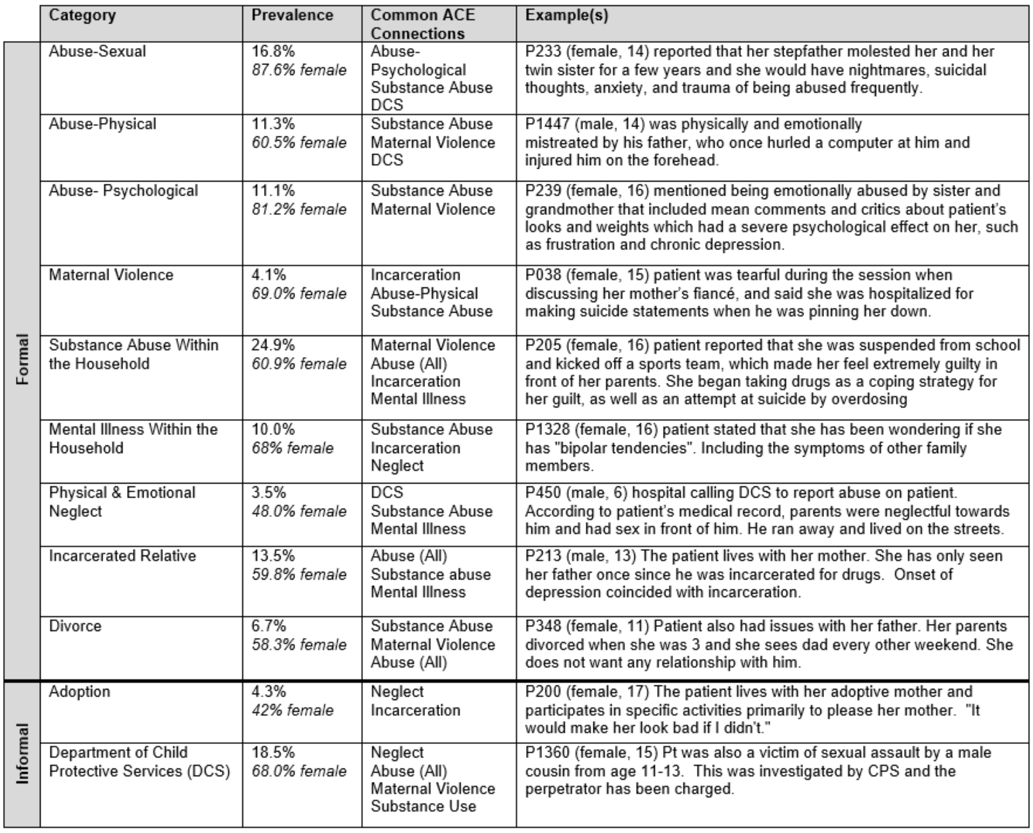


Figure 5.3: Different ACEs Associated with Full Dataset (n=719)

episodes over their lifetimes, the cumulative percentages may seem different. In general, all the ACEs were higher within female patients than male patients, except neglect and adoption. Beyond the 10 most traditional indicators of ACEs, we decided to include adoption and involvement with the DCS as ACEs in the study, as first) the clinical partners of this study, based on their experience of working with mental health and youth populations, felt it was critical to look into a broader definition of ACEs with these two additional factors, and second) the prevalence of reports of these events present within the dataset. For example, involvement of DCS was the second most common event found within the patient dataset related to other ACEs.



	Category	**Prevalence**	**Common ACE Connections**	**Example(s)**
Formal	Abuse-Sexual	16.8% *87.6% female*	Abuse-Psychological Substance Abuse DCS	P233 (female, 14) reported that her stepfather molested her and her twin sister for a few years and she would have nightmares, suicidal thoughts, anxiety, and trauma of being abused frequently.
	Abuse-Physical	11.3% *60.5% female*	Substance Abuse Maternal Violence DCS	P1447 (male, 14) was physically and emotionally mistreated by his father, who once hurled a computer at him and injured him on the forehead.
	Abuse- Psychological	11.1% *81.2% female*	Substance Abuse Maternal Violence	P239 (female, 16) mentioned being emotionally abused by sister and grandmother that included mean comments and critics about patient's looks and weights which had a severe psychological effect on her, such as frustration and chronic depression.
	Maternal Violence	4.1% *69.0% female*	Incarceration Abuse-Physical Substance Abuse	P038 (female, 15) patient was tearful during the session when discussing her mother's fiancé, and said she was hospitalized for making suicide statements when he was pinning her down.
	Substance Abuse Within the Household	24.9% *60.9% female*	Maternal Violence Abuse (All) Incarceration Mental Illness	P205 (female, 16) patient reported that she was suspended from school and kicked off a sports team, which made her feel extremely guilty in front of her parents. She began taking drugs as a coping strategy for her guilt, as well as an attempt at suicide by overdosing
	Mental Illness Within the Household	10.0% *68% female*	Substance Abuse Incarceration Neglect	P1328 (female, 16) patient stated that she has been wondering if she has "bipolar tendencies". Including the symptoms of other family members.
	Physical & Emotional Neglect	3.5% *48.0% female*	DCS Substance Abuse Mental Illness	P450 (male, 6) hospital calling DCS to report abuse on patient. According to patient's medical record, parents were neglectful towards him and had sex in front of him. He ran away and lived on the streets.
	Incarcerated Relative	13.5% *59.8% female*	Abuse (All) Substance abuse Mental Illness	P213 (male, 13) The patient lives with her mother. She has only seen her father once since he was incarcerated for drugs. Onset of depression coincided with incarceration.
	Divorce	6.7% *58.3% female*	Substance Abuse Maternal Violence Abuse (All)	P348 (female, 11) Patient also had issues with her father. Her parents divorced when she was 3 and she sees dad every other weekend. She does not want any relationship with him.
Informal	Adoption	4.3% *42% female*	Neglect Incarceration	P200 (female, 17) The patient lives with her adoptive mother and participates in specific activities primarily to please her mother. "It would make her look bad if I didn't."
	Department of Child Protective Services (DCS)	18.5% *68.0% female*	Neglect Abuse (All) Maternal Violence Substance Use	P1360 (female, 15) Pt was also a victim of sexual assault by a male cousin from age 11-13. This was investigated by CPS and the perpetrator has been charged.

Figure 5.4: Breakdown of ACE Categories, Their Prevalence in the Dataset, & How They Connect with Other ACE Categories.

Figure 5.4 provides more detailed information on different ACEs observed in this dataset. Patients discussed a variety of adverse experiences that ranged from being tormented by family members to being publicly shamed for weights and looks to issues of substance abuse within the household and the impacts that had on their mental health. The most prevalent ACE in the dataset was substance abuse within the household at 24.9% of all records sharing that code and the least prevalent beginning physical and emotional neglect with 3.5% of records sharing this code. Supporting the clinical team's inclination to add additional codes, the DCS code was the second most popular with 18.5% of records sharing this code in addition to being connected to many other common formal ACE categories. Within the notes, many patients talked about having mental illnesses, including depression, anxiety, schizophrenia, bipolar, and suicidality while connecting them with their adverse experiences.

When comparing the prevalence rates of the codes within the data analysis and the diagnoses from the patients' charts, we noticed that there were discrepancies between certain indicators. For example, physical abuse was present in 11.3% of the coded clinical notes yet only 0.6% of the formal diagnoses. Additionally, 16.8% patients within the dataset mentioned experiencing sexual abuse in their clinical note for the encounter, while only 3.6% of them had formal diagnoses. Upon further investigation into the patient's chart, it was observed that these had all taken place in the past and not listed as a current reason for the child's inpatient hospital stay. There are several reasons for this type of disparity between the clinical note and the formal diagnosis. The most common reasons include that the patient brings this up during their intake process but was never seen clinically (physically or mentally) for the incident, the clinical documentation of the incident took place in a system outside of the current health system, or this was the first time reporting the incident and thus there has not been enough time for the processes to take place for adding the diagnosis code into the EHR.

Exploring Adverse Events within Cyber/bullied Patients

While information on numerous ACE indicators gave us insights on the specifics/themes and impacts that led to patients' traumatic experiences, we also sought to see if cyber/bullying occurrences had an influence on such events and consequences. As mentioned, there were multiple ways patients indicated that they were either cyber/bullied or it contributed to their inpatient stay (e.g., intake survey, EHR notes or both); however such reporting was inconsistent across different media.Comparing survey inputs and unstructured clinical notes were useful, as the survey provided no localized context or detail while the EHR provided comparatively more details on the cyber/bullying event(s) and the environments in which it took place. For example, within patients who indicated experiencing cyber/bullying through EHR notes, cyber/bullying via social media was specifically documented in 5 of the patient records. The phrase "cyberbullying" or "online bullying" was often interchanged by patients with general bullying, which may have contributed to the lower frequency of cyberbully reports. There were additional contexts provided in the notes, such as some patients reported being cyber/bullied for their sexuality (1.1%), physical appearance (fat/ugly) (5.7%) and rumors (5.7%).

Different ACE Indicators within Cyber/bullied Patients. From their EHR notes, out of 87 cyber/bullied patients, 70% had at least one or multiple ACEs experiences. The data shows, all of the ACE related indicators were higher within patients who indicated being cyber/bullied (except only for DCS involvement). Reporting more on different abuse related events was higher within cyber/bullied patients (Figure 5.5. All these values are in percentages (%).). Along with sexual abuse, we noticed higher instances of cyber/bullied patients reporting psychological abuse than physical abuse in this subgroup, which was different from the pattern we observed within full dataset (n= 719). They reported facing cyber/bullying by peers/classmates, outside of the home. Specific online platforms like SnapChat, Instagram, Facebook, text messages, and online gaming portals were mentioned by the patients who faced such psychological traumas. For example, P1463 (male, age 13) mentioned about being bullied by acquaintances while playing online games where they asked him to kill himself. Apart from this, while DCS was the 2nd most reported instances within overall patient dataset, for more specific cyber/bullied subgroup, incident of incarceration or probation was more prevalent and was the 2nd most reported ACE indicator (Figure 5.5). Furthermore, instances of neglect also found to be higher than domestic abuse within bullied patients as compared to the overall trend we saw in whole dataset.

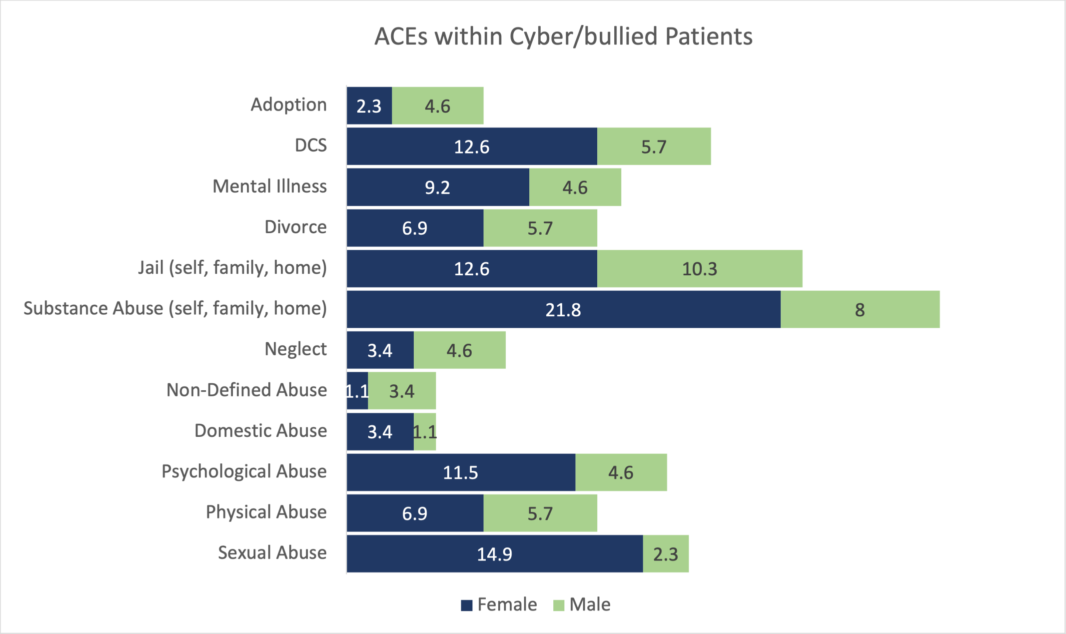


Figure 5.5: ACEs within Cyber/bullied Patients from Clinical Notes (n=87)

Gender Specific ACEs within Cyber/bullied Patients We also explored these ACEs within bullied patients from a gender (gender assigned at birth) specific lens. This provided us better understanding on how gender can play a role in experiencing certain ACEs within bullied patients. While similar to overall trend, female cyber/bullied patients reported higher rates of facing different ACE indicators compared to the male bullied patients, except for neglect, adoption and additionally non-defined abuse. Instances of abuse was extensively higher within female cyber/bullied patients. Females made up the bulk of the patients who were harassed for their physical appearance (80%), as they were fat shamed and termed ugly in both online and offline. Patients who were bullied for rumors, particularly sexual rumors (both offline and online) where they were suspected of engaging in sexual contact with classmates or professors, were overwhelmingly female as well (87%). Male bullied patients reported more instances of non-defined abuses in their clinical notes compared to female bullied patients who were more specific in describing their abuse incidents. Cyber/bullying also was a contributor to their experience of engaging with substance abuse. Both male and female patients got addicted to alcohol, meth, cannabis, marijuana and so on for issues like losing weight after being bullied online and offline by peers. P273 (female, age 16), who had symptoms of eating disorder, reported using methamphetamine to lose weight after getting bullied at school for her weight issue. While drug misuse was the most common ACE among male patients in the entire sample, instances of receiving probation was the most common ACE indicator within cyber/bullied male patients. As cyber/bullied male patients reported higher engagement with serious physical fights at school to resist the perpetrator they meet on a regular basis, it can impact the higher instance of probation they faced.

Adverse Consequences within Cyber/bullied Patients with ACEs

Analyses of patient data have also revealed many social, behavioral, and clinical implications of ACEs in adolescents, particularly those who had past experiences with cyber/bully.

Social and Behavioral Cues within Cyber/bullied Patients Notes from the EHR indicated that the struggle of being cyber/bullied and the presence of related ACE events had significant consequences for the patients. For instance, patients had multiple instances of being violent or having troubles with schools and peers, suicidal ideation/attempt, lower academic grades, higher instances of changing/quitting schools, severe mental distress, having eating disorders, relationship issues with parents or other members of the families and so on– all due to their experiences of cyber/bullying. However, the frequency of these impacts across all the bullied patients (from the EHR notes) were not the same (Figure 5.6. All these values are in percent-

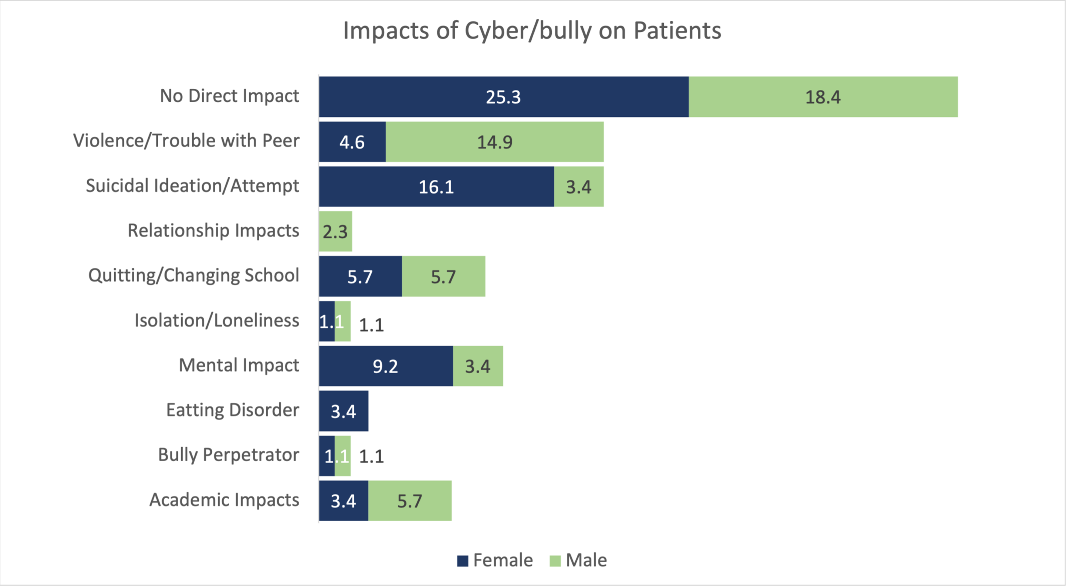


Figure 5.6: Social & Behavioral Impacts of Cyber/bullying on Patients

ages (%).). We have discussed some of them below.

Violence/Trouble with peer and school. Violence was one of the most common effects we observed among bullied patients, especially within male patients. Notes from P328 (male, age 15), for instance, reported that the patient was frequently bullied at school and often engaged in repetitive arguing with teachers or fighting with peers that always ended up with suspensions and detentions (ten times in the previous semester). Additionally, the patient also threatened to bring firearms to school with the intention of hurting his bullies. Whereas such extreme incidents or implications of violence were prominent within male patients, female patients also had violent experiences due to being bullied via online social media. For example, P394 (female, age 14) reported beating down a girl from school who had been cyber/bullying her and calling her fat online constantly, which also ended in probation. Cyber/bullying also impacted family/friends relationships (observed only within male patients) where patients would behave violently and rudely with their close ones as to express their frustration of being bullied.

Suicidal Ideation/Attempt. Suicidal ideation/attempt was prevalent within bullied patients along with violence (19.5%). However, instances of suicidal ideation/attempt were more prominent within female patients than male patients (Figure 5.6). In fact, this was the most prominent impact found within female patients who were bullied. For example, notes from P406 (female, age 16) reported the patient having extreme suicidal thoughts as her story about being raped by a family member was spread at school, making her a target of cyber/bullying from her classmates. Another patient, P033 (female, age 16), attempted to overdose and kill herself because she was being cyber/bullied on social media and was called a "hoe" by her classmates for the rumor of having sex with a guy. Patients mentioned using different means to take their lives ranging from overdosing with Adderall, Mucinex, Aspirin, or rat poison to physically hurting themselves with knives, razors or guns.

Mental most prominent impacts and Eating Disorder. Patients mentioned having diverse range of mental impacts due to being bullied, however, such impacts were more vivid within female patients as opposed to male patients. Such mental impacts included anxiety, lower self-esteem, stress, depression and anger. P1360 (female, age 15), for example, acknowledged feeling helpless and hopeless as a result of being bullied through social media as well as offline at school where others commented hurtful and derogatory things to the patients, exacerbating her sense of worthlessness and driving her to be highly self-critical and detest herself. Some patients, prominently females, complained about developing eating disorders (ED) such as bulimia, anorexia, and restriction due to being cyber/bullied. None of the male patients reported having ED issues.

Quitting/Changing School and Academic Impacts. Several of the patients reported that being bullied had a negative influence on their academic performance. Leaving, changing schools and most commonly having negative impacts on academic grades were reported within cyber/bullied patients, especially within males. Rumor was one of the reasons why some female patients were bullied and had to quit/change schools. In few instances, academic im-

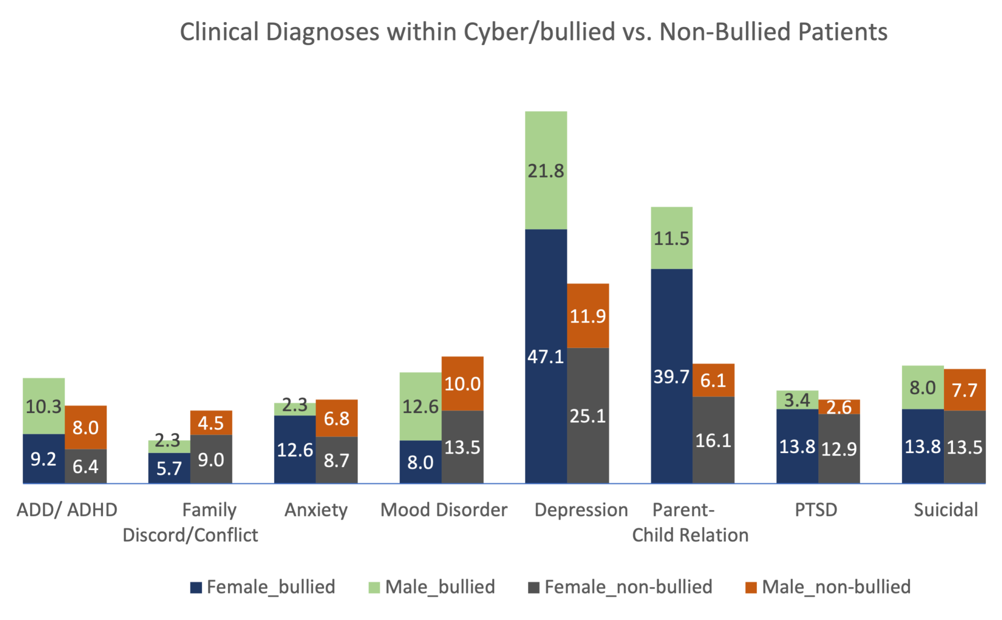


Figure 5.7: Clinical Diagnoses within Cyber/bullied & Non-bullied Patients

pacts due to cyber/bullying were obscure within patients' clinical notes. For example, 10.3% of the cyber/bullied patients expressed their frustration at their schools because they did not receive any support from the authorities after reporting cyber/bullying instances to them. While these demographic contexts and consequences from EHR notes were crucial, they were critically missing from the overall understanding of ACEs within patients.

Association of Clinical Diagnoses and ACEs with Cyber/bullied Patients While patients in this dataset indicated suffering social and behavioral consequences as a result of cyber/bullying and ACEs in their unstructured notes, we used information from their clinical diagnoses as well to explore these consequences further. For example, out of 87 cyber/bullied patients, 60 (67.9%) were clinically diagnosed with depression (Figure 5.7. All values are in percentages (%).). While the level of depression could range from major to minor and the episodes could be recurrent or a single event, my analysis on the data showed the number of this diagnosis almost doubled within cyber/bullied patients, especially females, as compared to non-bullied patients. For patients who were clinically diagnosed with depression and also

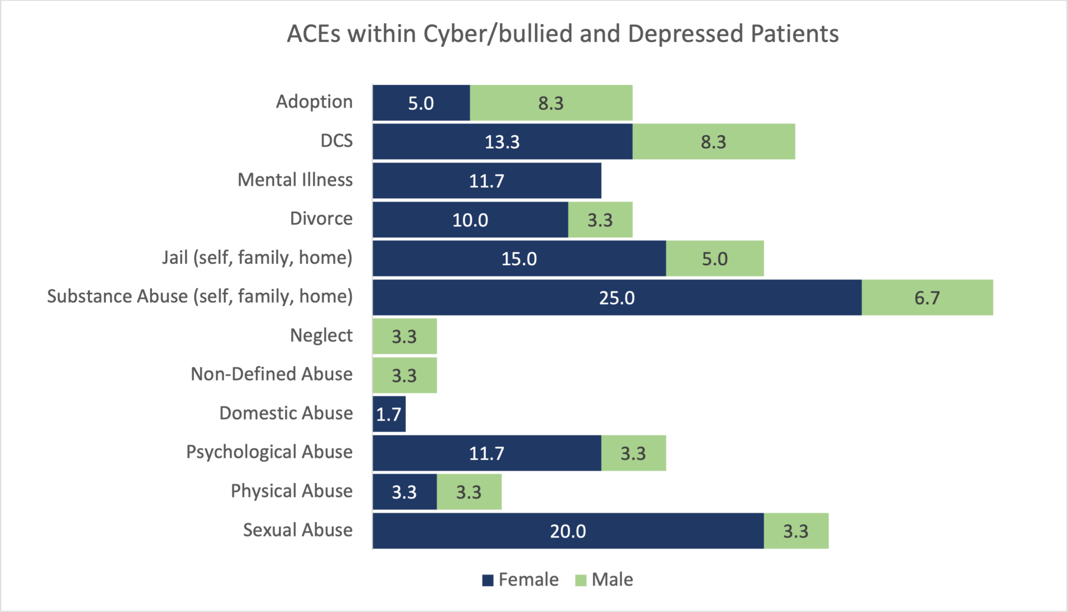


Figure 5.8: ACEs within Bullied & Depressed Patients (n=60)

were cyber/bullied, the most prominent ACEs were respectively substance abuse, sexual abuse, DCS, jail, psychological abuse, divorce and adoption, mental illness, physical abuse, neglect and non-defined abuse, and finally domestic abuse (Figure 5.8. All these values are in percentages (%).). This finding was slightly different than the previous observations, as within depressed patients, the instances of sexual abuse tend to be way higher, especially for females. Patients' narratives from EHR indicated majority of the bullied male patients who mentioned adoption and DCS involvement in their lives were clinically depressed. Within females, instances of family incarceration were higher than DCS instances. Additionally, within all forms of abuse, domestic abuse was only reported by females. None of the male patients who were clinically depressed reported domestic abuse within family.

While mood disorder (moderate to severe) was comparatively less common among cyber/bullied patients than non-bullied patients, the percentage of cyber/bullied men being clinically diagnosed with mood disorder increased. Mood disorder within non-bullied patients included substance induced mood disorder, sad mood along with general mood disorder; however, for bullied patients, diagnoses of disruptive mood dysregulation disorder, general mood disorder, and mood disorder with psychosis were more common. ADD/ADHD diagnoses were higher within cyber/bullied patients, especially within male patients. Clinical diagnosis of suicide ideation/attempt was also higher within cyber/bullied patients as compared to non-bullied patients.

The study showed that ACEs are prevalent within the entirety of the dataset and the subset where cyber/bullying contributed to the hospitalization. For those where cyber/bullying contributed to hospitalization, there were higher levels of ACEs associated with psychological abuse, neglect, divorce, substance abuse and incarceration within the home than the general patient population. While this specific hospitalization is focused on triage and stabilization, these indicators could be important for clinicians and other support mechanisms who will provide the child with ongoing treatment. By pinpointing these specific ACEs that are more prevalent within this subpopulation, targeted treatment and support is possible, potentially mitigating or dampening the potential impacts of these later in life [419].

Discussion

ACE Indicators, Gender, and Cyber/bullying

ACEs have the potential to affect an individual's life trajectories including lower life expectancy [551] in addition to social and economic damage [290]. When examined at a community level, these long-term effects have a serious impact on public health [53]. This study sheds light on the experiences of ACEs within patients using unstructured clinical data (unlike the more common assessment which uses formalized screening [140]), which also provided in-depth knowledge on social, behavioral and clinical impacts on patients' lives that include being violent or suicidal to dropping out of schools. Analysis of the dataset shows all traditional indicators of ACEs were reported by the patients, with highest being substance abuse, sexual abuse and incarceration/jail. Additionally, we have also identified an alarming majority of patients who were adopted or engaged with DCS reported to have experienced multiple ACEs as well as having a greater number of mental and physical health problems. Despite a number of studies suggesting that adopted children have greater emotional and behavioral issues than children in the general population [330, 338], there is currently little study on their vulnerability to ACEs [54]. Despite the fact that ACEs frequently co-occur [221, 199], most studies evaluating the impact of adversity in adoptive samples have focused on individual adversities rather than cumulative risk [559, 54]. The findings also revealed the co-occurrence of various ACEs in adopted patients, including drug abuse, emotional, physical, and sexual abuse, neglect, and incarceration.

Further investigation of patients' clinical narratives/notes via the lenses of gender, clinical diagnoses, and cyber/bullying indications allows us to gain a more comprehensive view of ACEs. For instance, prevalence of most adverse experiences such as sexual abuse, psychological abuse, substance misuse, and mental illness were higher among cyber/bullied females. Cyber/bullied female patients were also found to be clinically diagnosed with depression or suicidal attempts/ideation more than male patients in the same sub-group, whereas male patients had higher instances of having undefined abuse and being diagnosed with ADD/ADHD and mood disorder. Two inferences can be made from this: first, female children and adolescents are more likely than male children and adolescents to be victims of ACEs, especially sexual abuse, and second, female patients are more likely to report experiences of ACEs and cyber/bulling that leads to more clinical diagnoses than male patients. Penderson reports similar findings where females, in a non-clinical context, reported significantly a greater range of ACEs and mental health, social, and emotional difficulties in adulthood likely than males [276]. The female patients who grew up in a sexually abusive dysfunctional household had a higher probability of experiencing adverse childhood trauma. The gender differences in rates of ACEs, particularly relating to sexual abuse, are consistent with existing evidence, as approximately 20% of females in the US have been exposed to serious sexual violence in their lifetime, with the majority of these women (79%) reporting their first sexual assault in childhood or young adulthood [122, 276]. Under-reporting by male patients is also not uncommon in clinical settings simply due to their general unwillingness to report [231, 432, 276], which possibly limits reporting of other forms of traumatic exposures they may have experienced in their childhood [613]. Prior work in CSCW also has discussed significant differences in the health consequences experienced by different genders [177]. Thus, to identify people at higher risk, it's crucial to understand how different behavioral and mental health concerns manifest themselves in different gender groupings.

Complexities Integrating ACE Data in EHRs

In healthcare domain, EHRs are the *de facto* standard for storing medical information for patients [163, 603, 540]. While some of these data points are stored as discrete fields within the EHR, some are documented in an unstructured format within patient's narratives/notes by the providers or even scanned in as media attached to the patient's encounters. Since the goal of this study was to contribute to the scarce research examining the association and consequences of the experiences of ACEs within youth populations who have been cyber/bullied, we opted for a combination of data formats that helped us to qualitatively analyze unstructured patient narratives through the lens of discrete structured data. However, the use of these observational/clinical data, both structured and unstructured, for health research present some practical challenges, as there is a lack of a systematic methodology or workflow that justifies how health-related data should be linked and used to identify adverse mental and behavioral health experiences within patients.

Inconsistency Between Multiple Data Sources

The discrepancy between multiple data sources, which is rarely analyzed or addressed during the treatment process, was one of the key shortcomings the study found in EHR data quality. Even though the inpatient survey on cyber/bully screening was designed to collect discrete information about patients' cyber/bullying experiences, it did not capture the full panel of patients where these events were noted when the survey results were compared against data within the EHR. In fact, closer to half of the patients (45.1%) did not mention cyber/bullying in their surveys yet it was documented within their unstructured notes and/or diagnoses within the medical record. We would have missed a substantial number of cyber/bullied patients if we hadn't integrated unstructured narratives and structured survey inputs to analyze adverse childhood experiences within patients. Ignorance of such integration would have resulted in inaccurately assessed variables, missing data, confounding, and limited knowledge on patient's health and experiences [119]. Despite the fact that both structured and unstructured data offer additional and useful information on patients, the absence of integration across different sources in the EHR can potentially result in partial and even erroneous outcomes that highlights the significant performance disparities, system's lack of interpretability and the disparate data within the EHR itself.

Challenges in Data Integration and Interpretation

The results on different social and clinical constructs related to ACEs have shown the importance of adding additional layer of data screening and integration into EHR, a practice currently missing in clinical settings. As EHRs grow more common in medical practice, data integration with EHRs will become more important in tactics to inform providers of collaborative decision-making possibilities [371]. Clinicians utilize EHRs to record patient information, while hospital administrators use EHRs to create data to assess healthcare quality and efficiency. For example, DCS and adoption being consistently common, especially among cyber/bullied and depressed male patients, emphasizes the need of using these non-ACE indicators in the diagnostic procedure to evaluate the prevalence of ACEs in patients. While adding this data to patients' EHRs will aid clinicians, nurses, and therapists in creating better treatment plans for their patients who experience these particular events, it will also aid health administrators in suggesting better screening procedures and metrics that take into account the patients' experiences. Additionally, this enables patients to collaborate with clinicians during the decision-making process when there are trade-offs between treatment alternatives, ensuring that patient preferences and values are incorporated into the medical plan [216]. While these distinctions may appear insignificant, breaking down complex phenomena like ACEs into their most basic components and using structured data as lenses to evaluate unstructured data allows for a more comprehensive and fair health evaluation of patients.

The socio-technical challenge of efficiently and effectively integrating observational information from EHRs in combination with discrete data to identify potential clinical or health related issues within patients can impact internal validity and external generalizability of resulting inferences [86]. Socio-technical challenges include the potential for biased algorithms that benefit certain subgroups of patient populations (e.g., using race to predict treatments in the presence of health disparities), effects on patient–clinician communication, the need for new skills and workflows to practice medicine, and so on. Majority previous work in the healthcare domain focused on prediction modeling by utilizing either structured data or unstructured clinical notes with only a few studies exploring both [497, 645]. For example, [540] presents insights into the integration of structured and unstructured data to automate clinical code assignment. The study found that the information contained in unstructured data is insufficient for assigning clinical codes, and that adding structured data greatly enhanced performance. When we used discrete variables from surveys as lenses to analyze unstructured data, reporting of different ACEs among patients differed considerably. While the unstructured data in EHRs was useful for identifying a pattern of common ACEs and their links to non-ACE indicators (e.g., adoption and child protective services for patients), things became more complicated when structured and discrete variables, like cyber/bullying, gender, and patient clinical diagnoses, were added to the analysis. The results obtained with and without these filters revealed subtle, but substantial variations, suggesting discrepancy in the pattern of ACEs reported by patients.

Heuristic Design Guidelines

Clinical Guidelines for Assessment and Decision-Making

The data shows the common nature of ACEs along with the mental and social health implications they have on patients. Yet, to date, ACE screenings have not been extensively implemented in routine primary care due to potential patient and provider discomfort, different socio-technical challenges and internal complexities of data integration [513]. However, most patients were eager to perform ACE screens, according to a comprehensive literature of ACE screening in clinical settings [260], whereas clinicians thought ACE screenings built a trusting connection, enhanced empathy among patients, and led to better communication [255].

- Adverse Childhood Experience screening should be standard of care similar to depression, anxiety, and suicidality screening. As there is substantial evidence of association between ACEs and social, behavioral and clinical implications within patients, screening of ACEs should be integrated within the EHR system to provide clinicians with a direct, more objective measure of these issues.

- The ACE screens can be completed in a number of contexts, such as during a home visit, before or during an office appointment or hospital admission, or even separately in a group setting. For example, a study by [436] discussed pregnant women preferring outpatient examination rooms for self-administered ACE screenings.

- As the ACEs have become more common within younger populations, non-ACE indicators, such as DCS and adoption, should also be included in the core definition of ACEs. As they were found to be frequently linked with adverse experiences within younger patients, the definition of ACEs needs to be reevaluated, so that providers can look for these indications during their discussions with patients.

- Since male/female gender differences among patients have an influence on ACEs, cyber/bullying encounters, and a range of mental and behavioral consequences, inclusion of a broader spectrum of gender (including non-binary) in clinical assessment is important.

- Cyber/bullying assessment tools should be improved/re-evaluated for clinical relevancy. For example, rarely screening tools for cyber/bullying in clinical settings are either reliable or validated in assessing the psychometric characteristics of cyber/bullying within younger individuals, and can standardize the conceptual basis of what constitutes cyber/bullying in different environments [92]. The vast majority of existing tools in clinical settings are rarely relevant and unable to screen these adverse socio-technical events within youth patients.

Computational Guidelines for Data-Driven Decision-Making

In addition to the clinical guidelines, the findings of this study imply that there are contextual and quantitative distinctions between non-bullied and cyber/bullied patients with ACEs that should be included and studied for improved collaborative decision making in clinical settings. Since EHRs have been regarded as a promising means of providing medical practitioners with computational information about a patient's condition to aid them in making better decisions in a variety of disciplines [369], it is critical to establish computational guidelines for better data integration, analysis, and interpretation of EHR data.

- The results outlined data mismatch between inpatient survey and patient narratives. To ensure consistent integration of patient data into the EHR, instead of scanning structured inpatient survey inputs as an image, a framework or basic dashboard can be incorporated into the system to translate these data as discrete fields into patients' health records.

- Automated ACE detection from unstructured clinical narratives can be accomplished using technological solutions, such as natural language processing (NLP) of free-text fields, when objective data from screeners are not available. Potentially, leveraging data from clinical narratives for the assessment of ACEs, EHRs could provide a prompt to the clinicians if some form of ACEs is positive within the narrative, with recommendations for helping families understand how life experiences shape mental development and health, asking the patient/family if help is desired, and providing referrals to the appropriate resource or service [81]. However, such approaches may lead to false positives due to technological limitations.

- Researchers and system designers in the Machine Learning and HCI domains must collaborate with psychometricians in the healthcare domain to optimize the diagnostic categorization of ACEs and cyber/bullying assessed by quantitative models in healthcare. Psychometricians concentrates on developing and validating model or tests that assess complex psychological concepts, or constructs, such as a person's motivation, anger, behavior or personality [515]. As the events of cyber/bullying and trauma within youths continuously rise or change forms, complementing Machine Learning-based analysis with the analytical workflow of psychometric approaches will maximize accurate collaborative decision making on patient assessment of ACEs and appropriate treatment process [266, 498, 504].

- It's crucial to establish which health-related factors should be included in computational models to predict/identify ACEs, as well as how intended outcomes of such events (connected to mental and behavioral effects in children) are presented or interpreted in clinical contexts. Theoretical frameworks for algorithmic decision making suggest that computational tools should support human discretion while still complying with current policies and standards and presenting data in an interpretable manner [535]. As clinicians and other stakeholders must be able to interpret the machine learning output, the necessity for prediction explanation within the algorithm and designing around other interactions (e.g., data collection, input, visualization, etc.) is critical [271].

The objective of implementing these computational guidelines into healthcare is to improve decision-making of the providers by providing efficient, consistent, accurate and interpretable outcomes. There is no question that computerization has made patients' records more available and legible to providers in clinical settings. However, as EHRs have evolved, attempts need to be made to improve the efficiency of electronic documentation [163].

Conclusion

This study analyzed patients' data who were admitted at PBH institute's youth inpatient facility between June 2018-January 2019. The aim of this study was to understand the association between adverse experiences faced during childhood with concerns like cyber/bully in a clinical setting, since both of these indicators can have harmful short- and long-term mental and behavioral consequences. I investigated patients' electronic health records, triangulating between clinical diagnoses and clinical narratives/notes. I employed deductive thematic analysis on the unstructured narratives and uncovered distinct indicators of ACEs and non-ACEs common within patients. Insights from my analysis on the ACEs identify the importance of exploring unstructured narratives from patients' EHRs in the absences of a formal screening, as the presentations and impacts of ACEs and cyber/bullying on patients differ extensively, specifically when inspected through the lenses of gender and clinical diagnoses. Finally, this study provides clinical and computational guidelines for improving the assessment and treatment outcomes of ACEs in clinical settings utilizing both structured and unstructured data as design considerations. Future work might seek to integrate and validate these guidelines and provide empirical results in order to assess ACEs and other adverse events in patients for better, more targeted treatments and outcomes. Furthermore, an emphasis on developing a curated clinical and socio-technical workflow for clinicians that facilitates improved treatment through structured data collection, data integration, and access to the patient's EHR is required.

CHAPTER 6: ASSESSING THE VALIDITY OF A CYBERBULLYING SCREENER IN AN ADOLESCENT IN-PATIENT CLINICAL SETTING

Introduction

Bullying, both face-to-face and online, can have serious effects on its victims that result in a range of mental health problems, substance misuse, academic difficulties, and other adverse consequences [490].Cyberbullying may be more prevalent than traditional bullying since traditional bullying often occurs only at school and is abated at home, whereas victims of cyberbullying can be targeted at any time and from any location, and the potential audience is quite broad [490]. For example, a recent national survey of 2,546 US students (aged between 13-17) showed approximately 46% of them reported experiencing cyberbullying in their lifetimes [471].

Cyberbullying is defined as a form of bullying or harassment using electronic means [564], and has been an issue since the 1990s when personal computing became more affordable, and online forums provided a platform for people to bully and harass each other online [575]. The high prevalence and negative consequences of cyberbullying highlight the necessity for systematic assessment to detect these experiences in adolescents as early as possible, justifying the use of screening tool [249, 420]. Measuring cyberbully within youth is difficult as there is no single, universally accepted scale that can measure all important socio-cultural factors that contribute to different cyberbullying experiences. This problem is made even more difficult by the ambiguous terminology and common difficulties with accounting for self-reported activities [484]. While there are distinct differences between offline and online harassment, they also do not necessarily happen in isolation of each other. Experts have begun to doubt the value of drawing a line between traditional bullying and cyberbullying because of their close connections [353]. Thus, for the purposes of this paper, we will use the term "**cyber/bully**" as a label for bullying that is taking place regardless of the mode in which it takes place (in-person vs. via technology).

Cyber/bullying has been the subject of substantial research in CSCW and HCI [562, 154], but the majority of the studies have used public surveys and data analysis to operationalize the problem, with very few studies employing direct clinical findings [186, 511]. In reality, most anti-cyber/bullying efforts are initiated and directed by the education system [88] even though 1) cyber/bullying is associated with significant health problems [399] 2) cyber/bullied youth seek the help of health care providers [548] 3) cyber/bullying of any type can be difficult for adults to witness or detect, and 4) many schools have decided that cyber/bullying in particular falls outside of their mandate for intervention, although they are increasingly recognising that this is not the case [598]. Given that victims, perpetrator or even the bystanders [321] are unlikely to report cyber/bullying to adults, health care providers may play a vital role in uncovering these experiences that would otherwise be missed.

Therefore, this study seeks to explore whether current assessment processes within healthcare systems incorporate technology use concerns and/or associated negative experiences for better, more targeted treatments and outcomes. That is, do they center the patients at all? Using statistical methods, such as exploratory factor analysis and reliability analysis, the study explicitly investigates the reliability and validity of the screening instrument used at Parkview Behavioral Health Institute's inpatient facility to screen for adolescent cyber/bully experiences during patient intake in acute setting. Along with n=382 patient data, the study also explores n=331 parent data (collected during intake screening) to add more understanding on the usability of having cyber/bully assessment in clinical settings. We found:

- The quality of patient data produced by the current screening tool is insufficient, as the percentage of missing values within the dataset was extremely high. It indicates majority of the patients either did not interact with the screening tool or skipped questions for specific reasons. The highest percentage of missing values was found for the items that were designed to screen patients' cyber/bully related reporting behavior

- The screening instrument provides insufficient statistical assurances for assessing cyber/bully within adolescent patients. The overall effectiveness of the tool could not be justified since there was no precise theoretical foundation upon which this survey was built

- Compared to likert scale questions, items with yes/no values were noisy, redundant, and were unfit for construct validation

- There was significant discrepancy between the data collected from patient and parent intake survey. As a contrast to what their children reported through the screening, parents believe their children struggled the most with online based bullying than physical forms of bullying

The contributions of this study are three folded: 1) Using direct clinical insights from patient data, this study analyses the efficacy of current screening practices for socio-technical issues like cyber/bully within adolescents in healthcare settings to create better understanding and health consequences that would otherwise go unrecognized, 2) This study implies several shortcomings in the current operationalization of cyber/bully screening for diagnosis in clinical settings. First, the quality of the screening instruments or how the data is collected at hospitals is still not validated and reliable everywhere; second, the reliability and quality of the collected data are not ensured; and third, faulty/invalidated screening instruments and data can result in misdiagnosis and misseddiagnosis, 3) To ensure better engagement from the targeted stakeholders (e.g., patients, parents, clinicians) and accurate collaborative data-driven decision making during treatment, this study advocates that design of the assessment should be more patient-centred, include key constructs based on theoretical foundations, and consider triangulation of data for better understanding.

Cyberbully and Importance of Screening

Cyberbullying is defined as when someone repeatedly and intentionally harasses, mistreats, or makes fun of another person aiming to scare, anger or shame them using cell phones or other electronic devices [296]. Hinduja and Patchin (2010) have reported that like traditional bullying, cyberbullying includes “being ignored, disrespected, picked on, or otherwise hassled” [294]. However, when newer technological features are used to debase people, such as spreading rumors, stalking, or threatening, cyberbullying is more harmful and dangerous than traditional bullying. Continuous access to technology in the form of mobile digital technology (cell phones) is widespread among adults and adolescents. It’s been studied that being the victim of cyberbullying is associated with significant short- and long-term mental and physical health issues and academic achievement problems [605, 398]. Like traditionally bullied youth, cyberbullied youth report higher levels of depression and anxiety, emotional distress, suicidal ideation and attempts, somatic complaints, poorer physical health, and externalising problems such as increased delinquency and substance abuse than their non-bullied peers [360, 261, 609]. Since cyberbullying often goes unreported, it is important that adults be able to recognize the potential for victimization. If cyber/bullying victimization is suspected, a comprehensive evaluation of the adolescent’s use of technology as well as risk factors for and experiences with cyber/bullying should be conducted by the nurse or healthcare providers (HCPs) [137, 121].

In healthcare settings, screening is crucial. Consistent and frequent screening enables professionals to establish baselines, identify problems that require treatment, and offer information on the efficacy of intervention. Because of the severity of the problem and the possible long-term consequences, cyber/bullying requires screening. According to a study by Carter and Wilson (2015), 7.6% of participants were unsure if they had ever experienced cyber/bullying [32]. This is crucial to take into account while assessing a patient for suspected exposure to cyber/bullying because the kid or adolescent may have a completely different perspective or definition of cyber/bullying than the provider, making it easy to miss victims. It has been hypothesized that kids who are cyber/bullied visit the primary care clinic more frequently than those who are not due to the adverse physical and mental health problems they frequently experience [312]; however there is no data on these specific statistics. Thus, screening for cyber/bullying should be a part of standard of care in a clinical setting.

Different Tools for Screening Cyber/bully

Bullying Screening. Traditional or face-to-face bullying has been part of group dynamics since the earliest accounts of civilization. However, it was not until the later part of the 20th century where large-scale bulling in the public settings (e.g. schools, workplaces) gained increased interest in safeguarding against it [588].

The various bullying instruments measure both general and context-specific aspects of bullying. There are scales that focus on assessing general levels of victimization [222], differences related to gender [98, 156], the climate in which bullying is taking place [78], assessment of the forms of bullying [552], if homophobic content is related to bullying [503, 506], assessment of bullying in primary school-aged children [310, 589], and assessments that measure an individual bully's behaviors [65]. Examples of the common tools include the California Bullying Victimization scale which evaluates bullying on multiple dimensions–including physical threat/harm, verbal harassment, social harassment, and sexual harassment–assessing concepts like balance of power, intentionality, and frequency [222]. Another screener is the Child Adolescent Teasing Scale. This tool primarily focuses on verbal bullying across four contexts: bullying that targets a person's personality or behavior, family environment, school-based, and about an individual's body [616]. It additionally gauge's the degree to which the bullying bothers the individual and the frequency in which it takes place [616]. The Olweus Bully/Victim Questionnaire assess the same dimensions as the California Bullying Victimization Scale, but focuses more on bullying victimization with a focus on the gender difference in the experiences of the victims [98]. While these are not an exhaustive list of tools, they paint a picture of the diversity of the tools available for use to measure bullying in youth populations.

Cyberbullying Screening. Measuring cyberbullying is difficult because there are few valid and reliable instruments available, and there is an ongoing debate about the most appropriate methodological approaches. There are currently two approaches: (a) assessing cyberbullying as a function of the means used, for example, asking the frequency with which certain behaviors were suffered or carried out through Internet, e-mail, cellphone, and so on and (b) measuring certain behavioral categories regardless of the means used, for example, asking about behaviors such as lying, stealing someone's password, humiliating, and so on [407, 408]. Researchers generally use instruments that were developed for their specific studies, which have hindered the generalization of the nature and frequency of peer victimization across samples [249]. Moreover, many measures have not been adequately researched in terms of their psychometric properties [93].

There are instruments that can be used in most setting to measure overt and covert bullying victimization and perpetration, such as the Gatehouse Bullying Scale, Multidimensional Peer-Victimization Scale, Peer Victimization Scale, and Victimization Scale, Retrospective Bullying Questionnaire, Aggression Scale, Bullying-Behavior Scale [115, 97, 280]. These tools, however, are specific to traditional bullying [280]. The Cyber-Harassment Student Survey, developed in 2005, is a brief questionnaire designed to measure awareness and engagement in cyberbullying as both a victim and a bully

[280]. This tool, however, is primarily concerned with identifying how victims have been affected by cyberbullying, such as feelings of embarrassment, anxiety, or fear, as well as whether they have skipped school or done badly academically as a result of the victimization. It does not concentrate on determining whether or not cyberbullying victimization is occurring, or whether or not there are any health effects as a result of current victimization. [295] created the Cyberbullying and Online Aggression Survey, which measures cyberbullying victimization and perpetration as well as additional specific details about the encounter, such as bystander experiences [280]. However, neither of these instruments is well-suited for measuring the emotional and/or physical effects of cyberbullying or for enabling a conversation regarding cyberbullying behavior [121]. In a systematic review on Cyberbullying assessment instruments, [92] identified only a few screening tools to be either reliable or validated in assessing the psychometric characteristics of cyberbully within younger individuals, but was unable to standardize the conceptual basis of what constitutes cyberbully in different environments. Out of 44 cyberbully related instruments that this study reviewed, the concept of cyberbullying was only included in 21 of them, and 24 of the them include the concept cybervictimization demonstrating that the concepts employed in the instruments vary [92].

Institutional and Clinical Screening

There are currently no standardized processes or workflow across health systems for treating social and behavioral domains, such as cyber/bullying or other equally risky online practices, among extremely vulnerable and at-risk populations [599]. This is challenging for many reasons. Cyber/bullying related to youth often occurs at home or in other public spaces. However the consequences and ramifications often materialize at school [630] and related health effects can lead those targeted by cyber/bullying in the healthcare system [440, 594]. Because of this, the education system has led and coordinated the majority of efforts to prevent, identify, and be the initial intervening force associated with cyber/bullying [87]. However, school systems also struggle to detect and prevent cyber/bullying, allowing a large gap through which at risk youths may fall. Much of this has to do with adolescents being resistant to report incidences to teachers or school counselors and because the bullying is occurring off school campus. To address the lack of formal screening in schools, groups like the Anti Defamation League have programs like "No Place for Hate" which is a student-led school climate improvement program that is customizable to needs within the specific school climate [1], which has shown to be effective with cyberbullying issues [105].

Emerging evidence exists that routinely addressing the social determinants of health during clinical care can improve critical health outcomes [599]. However, despite considerable promise and action on this topic, empirical evidence on how health care systems can most efficiently and effectively collect patient-level social and behavioral data and use it to optimize regular care delivery is sparse [592, 599]. In the past few years, healthcare providers have been urged to take a more active role in preventing the long-term health consequences associated with youth cyber/bullying [217, 172, 605]. Providers are important stakeholders in promoting child health and their roles may include identification of health conditions, provision of health education, and advocacy within communities [421, 217]. Research suggests that youth and parents are willing to disclose to their physician concerns with cyber/bullying if the physician handles the disclosure in a caring manner [87, 547]. Most teenagers, on the other hand, would prefer to fill out an intake form before seeing a doctor, and others would prefer that their parents are not there when they describe their bullying experiences [547, 217]. Others suggest that health care practitioners should ask youth directly about bullying at school and online (both being bullied and bullying others) [362], including questions re-

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[1] https://www.noplaceforhate.org/the-program

garding duration, location, types of cyber/bullying, and how these cyber/bullying experiences have affected the youth. The integration of a thorough assessment tool is difficult since it can generate survey fatigue or responder fatigue in patients [246]. Survey fatigue happens when respondents lose interest and do not interact with the survey as intended [180]. A variety of factors are known to influence respondent fatigue, including survey length, survey topic, question complexity, and question type [459], which is why it is important to design screening tools that are efficient and right for target populations.

Therefore, this study tries to address these concerns, and aims to explore the current assessment process of technology use related concerns and associated negative experiences within adolescent in clinical settings at Parkview Behavioral Health Institute. I specifically ask:

- **RQ1:** *What questions have shown to measure the constructs of cyber/bully related experiences within patients during intake screening?*
- **RQ2:** *How do patients and their parents use the screening tool during in-patient admission? Does screening both patient and parent provide better result to assess cyber/bully in clinical settings?*

Methods

Clinical Setting

This research took place at Parkview Behavioral Health (PBH) Institute, a health system located in Indiana, United States. It includes in-patient capacity to service both adults and youths in acute settings. The in-patient youth hospital takes an integrative approach in that care teams include various types of providers which include: psychology, psychiatry, social work, counselors, nursing, and specialty services. The direct service area includes 15 counties with close to 1,000,000 individuals. The U.S. Census estimates that 23.1% of this population is under the age of 18 [131].

The Assessment Tools

The assessment tool at the center of this analysis was developed by the clinical staff, taking inspiration from other assessment tools as well as creating new questions targeted at issues of interest based on what was experienced within the unit. The patient and parent versions of this tool are further explained below.

Patient Intake Survey. The cyber/bully screening tool for intake patients is a 12 items tool designed to assess cyber/bully experiences within adolescent patients who get admitted at inpatient care at PBH institute. Patients have three options for taking the survey: 1) in front of their guardians, 2) alone themselves, and 3) with a nurse's assistance. The details of the tool is provided in Appendix D1. Each of these 12 items are further divided into multiple sub-items. For analysis purpose, I considered each of the options/sub-items as separate questions, which gave me total 43 items. Patients can report how they rank their experiences of cyber/bully instances and report those events with 5 point scale (ranging from 1 being never/never being upset/not safe at all to 5 being every day/extremely upset/extremely safe) and yes/no values (only exception one item with values yes/no/don't prefer to answer). All the items under cyberbullying and bullying frequency and feelings sub-scale and 5 items under safety sub-scale include likert based questions. For analysis purpose, I transformed the check/uncheck values as yes/no factors.

Parent Intake Survey. The cyber/bully screening tool for parents of the adolescent patients who admit at inpatient care is a 11 item questionnaire (with multiple sub-items) designed to assess how well they know about their child(ren)'s cyber/bully experiences. Similar to patient assessment, I also separated these sub-items, and ended up with 37 total items. The tool includes same questions with scales as patient intake assessment tool with only exceptions: 1) it does not include questions on technology accessibility, and 2) instead of item ("Did you report to your parents?"), it asks ("Did you report to the parent(s) of the bully?"). The rest of the questions are same as the patient intake form. The detailed assessment tool is provided in APPENDIX D2.

Throughout this chapter, I will use different acronyms for the items/questionnaires used in this study, which is added in APPENDIX D3 for reference. It also shows a comparison between the patient-parent tools.

Study Design

Since November 2018, PBH has integrated the patient and parent intake questionnaires as standard of care to identify the effects of cyber/bullying within their patient population. None of the survey's questions were compulsory, and the patient or parent could choose not to participate. Patients and Parents were individually requested to complete the relevant survey as part of the Patient intake process. The dataset for this research consists of a subset of the total data collected. A total of 536 Patient surveys were collected between February 2019 and November 2020. Once incomplete surveys were removed, a total of 382 Patient surveys remained. We then looked at the completed Parent Surveys for this subset and found 331 Parent surveys.

This study is part of a larger research initiative at PBH's in-patient youth behavioral health hospital population. It was approved as a retrospective chart review by the Parkview Health IRB. This was possible based on the surveys being a part of the standard of care in the Youth Behavioral Health Hospital. Data was collected through manual chart reviews. Because of the sensitive nature of the patients and their data, the team was given permission to "break the glass" (BTG) [505]. BTG is a way to override the strict access controls of the sensitive health data for the purposes of research in a controlled manner that is tracked for auditing purposes [225]. The research team received a list of Medical Record Numbers (MRNs) for all patients seen at the hospital from 2019 to 2021. The research team used those MRNs to access patients' Electronic Health Record (EHR). All surveys were administered by paper and then scanned into the EHR as a media file. The data from the surveys were manually collected and stored in a password protected csv file on a restricted server.

Patient Demographics

As previously mentioned, data was collected from a total of 382 patients who were admitted at PBH institute. The average age of patients was 14.63 (SD=2.47) years with the youngest being 7 years and the oldest 18 years old. Out of these 382 patients, majority put female as their legal gender (n=259, 67.8%), whereas male patients were 123 (32.1%) and only 1 patient did not have any information about their legal gender. Based on patient demographic showed in Table 6.1, 76.2% of the patients had white or Caucasian as their ethnicity, 11.8% were black or African America, 5.2% were Hispanic or Latino and 0.5% were either Asian or Hawaiian or Pacific Islander. Out of 382, 6.3% declined to share their ethnicity with the providers. The patient pool was from total 88 zip codes of which 13 were from out-of-state, leaving 75 unique zip codes from the state where PBH is located. For privacy and ensuring anonymity, we decided not to share anything specific about patient locations. However, we can provide aggregate information about the zip codes without

Demographics	**Patients (n=382)**		**Reasons for Admissions**	
Age	Average	14.63	Psychiatric Evaluation	37.1%
	SD	2.47	Suicidal	29.3%
	Range	7-18 years	Depression	11.4%
Gender	Female	259 (67.8%)	Aggression	7.2%
	Male	123 (32.1%)	Drugs/Alcohol	4.6%
	Other	1 (0.01%)	Psychosis/Hallucinations	4.2%
Ethnicity	White or Caucasian	291 (76.2%)	Self-Harm	2.0%
	Black/African American	45 (11.8%)	Homicidal	1.6%
	Hispanic/Latinx	20 (5.2%)	Behavioral/Mood	1.3%
	Declined/Unknown	24 (6.3%)	Stress/Anxiety	0.7%
	Other	2 (0.5%)	PTSD	0.3%
Location	88 unique zip codes across 6 states		Bi-polar	0.3%

Table 6.1: Demographics of Patients

sharing data that would violate HIPAA guidelines for anonymization [500]. The US Department of Defense classifies an Urban zip code as having 3,000+ people per m^2, suburban having 1,000-3,000 people per m^2, and rural having less than 1,000 people per m^2. Table 6.2 gives the zip code breakdown based on this definition and preponderance of patients in our dataset within those categories. An overwhelming amount (92.3%) of the patients in our dataset are from suburban or rural locals.

Classification of Zip Code	**% of Patient Zip Codes**	**% of total patient population from the zip codes**
Urban	2.7%	7.7%
Suburban	10.7%	32.0%
Rural	86.7%	60.3%

Table 6.2: Characterization of Patient Zip Codes

Additionally, we reviewed reasons for admission from the EHR. Apart from psychiatric evaluation, the most frequent reason for admission was suicide ideation/thoughts/attempts (29.3%) followed by depression (11.4%), aggression (7.2%), and drugs/alcohol/overdose (4.6%). Reasons with less than 5% prevalence include: psychosis/hallucinations/delusions, anxiety/stress, homicidal ideation, self harm, PTSD, and Bipolar Disorder.

Demographics	**Parents (n=331)**
Biological Mother (%)	206 (62.23%)
Biological Father (%)	49 (14.8%)
Step/Adopted Mother (%)	14 (4.23%)
Step/Adopted Father (%)	5 (1.51%)
Legal Permanent Guardian (%)	11 (3.32%)
Legal Temporary Guardian (%)	11 (3.23%)
Did Not Specify Relationship (%)	35 (10.56%)
Know Since Birth (%)	259 (74.25%)

Table 6.3: Demographics of Parents

Out of 382 patients, total 331 of their parents/guardians interacted with the parent intake screening tool. The rest of the 51 parents/guardians either declined to take the survey or did not interact at all with the tool. Out of these 331 survey participants, 77.033% were biologically related with the patients (62.23% biological mother, 14.80% biological father), 5.74% were step/adopted parents (4.23% step/adopted mother, 1.51% step/adopted father), 3.32% were legal permanent guardian, 3.23% were legal temporary guardian, and the rest 10.56% did not specify their relationship with the patients. Among these parent/guardians, 78.25% knew the patients since birth (Table 6.3).

Statistical Analysis

I have used multiple statistical analysis methods to analyze the data collected from both patient and parent survey. The approaches I used in this study to address issues such as missing values in data and to determine the efficacy of the tools are discussed below.

Multiple Imputation. Missing values were expected within dataset. While using of complete cases can lead to better results, the number of complete cases in our cases were too low (n=37) to use in our analysis. To statistically address this missing values in our dataset, we opted for multiple imputation (MI) [524]. Multiple imputation (MI) is a structured methodology to deal with non-response bias — missing research data that happens when people fail to respond to a survey [258]. Multiple imputation narrows uncertainty about missing values by calculating several different options ("imputations"). In this method, several versions of the same data set are created, which are then combined to make the "best" values. MICE is a multiple imputation method used to replace missing data values in a data set under certain assumptions about the data missingness mechanism (e.g., the data are missing at random, the data are missing completely at random) [71]. The chained equations approach is very flexible and can handle variables of varying types (e.g. continuous or binary) as well as complexities such as bounds or survey skip patterns. There are three typical mechanisms causing missing data: missing completely at random (MCAR); missing at random (MAR); and missing not at random (MNAR) [71]. MICE operates under the assumption that given the variables used in the imputation procedure, the missing data are Missing At Random (MAR), which means that the probability that a value is missing depends only on observed values and not on unobserved values [71]. As there was no concrete evidence to explain why we had missing values in the data, I assumed this missing trend as random and decided to apply MICE for multiple imputation in R.

Construct Validity & Reliability. To explore the reliability and validity of the patient intake tool, I used Exploratory Factor Analysis (EFA), as it is usually used when a researcher does not have any knowledge of the nature or the number factors hidden within the data [643]. Exploratory factor analysis, as its name suggests, enables researchers to identify the key variables needed to construct theories or models by using a collection of hidden dimensions and a set of indicators [593]. I conducted a principal component analysis (PCA) on the initial validation sample to determine the optimal number of factors to retain [643]. We kept factors with eigenvalues greater than 1.0 and inspected the scree plot as criteria to identify and retain underlying factors as suggested by the PCA [442]. In the present study, as I expected factors to correlate, I used an EFA with oblimin rotation criteria [643]. Bartlett's test of sphericity and Kaiser-Meyer-Olkin statistic were also determined in order to ensure factorability of the items [628]. The KMO statistics range from 0 to 1, with values closer to 1 denoting greater adequacy of the factor analysis (KMO $>=$ 0.6 low adequacy, KMO $>=$ 0.7 medium adequacy, KMO $>=$ 0.8 high adequacy, KMO $>=$ 0.9 very high adequacy) [628]. If the result of Bartlett's test is $<$ 0.05, factorial analysis can be used. The final solution was chosen based on two conditions: a) items were considered relevant for a factor if their factor loadings (FLs) were superior to 0.50; b) their communality is more than 0.45, c) each factor has at least 2 items. We also examined cross-loading items. After factor analysis was performed, the internal consistency of each factor was calculated using Chronbach's reliability alpha [590]. I used Polychoric Correlation matrices for factor analysis [250]. Polychoric correlation provides a comprehensive picture of the relationships between the variables, and employing this correlation in factor analysis allows for straightforward reference beforehand and validation afterwards on the selection of the number of factors, improving the outcome of latent structure [325]. The inclusion or exclusion of an item in a construct was determined in iterative manner by examining the items' factor loadings (FLs) and Cronbach's alpha to identify redundant items or items that did not sufficiently measure the same underlying construct.

Non-Parametric Inferential Testing As this study also explored the differences between patient and parent interactions with the screening tool, I used Mann-Whitney U test. Mann-Whitney U test is the non-parametric alternative test to the independent sample t-test [557]. Mann Whitney U test or Wilcoxon Rank-Sum test compares the means between two independent groups with the assumption that the data is not in a normal distribution. The sample mean ranks or medians (not means) are compared in the Mann-Whitney U test based on the shape of distribution of two independent groups, which distinguishes it from the t-test, which compares sample means. As many of the items included in the screening tools are ordinal (e.g. likert scale), the assumptions of the t-test are not met. Thus, I applied this statistical model to compare ordinal variables between patient and parent data and reported consistency/inconsistency between the groups by looking at the difference in their median.

Results

The primary aim of this paper was to explore the cyber/bully intake patient screening tool that was used at Parkview Behavioral Health Youth in-patient facility and measure the efficacy and reliability of the screening tool. Along with the patient intake form, the study also emphasized the variations in patient and parent use of the screening tool and added additional contexts to understand the usability of having a cyber/bully screening in clinical settings.

Inconsistent Definitions and Patient Engagement during Screening

Missing Definitions. Although the screening tool asks questions on both traditional bullying and cyberbullying, it doesn't give patients a clear definition or explanation of what constitutes as traditional bully or cyberbully or what some of the core themes are under these concepts. Due to the fact that the screening tool was not developed with a specific theoretical framework in mind, especially for cyberbullies, it severely lacks the ability to screen for crucial concepts like the different types of verbal, sexual, and racial online bullies, the idea of power disparity, intentionality, repetition, and other key concepts. Only a few examples of cyberbullying were given in the tool, and they may not have covered all of the essential elements of the definition of a cyberbully. The screening tool also alternated between traditional and online bullying screening questions, which may have been repetitive and confusing for patients. Inaccurate assessments of cyberbullying/bully behavior can result in large discrepancies in victimization rates among patients due to inconsistent definitions of these terms.

Missing Values. The results of our initial data analysis demonstrate how patients responded to various screening questions. There was a significant amount of missing values in our dataset where patients either did not respond to certain questions or purposefully avoided to provide any information. While none of the questions were mandatory to answer, the current structure of the tool was not always helpful to prevent these missing values. For instance, the survey included skip logic that allowed patients to skip multiple questions at a time. The missing data appeared to be random, as each item had missing values in it and there was no further explanation from the patients or providers on the pattern on this missing values; however, some questions had more missing values than others (Fig. 6.1). For example, the largest missing values (varying from 68% to 72%) were found in the dataset for items such reporting cyber/bullying incidents to parents, police, school, or someone else. It also had a high missing value when asked if they had ever been bullied or not (45%). For, Likert scale-based questions, the overall percentage of missing values was in the lower range (highest 31.8%) compared to binary scale questions. Questions about how people felt about being target of rude comments, rumors, threats, stealing, and attacks showed greater missing values. To address these limitation in the dataset, I used multiple imputation method, specifically multivariate imputation by chained equations (MICE), to handle and replace the missing data.

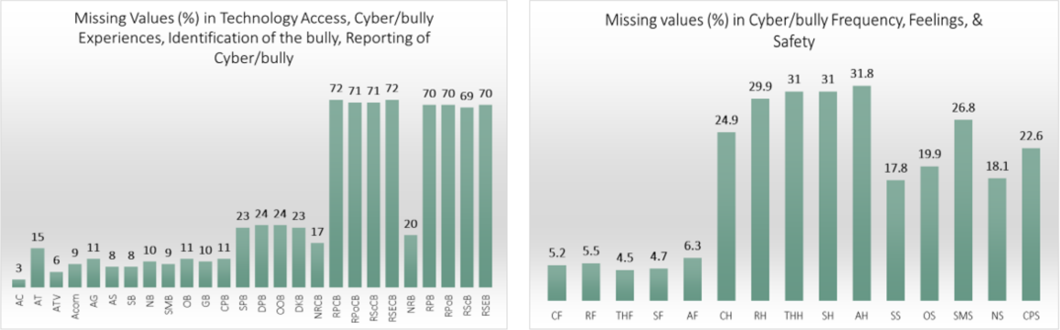


Figure 6.1: Missing Values for Binary & Likert Variables.

The total frequency/counts of responses for each binary and Likert-scale question are displayed in bar charts in Fig. 6.2 after they have been imputed. The left figure shows answer frequencies for yes/no types questions (yes: 1, no: 0), and the right side figure shows answer frequencies for likert scale questions. From binary scale questions, except for tablet accessibility, the numbers of 1 (indicating yes) were higher overall for questions with binary responses about the accessibility of different technologies. Except for the school setting, all other spaces showed a larger percentage of patients responding "no" when asked whether cyberbullying or physical bullying had occurred there. In terms of reporting behaviors, incidents of reporting to parents and school were more common for cyberbullying events compared to other sources, such as the police, or someone else. For traditional bullying, reporting to someone else was more common compared to other sources. With regard to 5-point Likert-based questions, the majority of patients gave 1 as their most common response, with the exception of questions about safety, where the majority of responses tended to be skewed to the right or to value 5, which indicates feeling extremely safe.

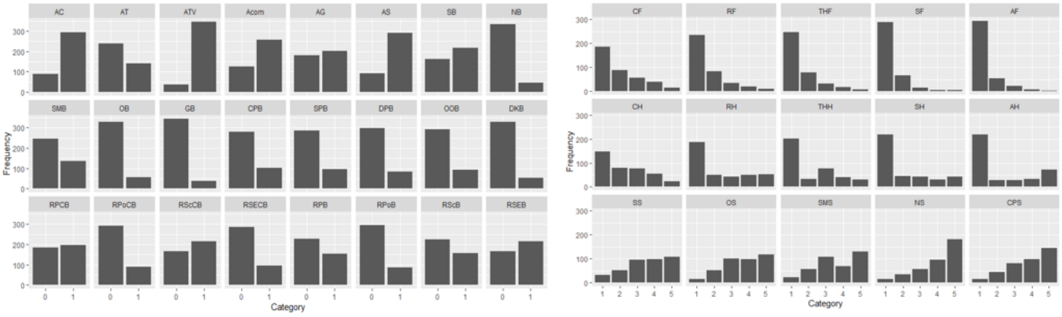
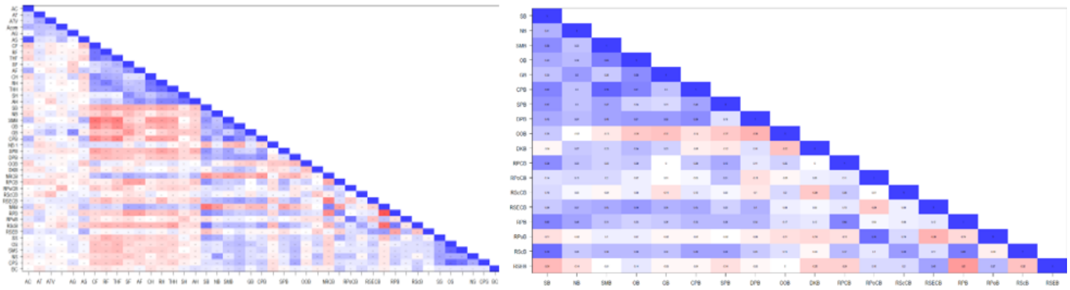


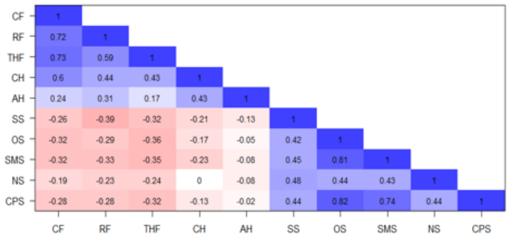
Figure 6.2: Frequency of Answers for Each Variable/Question

Construct Reliability and Validation



a) Overall polychoric correlation among all variables/items

b) Polychoric correlation among all binary scale variables/items



	CF	RF	THF	CH	AH	SS	OS	SMS	NS	CPS
CF	1									
RF	0.72	1								
THF	0.73	0.59	1							
CH	0.6	0.44	0.43	1						
AH	0.24	0.31	0.17	0.43	1					
SS	-0.26	-0.39	-0.32	-0.21	-0.13	1				
OS	-0.32	-0.29	-0.36	-0.17	-0.05	0.42	1			
SMS	-0.32	-0.33	-0.35	-0.23	-0.08	0.45	0.81	1		
NS	-0.19	-0.23	-0.24	0	-0.08	0.48	0.44	0.43	1	
CPS	-0.28	-0.28	-0.32	-0.13	-0.02	0.44	0.82	0.74	0.44	1

c) Polychoric correlation among likert-scale based variables/items

Figure 6.3: Correlation Among a) All Items, b) Binary-scale Based Items, c) Likert-based Items

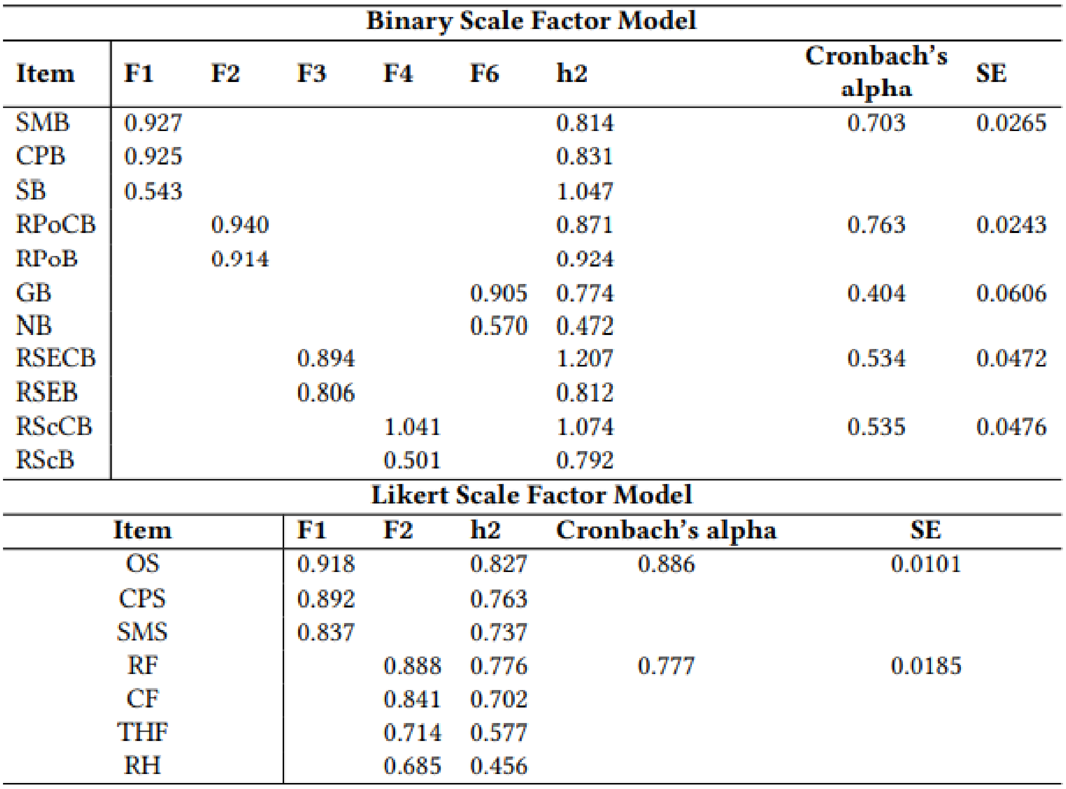
Survey Validation and PCA. As I separated all the items from screening into likert and binary scale based questions for clearer and more deeper understanding, I ran two separate statistical analysis to construct reliability and validity for both of these items. As our data was ordinal, calculations were performed on polychoric correlation matrices given that this is the recommended procedures when conducting EFA on categorical data [499]. In R package "psyche", the scaling thresholds as well as correlation were computed with function "polychoric" (Fig. 6.3 shows correlation among variables. The darker the shades of blue, the stronger positive correlation exists between the items. For binary and likert based items, I only included variables that had higher MSO values, which we have discussed below).

I calculated KMO factor adequacy for the items. For likert based questionnaires, the initial KMO value was 0.49. KMO is a test conducted to examine the strength of the partial correlation between the variables. As the KMO value is less than 0.5, this indicates that the degree of information among the variables overlap is unacceptable or has little to no correlation, in other words not suitable for analysis. To increase the KMO value for factor analysis, I removed some of the variables/questionnaires that had the lowest individual MSA (Measure of Sampling Adequacy) values (e.g., <0.45) in each iteration. After removing survey items, such as AF, SF, CH, SH, TH, and AH in multiple iterations, our final KMO value for final 9-item likert based questionnaires was 0.81, which showed presence of strong partial correlation. The result of Bartlett's test was $p < 0.001$, which indicates the variables in our dataset are strongly correlated, so a data reduction technique like PCA or factor analysis would be appropriate to use in terms of compressing these variables into linear combinations that are able to capture significant variance present in the data. I did similar reliability analysis on the binary based items from the survey (24 items), however, the KMO value for these items were extremely low (<0.27). Even after multiple iteration of removing items with low MSA (final count 18 items. Removed all access to certain technology related variables for lowest individual MSO), KMO value of 0.39 was yielded, which still was very low and indicated these items are not ideal to do factor analysis. However, we decided to report these results in order to investigate the outcomes that might be obtained when using PCA or EFA on these items as well as to critique the survey design.

A principal component analysis (PCA) was then conducted on these sample to determine the optimal number of factors to retain. A PCA oblique rotation (oblimin) was conducted on the final 9 item survey questionnaires (for likert scale questions) and 18 items questionnaires (for binary scale questions). For likert scale questions, the initial analysis on these items indicated two components be retained based on eigenvalues >1 that explained 63.26% of the variance in the sample. Factors with eigenvalues greater than 1.0 were kept and the scree plot was inspected as criteria to identify and retain underlying factors as suggested by the PCA. These results suggested two factors for EFA. Similar analysis on the binary scale items showed 6 factors models explaining 87.4% cumulative variance of the data.

Exploring Latent Factors through EFA. Within the development sub sample, an iterative exploratory factor analysis with oblimin rotation was conducted using the remaining items to explore the scale's factor structure and reduce the total number of items. In order to increase the factor analytic validity of the scale and to reduce the length of the scale, items with FLs below 0.50 were removed. There was no cross-loading in the model. Cronbach's alpha coefficients were computed for the remaining items to determine the internal consistency of the instrument.

Communalities of the 9-items ranged from 0.287 to 0.827 (Figure 6.4). For the items which had communality values less than 0.45 and loading less than 0.5 were removed from the factors for better results. We removed SS ("How safe do you feel in school?") and NS ("How safe do you feel in your neighborhood?") from the analysis due to having <0.5 as well as low communality (<0.45). Eliminating these items provided us higher cumulative variance (from 60.4% to 69.8%) and the communalities ranged between 0.581 to 0.888. After multiple iterations, we ended up with two factors model with comprised with 7 items. Domain one was measured by 3 items. They were OS ("How safe do you feel online?") with FL 0.949, CPS ("How safe do you feel on cell phone?") with FL 0.880, and finally SMS ("How safe do you feel on social media sites?) with FL 0.830. This factor was named as "Perceived Safety Online" and measures the extent to which adolescents scale their feelings of safety during online interactions and communications using modern technologies and online platforms. Cronbach's alpha for this factor showed strong internal consistency among the 3 items ($\alpha = 0.886$, se = 0.0101). The second factor was consisted of 4 items. They were CF ("Did you receive rude or nasty comments or texts from someone while you were online or on your



Binary Scale Factor Model

Item	F1	F2	F3	F4	F6	h2	Cronbach's alpha	SE
SMB	0.927					0.814	0.703	0.0265
CPB	0.925					0.831		
SB	0.543					1.047		
RPoCB		0.940				0.871	0.763	0.0243
RPoB		0.914				0.924		
GB					0.905	0.774	0.404	0.0606
NB					0.570	0.472		
RSECB			0.894			1.207	0.534	0.0472
RSEB			0.806			0.812		
RScCB				1.041		1.074	0.535	0.0476
RScB				0.501		0.792		

Likert Scale Factor Model

Item	F1	F2	h2	Cronbach's alpha	SE
OS	0.918		0.827	0.886	0.0101
CPS	0.892		0.763		
SMS	0.837		0.737		
RF		0.888	0.776	0.777	0.0185
CF		0.841	0.702		
THF		0.714	0.577		
RH		0.685	0.456		

Figure 6.4: EFA Results of the Binary Scale (Upper) & Likert Scale (Lower) Items

cell phone?") with FL 0.848, RF ("Were you the target of rumors or pictures spread online or on cell phones, whether the rumors or pictures were real or trues or not?") with FL 0.880, THF ("Did you receive threatening or aggressive comments while online or on your cell phone?") with FL 0.717, and RH ("Spread rumors or pictures of you online or on cell phones in the last year. How upset did you feel about it?") with FL 0.687. This factor was named as "Cybervictimization Frequency" and it measures how often certain types of online negative experiences, specifically targeted towards the victims by spreading/directly sending aggressive/harmful contents using online technologies, happen. Cronbach's alpha showed strong internal consistency among the 4 items ($\alpha = 0.777$, se = 0.0185). The inter-factor correlation between these two factor was (factor1, factor2): -0.408, which means they are inversely correlated in way that the more frequent online harassment or cyberbully happens, the less safe a victim may feel using technology.

A similar analysis was done on the items with binary values from the screener. After removing items with low FLs (<0.5) and low communalities (<0.45), we ended up with 6 factors with total 12 items. However, factor 5 only includes one item with low individual variance 8.7%. As it is recommended to have at least more than one item for each factor and each factor must only contain items explaining at least 10% of variance, we decided to not report results from this factor which only contained OOB ("I am only bullied in one of these spaces (either online or face-to-face"). Total variance explained by these 5 factors was 75.7%. Of these 5 factors, factor 1 was measured by 3 items. SMB ("I was bullied through social media") with FL 0.927, CPB ("I was bullied through cell phone") with FL 0.925, and SB ('I was bullied at school') with FL 0.543, This factor was named as "Technology Used for Cyber/bully", as it measures where or through which technology patients are getting cyber/bullied. Cronbach's alpha for this factor showed strong internal consistency ($\alpha = 0.703$, se = 0.0265). However, our calculation of reliability showed that if item SB is dropped, the value of Cronbach's alpha increases and becomes 0.710, which indicates that this item is not good to measure Factor 1. Factor 2 was named "Legal Reporting", which was created with item RPoCB (reporting cyberbully events to police) with FL of 0.940 and RPoB (reporting bully events to police) with FL 0.914. Cronbach's alpha for this factor showed strong internal consistency ($\alpha = 0.763$, se = 0.0243). This factor measures the latent construct of reporting behavior of patients, specifically to judicial system, against both traditional and cyber bully. The third factor was named "Informal Reporting" that included items RSECB (sharing/reporting cyberbully experiences to someone else like friends or siblings etc.) with FL 0.894 and RSEB (sharing/reporting bully experiences to someone else) with FL 0.806. This factor measures the reporting behavior of the patients, where they share their experiences outside of any traditional formal source (like parents/school/police) like to their friends or siblings with possible intention of getting mental/emotional support from them. However, Cronbach's alpha for this factor showed poor internal consistency ($\alpha = 0.534$, se = 0.0472). This indicates that items in this factor are poorly reliable to create a factor. The fourth factor was named "Academic Reporting", which includes items RScCB and RScB that screen patients whether they reported both cyber/bully experiences to school authority or not. Cronbach's alpha for this factor showed poor internal consistency ($\alpha = 0.535$, se = 0.0476) as well indicating poor reliability of the items. The last factor was also similar to the first factor, as it included items GB (bullied in online gaming) and NB (bullied in neighborhood). We named this factor "Location of Cyber/bully". Cronbach's alpha for this factor showed unacceptable internal consistency ($\alpha = 0.404$, se = 0.0606), which indicates that items in this factor are not reliable to create this factor.

Screening and Comparison Between Patient-Parent Data

To understand whether patient intake survey is correctly capturing the diverse spectrum of cyberbully experiences within adolescent patients much better, I decided to compare the patients' survey results with their parents' survey. As parents of these patients were also offered to take the screening survey (tailored specifically from parents' perspectives), majority of the questions included in the survey were same as the questions asked to the patients on the instances of cyberbully and traditional bully. For example, parents were asked to rank how safe their child(ren) feel in different spaces, just as it was asked to the patients. We observed some inconsistency in how parents responded to these questions vs. how patients handled these questions, which highlights the need of further explorations on the screening process on this issue.

Bullying contribution. As there was a higher instances of parent knowing the patients since birth, and majority of them were biologically related with the patients, I wanted to explore whether there is significant differences between parents and patients' perceptions of cyber/bully experiences as well as contribution of such events towards hospitalization. A significant differences between the opinions of cyber/bullying being the contributor towards patients hospitalization was observed. Parents seem to think cyber/bully acted as a contributor towards their child(ren)'s inpatient admission higher than their children. As we coded yes as 1, no as 2 and 3 as do not want to answered, the median value for patient group was 2, mean 2.19 whereas for parents it was median 2 and mean 2.06. The difference between their mean was significant <0.009 and the lower mean value means parents reported yes to the question as more frequently than the patients.

Perception over Cyberbully Victimization and Safety. I also explored how patient and parents interact with the cyber/bully and safety re-

Variable	**Median Score**		**Mean**	
	Patient	**Parent**	**Patient**	**Parent**
Frequency Report				
Comment/Nasty Rude Text	2	2	1.94	2.12
Rumor/Picture	1	1	1.65	1.69
Threat	1	1	1.57	1.86
Steal*	1	1	1.35	1.24
Attack	1	1	1.33	1.36
Feeling Upset				
Comment/Nasty Rude Text*	2	3	2.28	2.81
Rumor/Picture*	2	2	2.29	2.53
Threat*	1	2	2.13	2.47
Steal*	1	1	2.05	1.79
Attack	1	1	2.26	2.37
Feelings of Safety				
School	4	4	3.50	3.44
Neighborhood	4	4	4.06	4.13
Online*	4	4	3.67	3.49
Social Media*	4	3	3.61	3.37
Cell Phone*	4	4	3.82	3.54

Table 6.4: Mann-Whitney U Test Scores for Parent & Patients (N=331)

lated questions through the survey results. As the distributions of each likert scale based questions were not normally distributed, for these non-parametric distributions, Mann-Whitney U-test was used to test for group-wise differences by generation. From Table 6.4, significant differences can be observed between how patient feels or perceive cyberbully related events vs. how parents thinks their children perceive such events (significant values are indicated with an asterisk (*) mark for α=0.05). For example, there was a significant differences in how patients report the frequency of stealing happens in their lives vs. how parents think such events happen. Further explorations shows, patients report higher number of stealing frequencies than their parents think they face. Similarly, patients report significantly greater number for being upset for stealing events happened to them as compared to their parents. Interestingly, there was a significant difference between how patient and parent rank patients' feelings regarding receiving online comments/nasty texts, rumors/pictures, and online threats. While for physical bully, such as stealing, patients reported results were significantly greater than parents, for online based bully, parents reported scale was significantly greater than patients, indicating parents probable consideration of cyberbully as more severe than physical bully. Consequently, while comparing perceived safety of patients in different spaces, parents seem to think their children are less safer online (online, social media, cell phone) as opposed to offline spaces (school, neighborhood) as the U score shows significant differences between how patient ranked safety scale vs. how parents did. Therefore, there is an inconsistency between patient and parents on how they perceive cyberbully instances and its impacts on the patients.

Discussion

This study highlights the limitations and strengths of the existing cyber/bully screening tool for young and adolescent patients at PBH institute. The factor analysis was conducted to evaluate the instrument and also to reduce the large number of irrelevant variables to the number of possible manageable ones. The findings of this study emphasize the significance of creating a screening instrument that has been scientifically validated, assures patient-centered assessment, lowers the possibility of misdiagnosis, and triangulates data from both parent-child screening.

Patient-centered Engagement with Assessment

The results highlight considerable missing values within the dataset. Low response rates are recognized as evidence that a sample exhibits non-response bias and are often regarded as the most significant predictor of the representativeness of a survey sample and overall data quality [268, 370]. For analysis methods like machine learning, pattern recognition, or data mining algorithms in many fields, missing values are a common problem [542]. Unfortunately, missing values are inevitable in clinical data sets [179]. For these data sets, any patient records with incomplete data would be removed from a thorough case analysis. However, using solely complete patient data sets for clinical investigations results in a substantially lower sample size and less expressive statistical models [319]. Previous study showed the response to the NHS (National Health Service) inpatient survey tends to be lower amongst men, younger patients and non-white patients [251]. For surveys of particular patient populations, the evidence is more conflicting: some studies have found that older patients are less likely to respond [209, 527], while others have found the opposite [568], and others have found either no association with age [251] or that the youngest and oldest patients are less likely to respond [311, 487]. As the patient populations for whom this survey was designed target children and adolescents, it is possible that it has an impact on the response rate.

Structure of the survey can also have an impact on the missing values. While the use of skip sequencing reduces survey burden and time constraints, it has the potential to spread data quality issues across survey items, limiting informativeness of the tool []. As the target users of this survey are children and adolescents, it is important to focus on how the questions are phrased and formed to aid these patients who are already in an unstable mental and behavioral condition during admission. Health condition can have an impacts on how patients interact or engage with the survey. Previous research have discovered that patients who were severely distressed or was in bad condition health-wise when they were admitted to the hospital are less likely to reply to questionnaires [527, 311]. It is likely that such a condition could also apply to these young patients given that many of them were in critical health circumstances (e.g., suicidal, depressed) during admission; however, such correlations could not be established due to the lack of additional contextual information on this. The SIGCHI research community has been vocal about such challenges, advocating researchers to be more engaged with human-centered research by merging quantitative and qualitative methodologies to generate more in depth data-driven contextual knowledge [273, 586]. While computational approaches offer researchers access to large collections of data, the insights drawn may not have the depth of detail that qualitative approaches have added to the understanding of sociotechnical issues [56]. Since no follow-up measures were adopted after the screening (e.g., follow-up discussions/notes) to address the missing values or lack of engagement from patients, potential opportunities to contextualize such incidents in clinical settings in terms of patient engagement were lost.

It is critical to take into account the contextual constraints that frequently lead patients to avoid questions about their experiences with cyber/bullying during screening. For a lot of the same reasons why they don't ask for support after being bullied in person, young people don't ask for help when cyber/bullying occurs [639]. As a target, they feel humiliated or ashamed [639]. They fear retaliation and are afraid of coming out as a snitch and falling even lower in social standing [113]. Analysis of our dataset showed that while all the questions in our screening had missing values in it, certain variables, such as reporting related variables had higher instances of missing values. Many patients worry that disclosing this information may prevent them from using technology in the future, so they refrain from discussing them during screening [573, 242, 547]. Parents frequently digitally ground their kids and teenagers for disobedience. According to the Pew Research Center, 65% of parents have punished their children by removing their access to the internet or phone [51]. Young people are aware that if they report or discuss about bullying and harassment, their parents may delete their social media accounts, take away their phones, or otherwise restrict their access to the online social world. Patient engagement with the screening tool is therefore more likely to be poor, and the likelihood of missing values in the dataset to be high.

Missing data can reduce the statistical power of a study and can produce biased estimates, leading to inaccurate diagnosis and treatment planning for patients in clinical settings. In order to better understand patients' experiences with cyber/bullying, it is crucial that we discuss this issue with them and identify whether this missing value is at random or not, and thus, modify the screening process and screening questions accordingly.

(In)efficacy and Quality of Data

The findings demonstrate that this inpatient patient survey provides insufficient statistical assurances for the intended use. The overall effectiveness of the tool could not be justified since there was no precise theoretical foundation upon which this survey was built and the quality of the data collected was not good enough to measure core concepts of cyber/bully. While some of the variables in our data-set showed strong correlations between them, many of them did not share that trait. This made it harder to measure the reliability and validity of the screening tool as the low correlation coefficients mean that the manifest variables are not related to underlying latent variables or are not good enough to measure underlying concept of cyber/bully [289].

As this study includes two models for variables with different scales (likert and binary), compared to likert scale based questions, binary scale based variables did poor to measure core themes related to cyber/bully. Since they had lower MSA values, it implied three major flags of these poor items: first, and above all, it is possible that these items are "noisy" and behave almost at random, and, therefore, lack discriminating power; second, the tool included "redundant" items that share specific content with other items in the pool [380]; and third, as these items contained majority of the missing values, it has possibly impacted the quality of results they produced. For instance, the screening tool included questions about identifying the individual who bullies them either offline or online, or in both spaces. I removed these items from the analysis because they had MSA values that were extremely low (<0.2). Possible reasons behind such low value can include: one, the way these questions are formed are confusing, and two, they are not measuring the value they are supposed to measure. However, deleting items with weaker individual MSA value did not enhance the overall MSA values, indicating that items with binary scales were not suitable for assessing patients' experiences of cyber/bullying. In terms of quantifying latent components, variables with likert scale values performed better. Even though the KMO value for these items was initially poor, the score became substantially better ($>$0.8) after dropping the items with low MSA values during measuring the adequacy of the sample in the study. For example, after dropping items that screened for how frequently physical forms of bullying instances happened with patients, the KMO value of the model increased. Previous research have explored the associations between cyberbully and physical bully, and shown that individuals who experience cyberbully, also experiences physical form of bully in school or other physical space [326]. As youth frequently mix their offline and online lives, there is a high likelihood that if someone is experiencing cyberbullying, more bullying is also occurring offline and vice versa [326, 91]. However, findings from this study indicates that physical bully related items, more specifically, frequency of physical bully related items are insignificant and do not measure the expected results from the patients in this clinical settings.

A commonly used rule is that there should be at least three variables per factor [628] and while EFA yielded similar findings for the likert based items, it was not the case for binary variables. Majority of the factors (except one) for this model had less than three variables, which makes it hard to interpreter the latent factors. The component "Location of Cyber/bully" was the only construct with three items, such as bullied at school, being cyberbullied on social media, and being cyberbullied via mobile phone. These items had substantial positive loadings on this factor. It's important to keep in mind that this factor does not include items that measure physical or online bullying in spaces like neighborhoods, chat rooms, or specific online games, indicating that these variables are either not significant or do not have a strong relationship with other things in this factor to create this construct.

The results of the EFA on likert scale variables yielded two factors: "Perceived Safety Online" and "Cybervictimization Frequency". The Cronbach's Alpha Reliability of this two factors were 0.777 and 0.886, which shows strong correlations between items or factors. The factor "Perceived Safety Online" includes items that only focus patients' perception of safety during their interaction and communication through platforms like social media, general online space (e.g. chat rooms), and cell phone. It's important to note that, similar to factor "Location of Cyber/bully", this factor also disregarded items that focused on perceived safety in physical space like school and neighborhood, which supports my previous observations and indicates that items that focus on the physical aspect of the questions, do not do good in the survey and are not measuring the quality data. This finding also adds to the existing literature on the connection between the victim of cyberbully and perceived safety concerns. According to Sourander et al. [569], cybervictims scared for their safety. Another study showed, students who were victims reported feeling significantly more unsafe than students not involved in cyber bullying [240]. Items that largely focused on cyberspace-related issues outperformed offline or physical form-related questions, indicating that patients may not have properly conceived traditional bullying questions or that the questions are not significant enough to be included in the screening. Similar finding was also observed for the construct "Cybervictimization Frequency". This factor included online or internet based bullying frequencies related items and excluded items with physical bully related victimization.

While two factors model is fairly common in cyberbully assessment studies [184, 129], this survey failed to address some of the core concepts of online bullying that is important to explore within patients who are victims. For example, previous research on existing Online victimization scale (OVS) suggested 4 factor model that includes general victimization, sexual harassment, individual racial discrimination, and vicarious racial discrimination [601]. 4 factor model was also validated by previous study that assessed cybervictimization through latent factors of written-verbal, visual-sexual, online exclusion, and impersonation forms of bullying [46]. While this screening tool did include questions about threats, spreading rumors, and harsh or ugly comments, it did not include any screening for sexual, online exclusion, or impersonation forms of bullying, which is an important component of the definition of cyberbully.

The results of this study are instructive because they shed light on the data quality and effectiveness of the screening tools used at PBH instute by examining which questions are associated and produce latent factors to evaluate patients' experiences with cyber/bullying. Even though the factor analysis of questions using binary scales did not produce any relevant constructs, it did offer us an indication of how (in)validated and (un)useful these surveys were for measuring latent cyberbully constructs.

(Dis)Agreements Between Parents and Children Screening

Based on the findings, there is considerable differences or disagreements between patients and their parents in terms of how they report cyber/bully related experiences using the screening tools. Specifically, out of 331 patients, only 53 reported cyber/bullying as a contributing factor to their hospital admissions (around 16.5%) as opposed to their parents (24.3%) and the Mann-Whitney test scores indicates the differences in their scores are statistically significant. Similarly, there is also significant differences between these two groups in terms of how they report physical bully vs. cyberbully frequency, feelings, and safety related questions. Parents in our study seem to think their children struggle the most with online based bullying compared to what their children report through the tool. It is possible that children who are going through traumatic experiences, like cyber/bully, may not always accurately report their internalising behaviors or experiences (i.e. private or sensitive experiences and thoughts) [527, 311]. While the screening tool under investigation in this study attempts to gauge the extent to which cyber/bully events have negatively affected their patients' lives, both physically and psychologically, focusing solely on the youth inpatient test may not necessarily produce the best outcomes. Questionnaires completed by both the parent and child can serve as beneficial supplements to the clinical interview and are increasingly being utilized as screening tools in the assessment process [561]. However, in terms of reporting a problem, having differing outcomes or disagreements between patient-parents are nothing new [160]. Several different assessment methods, such as structured and semi-structured interviews, rating scales, and questionnaires [160, 29], have shown to have low parent-child agreement.

Children and adolescents may be more hesitant to acknowledge they are being cyber/bullied in front of their parents for fear of having their online time limited or their electronic devices taken away [573, 242, 547]. Restrictions might feel like more mistreatment and may exclude teenagers from a source of social support as technology advances and they grow more reliant on their electronic gadgets for social connection. Although the purpose of utilizing a screening tool is to determine how severely or to what extent young and adolescent patients are exposed to cyber/bully events, it's probable that screening patients alone won't be sufficient owing to their reluctance to be honest about their online activities. Additionally, the pattern of different reports between parents and adolescents may also be influenced by variations in item wording and scale length [72]. The parallel nature of the scales is unimportant if what is sought is a parent's perspective on their child's cyber/bully experiences; however, if what is required is for the parent to provide a proxy report of the child's cyber/bully experiences, i.e., one that can substitute for the child's report, then it is crucial that the measures be parallel [611], as is the case at PBH institute.

When children are unable to provide self-report, reliable and valid parent proxy-report tools are crucial primary outcome measures [611]. Researchers and clinicians should carefully assess what they hope to accomplish by using a parent-completed report and must modify the questionnaires to include the proper components and examine feedback from both patients and parents, as data triangulation like this increases the validity of the findings [516].

Implications for Misdiagnosis and Missed Diagnosis

Screening is an important part of preventive medicine. However, the lack of a reliable screening tool and accurate information regarding patient experiences may make it challenging for healthcare providers to produce an informed diagnosis and provide patients with individualized care for better health outcomes. Social computing community has long been intrigued by the difficulties and complications that come up when handling patient related data in highly collaborative hospital systems and teams [493]. Yet, the ability to use accurate data for collaborative decision making in healthcare to provide the best and most informed treatment to patients, subjected to cyber/bullying, is currently limited and complicated. Due to the current screening survey's failure to detect the core constructs of cyber/bully incidents in youths, such as identifying types of verbal/sexual/written/visual cyberbully patients are facing, involvement with cyberaggressive behaviors, anonymity, or power imbalance they face [463], it may only evaluate a tiny fraction of patients during screening, potentially overlooking significant mental and behavioral implications of these events limiting physicians' ability to work with their patients.

HCPs should review their patients' clinical intake forms to ensure that proper questions related to cyber/bullying are included in the screening. The first stage in choosing or developing a screening tool in healthcare is to decide on two crucial factors: the patient types you want to concentrate on and the health issues you often discuss with those patients [223]. As the current tool aims to address cyber/bully-related issues in younger patients, it is vital to investigate what prior studies have revealed and what pertinent critical concerns have frequently been noticed while interacting with this particular patient group. Even though clinicians might want to predict their patients' mental health indicators by gathering accurate data, doing so without first verifying and validating that certain behaviors measured by asking the questions are, in fact, good indicators or proxies can lead to inaccurate information or patient misdiagnosis [55]. To guarantee the construct the providers are seeking to capture, the key concern is how valid the measurement is for capturing cyber/bully. For example, HCPs working with teenagers should be aware of the strong and distinct link between cyberbullying and suicide [451] and include self-harm and suicide based screening questions [327], which are currently absent from the tool. Not asking patients who have been cyberbullied about self-harm can cost providers the chance to identify patients with suicidal thoughts and other mental health issues early on. Early detection and treatment of mental health issues can enhance quality of life, lower medical expenses, and lessen problems from co-occurring behavioral and physical health conditions [422].

Limitation & Future Work

The study has some limitations. The first limitation is related to the method of analysis. Exploratory Factor Analysis (EFA) is an advantageous statistical method used to examine the construct validity and psychometric properties of an instrument. However, a Confirmatory Factor Analysis (CFA) should be conducted to further the knowledge in this area [640]. CFA allows the researcher to test the hypothesis that a relationship between observed variables and their underlying latent constructs exists. Additionally, while the items dropped from the analysis to build factors may not have validity in the tool, they might have clinical importance and needs to be discussed/raised during screening or discussions with the providers. Future work should also unpack this and focus on how we can reform/rephrase the questions to ensure reliability. The second limitation is the response bias during screening. As the patients were allowed to skip questions or the entire screening, total complete cases within dataset were very low, which could have impacted the overall results of this study. While Unbiased results can be obtained even with large proportions of missing data (up to 90% shown in our simulation study) [387], provided the imputation model is properly specified and data are missing at random, we could not confirm whether this missingness was random or not. Further explorations need to be done to ensure why there is huge missing values in the dataset and what can be done to limit the frequency of this missingness. However, the missing responses are to be expected as they were collected during the intake process to an in-patient mental health facility. There are valid health reasons that would keep youth from adequately answering or completing this questionnaire. Future work could focus on the clinical workflow, assessing completeness of data if the screener is deployed at different times of the in-patient stay (e.g. at discharge, after 12/24 hours, etc.). In addition to this, it should be acknowledged that the sample used in the present study should be considered to represent the majority of White or Caucasian populations who are primarily from suburban and rural areas. Hence, readers should exercise caution when generalizing results from the present study to general populations from different demographics. Since the outcomes of this study showed strong potentials for screening young patients for cyber/bullying in clinical settings, future research should investigate how these data are incorporated into the system and used by clinicians to provide improved clinical guidelines for the patients.

Conclusion

This study seeks to investigate the existing assessment process of technology use-related negative experiences, such as cyberbully, among adolescents in clinical settings. By examining the validity, reliability, and interactions of PBH institute's youth intake patient screening instrument and the supplementary parent survey they offer, the study focuses on how adolescent cyber/bully experiences are screened during patient intake. As there is no single, universally accepted scale that can be used to measure all important socio-cultural factors that contribute to different cyberbullying experiences and the mental and physical harm they cause younger populations, the effectiveness of the assessment procedures currently being used at various healthcare facilities to help younger patients who are having difficulties has not received much attention. This study implies several shortcomings in the current operationalization of cyber/bully screening for diagnosis in clinical settings from the perspectives of the quality of the screening instruments or how the data is collected at hospitals, the reliability and quality of the collected data, and the faulty/invalidated screening instruments and data that can result in misdiagnosis and missed diagnosis. By highlighting the present limitations and implications of using a validated screening tool to assess cyber/bullying among teenagers, this study adds to the conversation of integrating socio-technical knowledge and human-centered designs principles to clinical practices.

CHAPTER 7 - INTEGRATING DIGITAL SIGNALS OF CYBERBULLY INTO PATIENT'S EHR- A PROPOSED ASSESSMENT WORKFLOW

Introduction

It is beneficial to screen adolescents for involvement with cyberbullying when they are admitted to a healthcare facility [605]. Knowing that a patient is being bullied by peers, and that cyberbullying in particular has a particularly negative impact on their well-being, screening for such events should be incorporated into a healthcare practitioner's treatment plan. Since victims of bullying and cyberbullying typically may not want to talk about their situation, especially with adults, healthcare professionals should be equipped with information about probable indications and symptoms to be aware of [605].

However, many healthcare providers lack the capacity, workflows, and incentives needed to create systematic screening for socio-technical concerns like cyberbullying among their patients [161, 31]. There are presently no standardized procedures or workflow across health systems for treating social and behavioral domains, such as cyberbullying or other equally dangerous online activities, among highly vulnerable groups [599]. Many healthcare providers are even reluctant to screen patients for bullying involvement because they lack education and training on bullying prevention [410]. Providers express concern about not understanding how to ask the questions and may be hesitant to inquire about social problems in the absence of a standard protocol [453, 556, 599, 475]. Efforts to incorporate social-factors questions into clinical practices can take advantage of the increasing utility of EHRs to potentially help remove personal discomfort and distinctive variation among patients and providers, while also allowing flexibility to address patients' unique social needs and identify and track relevant community-clinical linkages [243, 263, 264].

Therefore, in this chapter, I propose design recommendations that add to the existing assessment process of screening online risky behavior and experiences, such as cyberbullying, within adolescent in clinical settings and seeks to develop a comprehensive blueprint/workflow for integrating and accessing information from the screening into patient's EHR.

Cyberbully Screening and Clinical Workflow

Cyberbullying is a common issue that has serious repercussions for teenagers and young adults' physical, mental, and behavioral health [121, 332, 414]. Since cyberbullying often goes unreported [34], it is even more important to screen and be able to recognize the potential for victimization. If cyberbullying victimization is suspected, a comprehensive evaluation of the adolescent's use of technology, as well as risk factors for and experiences with cyberbullying, should be conducted by the nurse or healthcare professionals [137, 121]. However, integration of such a comprehensive assessment tool is challenging, as it can cause survey fatigue or respondent fatigue within the patients [365], which is a well-known event in academia as well as in the healthcare domain that occurs when respondents lose interest in the survey they are taking and give unsatisfactory results or withdraw prematurely [180, 365].

Despite the fact that adolescents and clinicians are open to risk behavior screening in all settings and prefer electronic screening to a face-to-face interview, prior research shows that risk behavior screening and treatments are underutilized in emergency rooms and hospitals [488]. According to [475], many healthcare practitioners are unable to identify and treat their patients' online activities linked to dangerous health behaviors because of the age gap between them and their patients as well as their discomfort with technology. Nurses and health care professionals need to be aware of the impact that technology and internet use have on adolescent health. There are certain adolescents who are at a higher risk of being bullied, therefore early detection is important and a significant step for the provider to take [63]. Adolescents who are overweight, have a physical or mental impairment, are from a low socioeconomic background, are of a specific racial background, or are members of the LGBTQ community are more likely to be bullied during their adolescence [395, 301, 28]. Adolescent risk behavior screening that is inconsistent or inadequate in these contexts may lead to lost chances to intervene, decrease risk, and enhance health outcomes. There are presently no standardized procedures or workflow across health systems for treating social and behavioral domains, such as cyberbullying or other equally dangerous online activities, among highly vulnerable groups [599].

Workflow refers to the interaction of processes (made up of tasks) performed independently or collaboratively by the various agents/entities through which a clinic or hospital provides health care to patients [241]. The agents in a clinical system include but are not limited to, clinicians, technologies, and care delivery processes. Researchers in the field of health services have explored workflow challenges from a variety of perspectives, including mapping processes from other sectors (quality improvement, technology implementation, and process improvements) into health care [134]. Good workflow design has substantial (anticipated and unforeseen) effects on care delivery, and conscious workflow design has been proven to increase the efficiency of existing work processes or allow for job parallelization [135, 134]. Because of the complexity of most healthcare organizations and the separation of labor into specialist roles, workflow design is a challenging task.

Many hospitals and medical practices struggle to appropriately integrate social components and behaviors into patient's EHR since prior to deployment there was no thorough investigation of healthcare workflow [68]. The workflow for behavioral health integration (BHI) may differ from organization to organization depending on factors such as practice size, patient population, current staff capabilities, technology, and resources, etc. [6]. Because the same EHR model may not work for every medical institution, it is critical to create a systematic EHR that seamlessly fits into the workflow pattern of that specific medical organization. User competence and adaption are fundamental to the adoption of EHRs [147]. EHRs run the risk of slowing down practice, hindering clinical communication, jeopardizing patient safety, degrading clinical quality, and severely impacting the patient experience if the skills of using EHRs are not adapted properly.As a result, HCPs must consciously dedicate time and effort to becoming adept in the use of EHRs so that they can be easily incorporated into their clinical practice. Some steps need to be followed during the healthcare workflow analysis to implement the EHR system better. They include: 1) mapping of processes, 2) direct observations, 3) focusing on time and resource-consuming tasks, 4) multidisciplinary workflow analysis, 5) review of the mapping process, and 6) designing the EHR with a team of multidisciplinary healthcare providers [458, 68, 241]. These suggestions can help medical facilities build a functional EHR system that incorporates socio-technical elements linked to cyberbullying more systematically and logically. The analysis of the healthcare process should never be ignored; otherwise, the EHR's failure is virtually guaranteed from the start.

Thus, I designed a qualitative study that includes interviews, card sorting activities, and direct shadow observation of different multidisciplinary healthcare providers working at PBH institute in a youth inpatient acute care facility. The focus of this study is to facilitate healthcare providers in assessing and addressing cyberbullying experiences within their younger patients by suggesting a reformed design structure/workflow and screening protocols. To do that, I address the below research questions:

- **RQ1:** *How can we refine/improve the existing screening tools for cyberbully experiences within adolescent patients?*
- **RQ2:** *How can the screening data be integrated into the patient's EHR, so that there is a structured workflow for the providers to access and address the information on their patient's cyberbully experiences?*

Clinical Contexts: The Current Screening Tool

My previous research in chapter 6 has highlighted the importance of refining the current assessment tool used at PBH for screening cyberbully experiences within young patients. As discussed in chapter 6, there are some limitations in the current cyberbully screening tool that have a major impact on what information is screened from patients in clinical settings, I have focused on recommending potential adjustments and revision to improve the tool and the quality of data it produces using multiple data sources for clinical perspectives as well as my own previous research findings. The information about the current patent intake screening employed at PBH institute has once again been updated for the readers' convenience below.

Patient Intake Survey

The current screening tool for intake patients is a 12 items tool designed to assess both cyberbully and traditional bully related experiences within adolescent patients who get admitted at inpatient care at PBH institute. Patients have three options for taking the survey: 1) in front of their guardians, 2) alone themselves, and 3) with a nurse's assistance. The details of the tool is provided in Appendix D1. Each of these 12 items are further divided into multiple sub-items. For analysis purpose, I considered each of the options/sub-items as separate questions, which gave me total 43 items. Patients can report how they rank their experiences of being bullied and report those events with 5 point scale (ranging from 1 being never/never being upset/not safe at all to 5 being every day/extremely upset/extremely safe) and yes/no, check/uncheck values (only exception one item with values yes/no/don't prefer to answer). All the items under cyberbullying and bullying frequency and feelings subscale and 5 items under safety sub-scale include likert based questions.

Methods

This study is part of a larger research initiative at Parkview Behavioral Health Hospital and was approved by the hospital's IRB. This was possible based on the surveys being a part of the standard of care in Parkview's Youth Behavioral Health Hospital. Although Parkview Behavioral Health Hospital offers three versions of this screening tool (an inpatient survey for the patient, an inpatient survey for the parent, and a discharge survey for the patient) for the youth facility, for the scope of the dissertation, I primarily focused on refining the inpatient youth survey for the patient, as 1) this is the primary screening tool that providers refer to, 2) the parent survey's questions are almost an exact replica of the inpatient patient survey but are phrased from the perspective of the parents. So, refining the patient survey will serve both purposes.

This qualitative study included participant interviews, card sorting, and shadow observation to investigate what screening and workflow-related concerns and challenges can arise in an inpatient adolescent patient facility. By triangulating data from multiple sources, I aimed to extend current clinical practices and build a design framework that includes not only an improved screening tool for adolescents with key social, cultural, emotional, and technical elements related to cyberbullying experiences, but also a curated workflow for providers facilitating better treatment that addresses issues such as standard data collection process from adolescent patients. Data was collected from May 11th, 2022 to August 25th, 2022.

Recruitment

To recruit providers for card sorting activities and interviews, I contacted a number of key stakeholders (two providers) at the Parkview Behavioral Health Institute who are in charge of leading clinical teams that interact directly with adolescent patients in inpatient settings. Using their internal network and snowball sampling approach (at the culmination of each interview), I uncovered a variety of subject matter experts to recruit for this research.

Participant ID	**Participant Occupation**	**Practice and Responsibility**
P1	Behavioral Health Specialist	1. Mostly facilitate group interventions 2. Need based one-to-one counselling 3. Documentation
P2	Nursing Services Manager	1. In charge of the team and problem solving 2. Implementation and development of policies and standards
P3	Director of community support services & Registered Nurse (RN)	1. Grant writing 2. Day to day interactions with patients for medications, referrals
P4	Nurse Lead	1. Work on the floor and provide patient care 2. Help the manager in administration work 3. Handle all documentations and processes during patient admission, and discharge
P5	Behavioral Health Specialist	1. Work with patients day to day 2. One-to-one counseling for specific panel of patients
P6	Therapist	1. Handle patient care 2. Conduct group and family therapy 3. Participate in treatment planning for patients

Table 7.1: Participants Details for Interview & Card Sorting Activities

Participants

In total, six providers agreed to participate in my card sorting activities and follow up interviews. Table 7.1 provides a full list of these participants and aspects about their practices. All of the participants worked for PBH Institute and were employed as behavioral health specialists, registered nurses, therapists, or nursing managers etc.. During shadow observation, I followed a range of healthcare professionals who had specialized duties and interacted with the young patients on a daily basis as multidisciplinary care unit. As in occasions, multiple providers collaborated (e.g., during treatment planning), I emphasized more on the provider roles during those observations, as it allowed me to contextualize my data and gain insights on the internal workflow. The roles and responsibilities I followed during shadow observations are described below:

- **Mental Health Technicians:** work on the floor and keep a chart of day-to-day activities of the patients
- **Healing Group Therapist:**Therapist who works with the patients through art. Does not directly talk about issues, but let patients to acknowledge their issues through art
- **Group Therapist:** Therapists talk to the patients in groups and try to address issues based on themes (rating the treatment, how they feel etc.). Groups are created based on compatibility (girls vs. boys, similar ages, similar experiences etc.)
- **Nurse Practitioner:** She talks to patients one to one and does daily updates with the patients. Keeps updates on the medications, the issues they are facing and so on.
- **Registered Nurse:** She oversees all the activities of the nurses, helps with patient admission, discharge, form fill-ups, medications, treatment planning, educational resources
- **Family Therapist:** Tries to get a full picture of the issues patient is facing by talking to both patient/guardians, addresses issues and tries to explain to the patients, works on probable ways to work on the issues

- **Treatment Planning Group:** therapist, counselor, Nurse make a team and talk to the patients about their overall progress, refer to the forms they have filled up, answers questions, create treatment plans curated for the patients based on their performance, screening and all

Data Collection and Analysis

Card sorting. Card sorting method was used for data collection to uncover how the providers' domain knowledge was structured around the cyberbully screening tool implemented at PBH [554]. More specifically, I followed closed card sorting structure [655] where the participants were briefed beforehand and given a predetermined set of category names that were related to the core concepts of cyberbully (e.g., types of bully, frequency, technology used, consequences, coping and reporting strategies etc.), and they were asked to organize the individual cards, in this case individual questions, into these predetermined categories. These specific questions were taken from various cyberbullying screening tools already in use in various fields (academic institutions, anti-bullying organizations, websites, etc.), and each question within a given category differed from the others in terms of the question's structure, the options offered for it, the way it was phrased, etc. This gave the providers a wide range of options to choose from. This method helped me to explore how well an existing category structure supports the content, from a provider's perspective. As the participants were asked to rank the questions from best to worst based on their own knowledge and perceptions, it helped me identify the questions that would be most helpful for the patients as well as the flaws in the screening tool that PBH currently uses.

The average time spent for this activity was around 25-35 minutes. As the card sorting was done online, categories were shared through Microsoft Team's interface where the questions under each category had an associated number. Providers were asked to rank those based by referring these numbers. While I moderated the activity, another researcher helped me noting down the results from the activity. The card sorting included eight categories, each of which contained a number of cards or questions sourced from various existing screening tools. The tools I took reference from were: [344], [18], [544], [288], [418], [46],[601], [375], [10], [9], [473], [472], [376], [280], [14], and [304]. As these tools were either validated or have been used in similar settings, I decided to include them in the card sorting activity. The categories included in the card sorting were: types of cyberbully, technology used, frequencies of cyberbully, consequences/feelings after cyber/bully, coping strategies, reporting strategies, bully identity, and external factor for being bullied (please check Appendix E1 for details). Because different categories or themes had a variable amount of questions, the scoring scale varied accordingly (e.g., 1-5 or 1-7 where 1 being the best and 5/7 being the worst). The providers also shared their reasoning and explanations of choosing certain questions over other while conducting the card sorting, which provided us additional information on their thought process. Data collected from these questionnaires were analyzed using basic statistical analysis methods (mean, standard deviation, percentage).

Semi-structured Interview. Online semi-structured interviews were conducted with the participants as follow up of their card sorting activities. The interview lasted in average for about 15-20 minutes. There were total 6 primary questions while each having multiple sub-questions (for reference, check APPENDIX E2). The themes of the questions included their responsibility at PBH, their interactions with the screening tool and patients, their perceptions of the current tool and process of using the data, and improvement recommendations.

I used an inductive thematic analysis approach to review of the interview transcripts. As the interviews were semi-structured and typically included the same list of questions focused around a fairly narrow set of topics (such as inconsistent data integration, language barriers within the scale), some themes that consistently arose without being directly asked (such as information gap between providers, clinicians' knowledge on patients' screening and related resources, challenges of integration and so on).

Shadow Observation. As another qualitative research method, I performed shadow observation [397] of the staff at PBH's inpatient adolescent unit for a total of 14 hours over the course of four days. I investigated what various professionals—therapists (described in previous section), nurse practitioners, mental health techs, etc.— do or how they interact with their patients in daily basis, particularly when it comes to cyberbully screening.Data collected through this method were recorded as field notes by me and another Parkview Research Center researcher, and were later sorted into key themes that tied back to cyberbully screening and the inherent clinical workflow that goes behind it. There was no interference from us during data collection, which could have disrupted the natural process of conducting activities in the facility.

Results

In this section, first, I give a brief description of the overall PBH inpatient treatment programs that aim to offer support to youth whose mental health require short-term intervention in a supportive environment. This process was outlined based on data collected from the shadow observation. Second, I discuss the findings from my card sorting activity and provider interview to outline the specific implications for an improved screening tool. Third, I review the clinical process around cyberbully screening followed at PBH while identifying the problem classifications using data interview, card sorting, and my shadow observations.

PBH Service Overview

Through their highly skilled, interdisciplinary staff of psychiatrists, social workers, nurses, and mental health technicians, PBH's primary purpose is to establish a unique treatment plan for each patient in order to support healing and recovery. Treatment plans may incorporate a variety of mental health tools, including family therapy, group interaction, therapeutic recreation, medication and other approaches. When patients finish the treatment program, these tools, together with further outpatient therapy and resources, assist in paving the way for healing and recovery. While inpatient facilities provide patients with tailored treatment plans in a therapeutic setting with few restrictions, the program is typically organized around specific intervention strategies that support patients in addressing their unique challenges. Usually, the inpatient treatment program at PBH last for about 5 days in average for patients. Each day is structured around a specific set of interventions (Figure 7.1) that aid patients in developing the behavioral and cognitive abilities necessary to handle their own challenges.

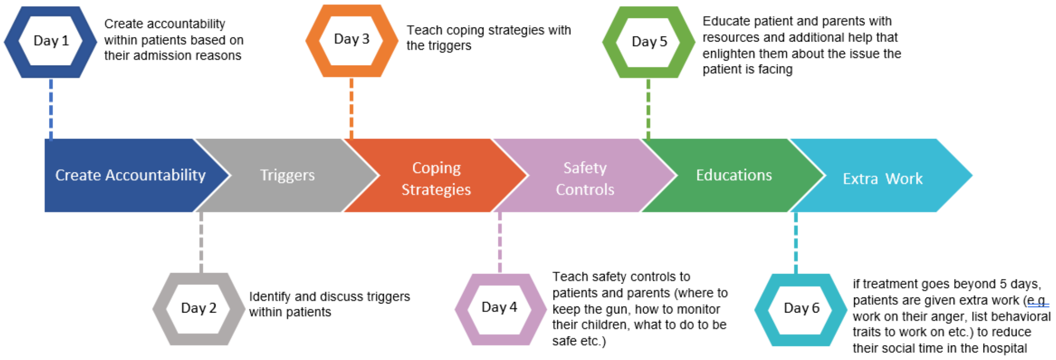


Figure 7.1: Process of PBH service

Day 1: Day 1 is focused on creating accountability within patients based on their individual admission reasons. Accountability in this settings refers to ones willingness to be honest about their behavioral and cognitive concerns and the choices they have made concerning it. The goal is to create a sense of responsibility for their actions that may harm them or others around them. Different activities like filling out surveys, listing their behaviors/actions, discussing these issues in group therapy are part of the intervention.

Day 2: The focus of the 2nd day is to identify and discuss triggers with the patients. Adolescents may have a cascade of emotions provoked by their experiences, such as helplessness, immediate danger, betrayal, alienation, or the drive for retaliation, for which many of them are admitted in this facility. The goal is to raise awareness by teaching them how to recognize these predisposing factors that may activate painful or harmful/risky actions in the real world.

Day 3: As a continuation of day 2, on day 3, the patients work on the coping strategies for their individual triggers. The goal of these coping strategies is to eliminate, avoid and reduce the impact of triggers and emotional reactions in the patients. Interventions through group therapy and one to one conversations with the nurse practitioners help individual patients to learn more about these coping strategies that can help them with emotional, behavioral, external or internal triggers.

Day 4: Day 4 focuses on teaching different safety controls to both patients and their parents/guardians through family/group therapy, one-to-one discussions. As children are often open to engage in risky behaviors, the interventions at PBH focus on guiding and providing age-relevant ways to approach these experiences.

Day 5: The 5th day, which is typically the day patients are released from the hospital, is mostly dedicated to providing patients and parents with resources and any extra referrals or assistance related to the issue(s) for which the patient was admitted. The objective is to influence patient behavior and provide the knowledge, attitude, and skill adjustments required to maintain or improve health. These resources may include fliers, posters, outpatient referrals, website links, information on social workers, NGOs, or specific programs that may assist patients in addressing behavioral and cognitive issues.

If the interventions and treatment seem not to work properly for any specific patient, they are not discharged and asked to stay longer to work on their issues. Activities include extra loads of work with limited social times for patients.

Provider Perception on Cyberbully Assessment in Clinical Setting

My findings reveal several major challenges around implementation of cyberbully screening in clinical contexts. Although PBH has adopted mechanism to assess young and adolescent patients to gauge their exposure to both traditional and cyberbullying, the providers expressed some concerns about the way the screening questions are structured and the information are shared within the multidisciplinary care team in this inpatient facility.

Card Sorting Results. The primary goal of the card sorting exercise was to determine the optimal structure for a question under several topics or fundamental principles linked to cyberbullying. While some of the aspects of cyberbully were already in the current screening tool, I added others based on my own study and current literature. The current tool, for example, only inquires about one aspect of the emotional consequences of being the target of cyberbullying; however, the card sorting activity included additional aspects such as behavioral impacts, coping strategies, and external factors to gather more information on the patients' cognitive, behavioral, and contextual background.

I segmented the card sorting activities under eight themes and the providers ranked the best to worst questions under each of those themes. The results of the best and worst question selected by the providers are given in Table 7.2 below that include their average rank, and highest agreement rate within providers. Each of the topics mentioned in Table 7.2 had different number of questions and providers ranked them based on their language, options, structure preferences. The table includes only the best and worst ranked questions based on the average rank calculated. Highest agreement rate was calculated based on how many providers came to an agreement on a specific rank for that specific question. The maximum agreement rate across providers ranged from 33% to 100%, while the average rating ranged from 0.5 to 6.5. Because

Topic	Best Question	Avr. Rank	Highest Agreement Rate	Worst Question	Avr. Rank	Highest Agreement Rate
Types of Cyberbully	Q 3	2.3	33%	Q 7	5.5	33%
Technology used for Cyberbully	Q 7	2.0	50%	Q 6	6.5	67%
Frequency of Cyberbully	Q 4	2.0	33%	Q 5	4.0	83%
Consequences/Feelings After Cyberbully	Q 4	2.3	50%	Q 3	3.0	50%
Coping Strategies	Q 1	2.0	67%	Q 3	2.6	50%
Reporting Strategies	Q 3	1.5	83%	Q 1	2.5	83%
Bully Identity	Q 2	1.5	67%	Q 1	2.5	67%
External Factor for Being Bullied	Q 1	0.5	100%	Q 2	1.0	67%

Table 7.2: Results from Card Sorting Activity with the Providers

each themes had a different number of questions, the average rank scale fluctuated. If the average rank is low, it means the question has received better ranking from the providers. It's interesting to note that several of the questions with the worst ranking had the same formatting, options, and languages as the questions that are included in the current screening tool. For example, the worst rated question under types of cyberbully is Q7 which says "indicate how often you've been victim of the following situation in last 3 months (1=never; 2=rarely;3=often;4=always). This is quite similar to how the existing screening tool looks for instances of cyberbullying in patients; the structure is complicated and demands more in-depth patient attention, which might not always be possible in that setting. Instead, the providers recommended to choose the structure of Q3 that is straightforwards, provides multiple options with enough details.

For question under the theme of technology used for cyberbully, the best rated question was Q7, whereas the worst rated was Q6. While both of these questions were multiple-choice, the structure of Q7 was more direct and had more choices than Q6, which was structured in a passive phrase and had relatively limited options. For the frequency of cyberbullying, the highest rated question was Q4 and the lowest rated was Q5, which also had one of the highest provider agreement rates (83%). The layout of these questions differs substantially, as one included several categories alternatives to choose from (ranging from never to almost every day), whereas the other did not contain any options and left it open-ended for the patient to fill out. For consequences/feelings after cyberbully theme, the best rated questions was Q4 (average rank 2.3), whereas the worst rated was Q3 (average 3) with both having 50% agreement within providers. While Q4 offers a clear inquiry with a wide range of emotional and behavioral repercussions to select from, Q3 was ambiguous and only addressed one component of emotional consequences (being upset), which is also similar to the current tool. For coping strategies, the best and worst ranked question was respectively Q1 and Q3. Even though Q1 had the best average rank, the providers also liked Q2 for its range of options. The existing structure of asking reporting related behavior among patients in the instrument caused the providers to voice serious concerns. They acknowledged that many patients found it to be redundant, difficult, and perplexing, which also led to many missing values in the data. As a result, they recommended changing the existing questions into multiple-choice ones, ranking Q3 as the best one because it was simple and offered the most options. Similar results were observed for bully identification and external factor of being bullied, as the best questions in these categories were clear, straightforward, and offered a number of options, which would assist patients and providers gain better information on the issue.

Provider Interview. As a follow-up to the card sorting, I conducted brief interviews with the providers to gain a better understanding of their perceptions of the present screening tool, the improvements that are needed, and the problems associated with integrating the tool and information in the EHRs. The results highlight some of the key issues that providers felt needed to be addressed for better patient-focused and patient-friendly screening mechanisms as well as efficient systematic integration of the information that is effective and helpful for providers during treatments.

Addressing Mental Burden and Survey Fatigue. One of the providers' main concerns was the inefficient design of the screening instrument, which was especially troubling for adolescents and young patients. As these young patients may not be in a stable state when they are admitted, having a complicated screening instrument can add to their mental burden. For instance, 4 out of 6 providers mentioned about mental burden that can be caused from a complicated screening tools. As the current structure of the questions include ranking, it can confuse patients, and may require additional effort from the patients. For example, provider P5 shared,

> *Ranking does not work and can be confusing for patients and parents who are not educated/mentally properly developed*

Additionally, provider P2 shared,

> *I personally do not like the ranking in the questions. It requires additional time for patients to comprehend the question and the instructions to answer them using the ranking*

My data from shadow observations also backs up this phenomena, where younger patients had difficulty filling out the survey on their own and had to frequently ask the nurse to explain the questions and how the ranking worked. This not only can have an impact on their self-esteem, but also added to the time constraint that often is a big challenge in a clinical setting. In some cases, the nurses would rephrase the questions to make them clearer and/or to save time, which is particularly problematic because it obscures the inquiries' original objective. Some providers preferred to use multiple choice questions instead of rank-based questions, as it provides more opportunities to report for the patients without requiring additional attentions for the ranking. For example, provider P6 said,

> *Multiple choice is better. It's hard to think of mindset of younger patients, but it's better to have more opportunities to report versus if you had less options to choose from*

Instead of spending time to rank each statement, providers preferred to provide different options to their patients, which will grab more information in lesser time. However, such integration of choices should be framed in a way that does not add additional burden for patients.

On the subject of burden, the providers discussed whether adding new questions to the instrument would increase patients' mental stress. While some supported the idea of adding questions that would provide further clarifications on the patients' bully related experiences, the rest shared their concerns. For instance, provider P4 mentioned,

> *Fewer questions are better. When you are first getting on the unit, it can be very distracting for patients. Filling out the current long-form survey can be challenging and add burden to patient's unstable condition*

Provider P3 further added to this concern,

> *Yes, they would get fatigued for the burden of added and longer questions..the current tool is already 3 pages..you could evaluate and see which questions are important and keep them in the screening*

As survey fatigue is a major concern in clinical settings, providers shared their concerns on the current length of the tool, which can certainly impact the way patients are interacting with the screening assessment. Instead of adding more questions, the providers suggested to rephrase or modify the current structure of the questions, that will produce better data and ensure more interactions from the patients. Majority of the providers even suggested to separate the traditional bullying and cyberbullying tool (they are currently screened together), as it would provide better contexts and less confusion for the children.

Ensuring Readability and Linguistic Components. In the topic of confusion, another important element that emerged from the provider interviews was concern about the readability and language components of the current tool. Although the screening tool is primarily intended to evaluate children and adolescent patients, the level of reading comprehension needed to complete it is much higher for a young patient. This complicates the screening procedure since patients require additional time and assistance to understand the meaning of the questions they are expected to answer. The majority of the providers voiced their concern about the language used in the tool and requested that it be rephrased or simplified to make it easier for younger children. For instance, P1 shared on this issue,

> *Patients' ability to communicate their experiences can be hampered by complex language. We should connect to them in a language they can understand and which encourages them to talk about their experiences with bullying, alienation, and the causes behind them. Being able to talk about those things is where I find usefulness of the tool*

Some clinicians advocated for the inclusion of informal language in the screening tool since many children and teenagers are not yet familiar with or lack the mental development to comprehend the concept included in the screening tool if it is written in formal or complex language. The suggestion was to keep the readability of the questions at a Grade 4 to 5 literacy level. For instance, provider P4 said,

> *The more informal the language, the easier it would be from a comprehension level. We should shoot for a 4th-5th grade reading level*

Because the majority of patients admitted to a youth inpatient hospital are aged 7 to 18, it is critical that the language used to create screening questions be comprehensible not just by older children but also by children who are in lower grades in school. The existing tool does not meet the readability level for younger children; thus, it is critical to work on this issue and create a more patient-friendly tool that allows patients to interact with it without adding additional stress and mental weight.

Integrating Sexual Cyberbully. While the literacy level of the screening tool was suggested, data from providers revealed extra concern over adding and carefully framing the questions on sexual bullying that happen through online platforms. Even though providers noted that online sexual bullying, trafficking, and blackmailing are some of the concerns that are widespread among patients, the current tool does not address this at all, resulting in the loss of crucial information from the patients. Provider P4 adds to it and said,

> *We definitely need to add something about sexual blackmail, sexual orientation, "slut" shaming (seems correlated with blackmail because the shaming is the outcome that the victim is trying to avoid) in the screening, as they are common with youths more than we know*

Additionally provider P2 shared,

> *The screening tool needs to tie to the experiences of sex trafficking and grooming with patients' online involvement. There are perpetrators who groom our kids (the patients)...That's part of cyberbullying...they're manipulating our patients by saying "If you don't do a sex job for me, I'm going to kill your parents." There's a population of them. It's hard to work on the unit without knowing who are these patients*

While today's youth are already hesitant to share their negative online experiences for fear of being chastised by their parents or losing privilege to access certain technology, not screening them for extreme situations like sexual bullying that happen online can seriously endanger their lives and have serious mental and behavioral health consequences. Despite the fact that it is crucial to screen patients for sexual bullying, providers also gave advice on how to approach questions in this area more carefully. Because many young patients may be unfamiliar with terms such as "sexual" or "sexual trafficking," the wording should be more instructive without any provocative connotations.

While providers shared their concerns and suggestions for making the screening tool more patient-friendly, their experiences working with the tool also helped me identifying systematic limitations that currently exist in clinical settings around screening. I am going to explore those in the next section.

Clinical Workflow Around Cyberbully Screening

My analysis of the clinical workflow based on shadow observation and provider interview around administering and integrating cyberbully screening at PBH revealed a number of problems (Figure 7.2). For example, some providers expressed their frustration over not being able to screen patients using electronic media, such as iPad or kiosk, because patients, who were frequently in unstable mental states, had a history of destroying or damaging those devices. Additionally, clinicians' level of familiarity with their patients' engagement with online platforms varied, as did their knowledge regarding specific activities their patients may be engaging in. It was evident that providers were not properly trained to use the tool during their treatment or interactions with the patients. Some providers were even unaware of the presence of the tool, which could ideally assist them in initiating dialogues about negative experiences their patients had in both the offline and online worlds, perhaps leading to serious consequences. This systematic gap in the information flow was evident, as provider P6 said,

> *I didn't realize there was a screening tool personally. I'm not sure where it's accessible for me to see the information for each patient. When I do therapy, it's hard as a therapist to determine what the areas of focus are for each patient and sometimes topics are skimmed over. A big factor is not knowing where the information lives.*

Within my dataset, only one provider responded that they regularly check bully related screening data of patients during the initial assessment process; however, this was not standard of care even in their own practice, as there was a gap in knowledge within the providers. Without screeners or other practices to directly investigate patients' technology use, the only way a clinician typically learns about these activities is through patients' direct disclosure during therapy or counselling. However, it was also problematic, as some providers mentioned of not being properly trained to address their cyberbully related concerns.

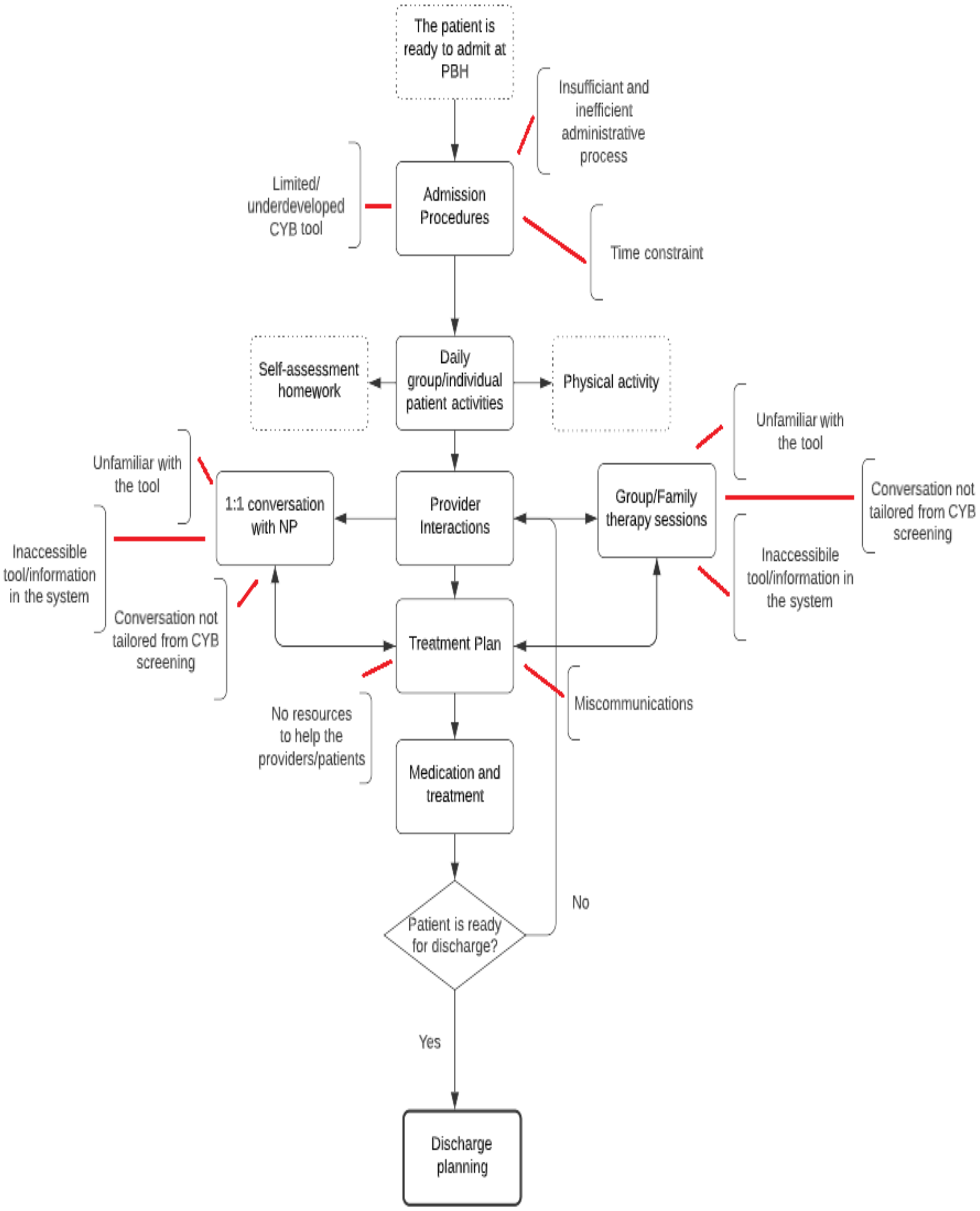


Figure 7.2: Extract from the PBH Inpatient Acute Care Admission & Treatment Process Model Indicating Identified Problems

To better identify and explore the current challenges and limitations that exist within the unsystematic implementations and integration of cyberbully screening at PBH, I have categorized these low level problems into high level categories following the approach mentioned in [277]. The approach combines the use of processes and goals, and the problem categories can be mutually inclusive, as processes within a clinical workflow are often interconnected. By process here, I mean a set of linked activities that produce a certain output [173]. Using Business Process Modeling Notation (BPMN) [157], I developed a process model or general workflow at PBH (Figure 7.2) solely focusing on the aspects of screening cyberbully of adolescents. It is important to note that this is not the complete PBH workflow, but rather a portion of the PBH youth inpatient acute care admission and treatment process model, which was created using provider interviews and shadow observation. In each step of this work process, the potential challenges and problems around implementing cyberbully screening and integrating the data is highlighted with red lines. To structure, document and analyze the problems they were classified into three problem classes.

Information Flow. Gap in information between providers, and in some cases, patients and their parents, presented a serious issue, as was clear from the interview and shadow observations. I classified these problems as information flow.Unawareness of the existence of the cyberbully tool and the objective of administering it at PBH, unfamiliarity with the screening questions, and unavailability of the screened information during treatment are a few of the significant information flow related problems that emerged throughout my data collection.

Even though cyberbullying screening was added to the PBH clinical workflow in 2018, many clinicians, including NPs, therapists, and mental health technicians, were unaware that such a mechanism was in place to screen child and adolescent patients with bullying concerns. There is no protocol in place to specify why this screening is conducted and how the data are used, which not only creates knowledge gap within clinicians, but also occasionally causes uncertainty among patients and their parents as well during filling out the form. For instance, during shadow observations, floor technicians and NP both expressed their surprise at discovering a tool for screening adolescents for cyberbullying at the time of admittance. For providers, this unawareness of the existence of screening tool also led to unfamiliarity of the questions included in the screening. This unfamiliarity heightened the risk of missing opportunities to discuss any concerns about cyberbullying with their patients, which was concerning, especially during therapy or one-on-one conversations between patient and providers.

Those who were aware of the tool, did not have much flexibility to access the screened information as well during treatment, which also exacerbated the gap in information flow within the clinical team. These screened data frequently lose their value and give clinicians untimely information as a result of the present practice of integrating data into patients' EHRs. Provider P6 echoed this concern and shared,

> *I'm not sure where it's [the cyberbully screened data] accessible for me to see the information for each patient. When I do therapy, it's hard as a therapist to determine what the areas of focus are for each patient and sometimes topics are skimmed over. A big factor is not knowing where the information lives*

The current approach of incorporating screened data into the system entails scanning the paper form and uploading it as a media file (image/pdf) in EHRs. The screened data remains in paper format during the course of treatment and is not integrated into the system until the patient is discharged. The system's manual and rigid data scanning structure, not to mention its delayed integration, are incredibly inconvenient and ineffective for both patients and providers, as such integration does not provide any actionable, searchable or discrete fields that providers can work with during clinical care or treatment planning. Healthcare providers might not even know how to access the pdf file inside the media tab in a time-sensitive circumstance since it is not displayed in the system's front interface. While integrated and systematic recording into EHR can increase patient engagement time and, as a result, the quality of treatment delivered, this was not observed at the PBH institute.As the current process of reviewing screening information comes only from the admission nurses and not the healthcare providers who directly engage with patients through counseling or therapy, it often created miscommunications among providers, produced poor quality of treatment interventions, and impacted the patient-provider relationship.

Behavior/Time. Problems in this categorization refer to the timing, ordering, and selection of tasks that occur inside the process. Examples include inefficient administration of cyberbully screening during admission, time constraints during admission and so on. The nurse frequently finds it difficult to conduct the cyberbully screening at the time of admission. As there may be a high volume of admission and discharge events happening simultaneously, nurses frequently struggle to examine all the screenings and help the providers with the evaluations. This is problematic, as based on the current practices, they are the primary source of patients' screened information for providers. For example, provider P1 shared in the interview,

> *The nurses are normally doing the surveys on intake, and it gets communicated to the team and whether it's a need or not*

Because of the current systematic approach, the entire assessment procedure may fail if the admission nurses and the providers do not communicate in a timely manner. Additionally, it is quite challenging for the nurses to admit patients as quickly as possible when there are several patients at once, which frequently results in them missing or even forgetting about administering the cyberbully screening tool during admission- an event that occurred multiple times during shadow observations. Some patients also struggle to fill out the form on their own for reasons like unstable mental and behavioral condition or mental development to comprehend the questions. In these situations, the nurses are required to read each of the questions to the patients, frequently more than once, and to record their responses. This adds extra time and delays the entire admission process. Due to time restrictions, some nurses may even choose to reword the questions or skip the entire survey if they believe the patient is not being bullied. This is problematic since it contradicts the entire purpose of the assessment and can result in missing values in the screening.

Organization. Based on my conversation with the providers and shadowing activity, I observed certain concerns regarding the availability of the training, information, and resources that most likely could assist clinicians and patients in having a more in-depth discussion on the subject of cyberbullying. I classify this kind of problems as organization. As the negative experiences related to cyberbully can range from rude comments to sexual trafficking, it is important that providers can refer to important resources and also can direct patients to related help. Physicians frequently reported feeling hesitant and uncomfortable regarding the screening tool and evidence-based techniques for handling mental health concerns, as well as not always having referral alternatives accessible. Even if the tools are scanned and added to the system, not all providers are knowledgeable or skilled enough to locate and use them effectively. This raises the concern of incorporating necessary resources and training within the clinical workflow that are accessible and shareable within the providers and patients. The current clinical workflow at PBH youth inpatient treatment facility includes educating patients and parents on various mental and behavioral health challenges, triggers, coping mechanisms, and safety mechanisms. As a result, it is simpler to add resources on cyberbullying assessments, triggers, repercussions, and the need to inform/share with parents/guardians/providers/social workers/DCS agents as it enables patients to manage these bad experiences outside of a clinical facility.

Design Consideration

As the problems within the clinical process are identified and classified, it is of interest to examine how design recommendations to address these problems contribute to high-level goals. This section highlights areas for improve-

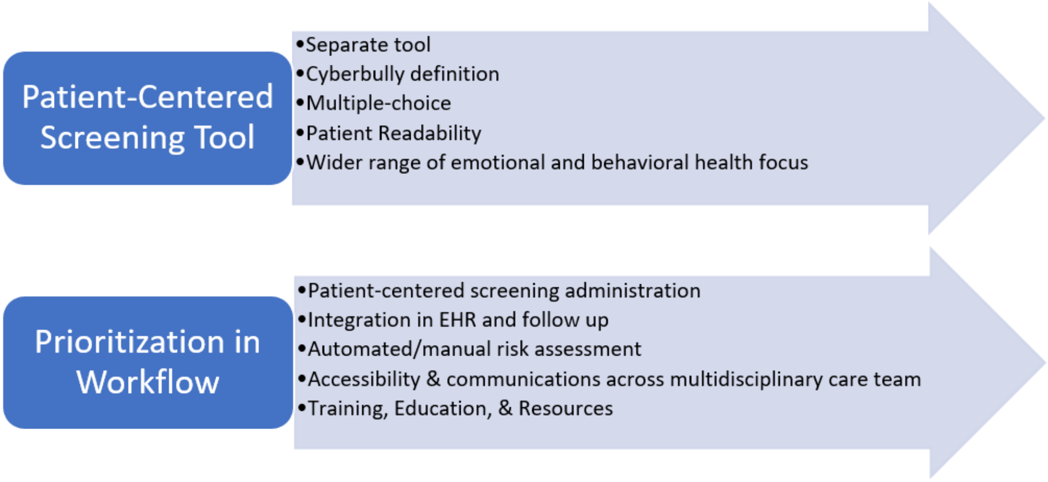


Figure 7.3: Goals Mapping for Improved Workflow

ment in the present screening and clinical practices at PBH that center on patients' cyberbully experiences. Based on my findings, two high-level goals are mapped out and discussed for my design considerations: 1) designing a patient-centered screening tool, and 2) making prioritization in workflow. These high-level goals are broken down into more manageable low-level objectives (Figure 7.3) that, taken together, will enable me to improve the current tool while more logically and methodically integrating it into the workflow.

Patient-Centered Screening Tool

For our goal of achieving patient-centered clinical practices, the first step is to design a refined screening tool that is efficient, and most importantly, considers patient related challenges during screening. The tool should be able to recognize key themes in cyberbullying and produce substantial and meaningful information that enables healthcare professionals to create more individualized and effective treatment plans for their young patients.

This leads to my first design recommendations for the screening tool: **separate traditional and cyberbully screening questions and create individual tools for both of them.** Combining both traditional and cyberbully related screening questions in one tool did not produce quality data (as seen in previous chapter 6) at PBH inpatient youth facility. While experts have begun to interchangeably use traditional bullying and cyberbullying because of their close connections [353], for the current model implemented at PBH institute, it did not perform well. Providers also voiced their concerns about integrating these two phenomena into one tool, because it may leave patients confused about the tool's true purpose and produce noisy results or data that may not be helpful to providers. Separating the instruments will make the assessment simpler and enable patients and providers to focus on these specific issues one at a time. While it may make the assessment more efficient from clinical perspectives, one major drawback of such separation of tool can be survey fatigue as patients may get overwhelmed by the number or length of the survey they encounter during admission [335]. Thus, it is utmost important to carefully analyze which questions should be included in the tool, how they are phrased, and how challenging it is to answer them for a young patient in an unstable mental and behavioral state. For the scope of this dissertation, I have focused only on developing a cyberbully screening tool that addresses that can help providers to assess core aspects of cyberbully without making the tool unnecessarily long or complicated. For reference, I have added the refined screening tool in APPENDIX E3.

Rather than blindly accepting, shortening, or expanding a certain existing scale to satisfy the need for an efficient assessment of cyberbullying, I chose to create a refined version of the cyberbully screening tool adapted from providers' recommendations, my own research, and current literature on existing tools (mentioned in methods section). This was done to guarantee that the core concepts of cyberbullying recognized as significant in recent studies and my own research were covered, making the tool more theoretically and empirically sound. This leads to the second design recommendation for the screening tool: **include a brief but relevant definition of cyberbully at the beginning of the tool.** Because of the inconsistency in definitions of cyberbullying, researchers varied in how they characterized the domain of cyberbullying activities, which might be troublesome during clinical screening [406]. While the likelihood of youths reading a definition very closely before answering questions is minimal, some researchers have identified the weak definition of cyberbully, or, to be more specific, the lack of it, as a key concern [405]. Including a definition of what constitutes a cyberbully at the start of the screening tool accomplishes two goals: 1) it sends a clear message to patients and providers about the purpose of the screening, and 2) it helps patients understand what kinds of experiences qualify as cyberbullying and allows them to link back to such incidents during counseling or therapy sessions even if they weren't included in the screening. While there is no golden definition of cyberbully, for this tool, I chose to adapt the definition provided by Juvonen and Gross that defines cyberbully as "anything that someone does that hurts, upsets or offends someone else" [332]. I chose to include this in the screening, because it does not constrain or narrow the concept of cyberbully to some specific scenarios, allowing patients to interpret it based on their personal experiences. I adapted this definition and redefined it as "People often do mean or bad things to hurt others on purpose. It can happen through any social media, online games, phone, or other devices. It is called cyberbully". While this refined definition remains broad, it relates back to the core concepts of cyberbully. Adding this definition at the beginning sets specific goals and expected outcomes from the screening.

As a third design consideration, I focused on the structure or format of the questions included in the screening. While ranked scales like likert scale based questions from the current tool performed better than yes/no questions (based on our efficacy study I discussed in chapter 6), the providers raised concerns about the time constraint, survey fatigue, and confusion that patients experience when completing these types of questions as they require increased attention from the patients. Findings highlighted younger patients struggling with the screening questions, as they had to frequently ask the nurses to clarify how the ranking worked. Keeping that in mind, I recommend: **modify the present question structure and include multiple choice answers in order to simplify and provide additional options to patients while screening.** While multiple-choice questions do not fully elicit a person' thought processes, they still allow efficient scoring and individualised feedback associated with question items [345]. One of the advantages of using multiple choice questions instead of scale based questions is that they could be self administration and could therefore be used for self assessment [27] and makes the tool more patient-centered and patient-friendly. This helps me to accomplish three goals: 1) it can be easily administered and will help to collect more information in short span of time, 2) items/questions will have low cognitive burden on patients, and 3) can increases reliability (the extent to which items in a measure co-vary) as well as construct validity (the extent to which a measure accurately estimates the construct of interest) [183, 405]. For example, my findings from previous chapter showed patients were consistently avoiding questions on their reporting behaviors in the screening tool, which produced huge missing values in the dataset. One cause for this avoidance could be the needless elaboration of the questions both with ranking and check/uncheck structure for each source of reporting media (parents, school, police etc.). I replaced them with one multiple-choice question, which now allow patients to simply check the options that they believe are correct, reducing significant wastes of time.In addition to giving patients a variety of options to choose from, these questions also include "other" as an option, enabling patients to add more information, if necessary, as well as "never" to prevent them from skipping the question and giving them a way to select "no" for each option.

Previous study on designing screening tools for children revealed that phrases that blame, accuse, or shame the child for what has occurred must be avoided [19]. Words with negative connotation can promote stigma and complicate conversations. The providers at PBH institute also echoed the same concerns and suggested to incorporate language in the tool that are simple in structure and require less cognitive burden and mental development from the patients. Thus, my fourth design suggestions focuses on the readability and linguistic components of the tool: **incorporate grade level 4 or 5 language into the tool with simpler phrases to help young patients comprehending the context/inquiry to which we are referring.** To achieve this, I utilized the website [25] to assess the readability of each phrase and sentence in the screening tool and only included statements with readability levels of grade 4 or 5. Previous study has discussed the importance of analyzing the linguistic components of a screening tool during development and shared that to guarantee patient comprehension, each item must be written below an eighth-grade reading level, clear of abbreviations, complex terminology, and compound question [461]. I streamlined the questions by changing the linguistic components, so that it is more comprehensible to the patients. For instance, instead of asking directly whether they were blackmailed for sexual explicit contents online, I rephrased the question as "took or created video or photos of me naked to blackmail", which clarifies the statement, removes sensitive and offensive/blaming connotations, and gives clearer contexts. This informal use of language helps providers to explain certain aspects of cyberbully in a way that is less complicated and more patient-friendly.

Previous studies showed that cyberbully related experiences can have severe mental, behavioral, and emotional impacts on a person [490]. It ranges from being sad to getting engaged in self-harm activities, including substance abuse or even committing suicide [360, 261, 609]. While the current tool at PBH attempts to screen one emotional aspect of being bullied by focusing solely on how upset patients are about being bullied, it falls far short of including other emotional and behavioral consequences such as feeling guilty, depressed, ashamed, beginning/increasing substance abuse, engaging in self-harm behaviors, and so on in the assessment. Therefore, as my fifth design recommendation, I suggest: **add questions that screen not just the emotional and behavioral effects of bullying on patients, but also their coping methods in response to these experiences.** These questions were adapted by combining multiple existing screening tool, such as [344] and [18]. By including these questions into the screening, clinicians will be able to pinpoint the target area through better risk assessment and provide patient-specific clinical treatment.

While my recommended screening tool includes some of the questions from existing tool, the design reformations I have mentioned above will certainly improve the quality and utility of the tool during assessment in a clinical setting.

Prioritization in Workflow

Patient-centered care requires patient-centered workflow. Healthcare delivery in a patient-centered workflow revolves around patients' needs and is organized with series of processes or actions that center around highest quality patient care [457]. Due to the highly collaborative and distributed nature of hospital work [80], patient-care team members rely on each other to deliver accurate and reliable information [424]. This collaboration can also be multidisciplinary, in which case primary care physicians, nurses, therapists, and specialists work together with their patients to ensure quality care and services [618]. EHR gives patients and doctors a place to collaborate, as it makes it easier for both providers and patients to access medical records, discuss about treatment options, and raise standards of care [610]. As a result, creating an integrated and better organized EHR for effectiveness and quality has recently received increased attention [303].However, without appropriate systematic adaptation, such data integration risks slowing down practice, compromising clinical communication, risking safety, lowering clinical quality, and negatively affecting patient experience [147]. Therefore, I propose design considerations (Figure 7.3) that add to the current assessment process of screening social and behavioral experiences among adolescents in clinical settings and establish a more comprehensive blueprint/workflow that prioritizes structured rules and clinical practices to ensure better patient care.

Patient-centered Screening Administration. The existing mechanism at PBH for conducting and integrating the data from cyberbully screening into patients' electronic records are relatively unstructured that adds to both provider and patient's physical and mental burden. There is no set approach that describes how the screening should be carried out with patients' comfort and related challenges in mind during admission. Due to the lack of a clear framework, the majority of the time, cyberbully screening occurs at the time of admission (self or nurse administered). This brings me to my sixth design recommendation: **instead of screening patients during admission, administer cyberbullying screening within the first 24-48 hours of admission and follow up**. As previously stated, overwhelming patients with multiple screening and paper work during admission can be troublesome, as they may become exhausted and feel even more disturbed to be in that setting [335]. The assessment of adverse events that have serious emotional and behavioral implications on patients might put extra strain on them during their hospitalization and may defeat the entire objective of serving patients in a supportive environment. Since the current clinical practice of developing a personalized treatment plan does not occur before day 2 or 3 of the inpatient program, having this additional time to screen cyberbully will have certain advantages: first, patients will have more time to complete the survey and won't feel rushed or intimidated during admission; second, allowing additional time can also result in better data from patients because they will be in a more stable state to interact and answer the questions; finally, and perhaps most importantly, for these systematic administrations, in addition to the admission nurse, mental health technicians on the floor can also help administering this tool during the patient's morning or evening routine, reducing effort and allowing the admission nurse more time to follow up on patients who are struggling with the tool. Currently there is no systematic practice of following up with patients, who either showed lack of interest to take the screening or intentionally left out questions to answer. If proper follow-up practices (e.g., follow-up discussions/notes) are developed after screening to address missing values or lack of involvement from patients, potential opportunities to contextualize such incidences in clinical settings in terms of patient engagement can be recognized.

Systematic Integration in EHR and Risk Assessment. A patient-centered workflow requires consistent provider interaction for individualized patient treatment and efficient information exchange integrated into care delivery, particularly around ongoing care interventions[457]. In healthcare domain, EHRs are the *de facto* standard for storing medical information for patients and providers[163, 603, 540]. While some of these data points are recorded as discrete fields inside the EHR, others are documented in an unstructured format by providers within patient narratives/notes or even scanned in as media attached to the patient's visits. The current practice of integrating cyberbully related screening information in the system raises certain major concerns: first, it is added to the system after the patient is discharged, and thus the multidisciplinary providers can not access them from the system during treatment; and second, the paper form is scanned as a unstructured media file in the EHRs, which is not actionable and does not provide flexibility to the providers to systematically access the information and assess their patients using the utility of the EHRs [411]. This leads to my seventh design recommendations: **opt for more strategic and timely data integration (immediately after administration) and presentation mechanisms that enable logical access to the providers dur-**

ing treatment optimizing patient care. Integrating screened data after a patient has been released is inefficient for both providers and patients, and it significantly impact how healthcare practitioners strategies and serve their patients. Patients may feel unheard and unsupported if the information shared during screening is not followed up by the providers during treatment [584]. Real-time data enables clinicians to make proper decisions based on comprehensive information.

Meaningful data integration and presentation will assist healthcare practitioners in identifying patients who are at higher risk while allocating resources/care team more efficiently. For instance, we can improve the current workflow by adding a discrete field/column in EHR that allows the nurse to check a button if a patient mentions "yes" to the question of being bullied or not during the screening [130]. When a screening tool is scanned as media, this specific column in the patient's electronic health record can alert providers, either manually (providers reviewing it themselves) or automatically (by a system-generated notification), prompting them to verify the detailed data scanned as media. Previous research has examined the feasibility of incorporating NLP in the system to convert screening results from image to text [361, 435]. Typical approaches to dealing with scanned documents include image preprocessing [267], optical character recognition (OCR) [305], and text mining [435], all of which have been demonstrated in the past to improve workflow in practical settings. OCR extracts words from scanned images and turns them to machine-readable text, while text mining further recovers clinically relevant information from them.

Additionally, leveraging data from clinical narratives for the assessment of cyberbully can also help clinicians assess and identify patients with higher risk. As, it is not uncommon for youths not to report negative experiences, especially bully related events, to any adult [605], adding additional sources to assess patient experiences should be a standard of care. When objective data from screeners are unavailable or do not provide quality information, automated cyberbully identification from unstructured clinical narratives can be performed utilizing methods such as NLP and machine learning approaches for free-text fields [331]. EHRs can provide a prompt to the clinicians if some form of bully related event is positive within the narrative, with recommendations and resources for helping patients with specific needs [81]. However, such approaches may lead to false positives due to technological limitations, and may require expert skills to work with such data.

Communication and Collaboration. One of the most significant difficulties for PBH's overall workflow was ensuring collaboration and correct information flow among all healthcare providers. There is a big vacuum in this space, as different providers are unaware of the screening tool and information it gathers on patients' cyberbully experiences. Even when information is available based on patient screening, it is frequently not accessible in the system in a timely manner and makes it harder for the team to engage in informed and collaborative decision making process for better patient care. This leads to my eighth design recommendations: **streamline information sharing between different health care professional to provide better patient care and collaborative decision making within the clinical team.**Streamlining communication ensures that all relevant parties have access to the same information with the least amount of risk of error and duplication of effort. Specific guidelines and procedures should be in place that require providers to assess patient documents in order to access screening information before engaging in group/family therapy or counseling. Reviewing these information beforehand will help to address two problems: 1) multiple providers will have access to the same information and thus will create limited confusions, and 2) the information will help providers to curate better patient-centered treatment planning and care. High-quality medical care combines evidence-based clinical care with a patient-centered approach that emphasizes collaborative goal-setting and relationship-centered support during treatment [460]. Such collaboration will not be possible if proper communication within multidisciplinary care teams and patients are not ensured during treatment interventions.

Previous research has highlighted the necessity of knowing clinician needs as well as a number of socio-environmental elements that aid in the deployment of effective collaborative decision support systems in clinical settings [369]. Additionally, this also enables patients to collaborate with clinicians during the decision-making process when there are trade-offs between treatment alternatives, ensuring that patient preferences and values are incorporated into the medical plan [216].

Training, Education & Resources. Although it is evident that practitioners' knowledge and awareness of cyberbullying is critical to the effectiveness of anti-bullying intervention programs in clinical settings, little to no emphasis has been given to ensure that it prevails [528]. In the context of addressing and treating patients with detrimental behavioral and mental concerns, previous research have suggested that due to limited knowledge and training, many physicians are uncertain how to manage suicidal ideation within at-risk patients beyond a basic risk assessment [366]. Although social media use has been pervasive for more than a decade, the education curriculum for health care professionals hasn't always updated to reflect this [475]. As a result, some clinicians lack the necessary training to address how such platforms affect patients' health behaviors and eventually fail to provide required support to the patients. This leads to my ninth design recommendation: **as standard of care, incorporate mandatory training programs for providers and provide accessible resources for effectively addressing and supporting patients who are victims of online based risky behaviors in clinical settings**. The training should focus on (1) building providers' knowledge on technological advancement, clear definition and core concepts of harmful behaviors online and their consequences on young and adolescent patients, (2) increasing their sense of patient expectations and clinical effectiveness of screening and assessing emotional, and behavioral risk factors of their patients using validated tool, (3) developing procedures and protocols for how adolescent patients are managed and their screening information are accessed and shared within different providers in the clinical setting, and finally (4) building strong outside referrals of medical and community linkage (e.g., NGOs, school, foster care, adoption agency etc.) that can further help patients once discharged [208]. Although not all specialty health professionals may embrace such integration of education and guidelines in the health care system, it is important to adapt and acknowledge the influence of growing technologies in their patients' lives.

It is important that clinical training not be viewed merely as an orientation. Clinicians need sufficient time to develop a strategy for how they will work collaboratively to manage adolescent patients in their particular setting and address concerns, health issues and risky mental, emotional, and behavioral consequences of cyberbullying. It is unlikely that a healthcare professional can resolve a bullying issue in a single inpatient visit [421]. However, as the current practice of providing treatment at PBH include educating patients and families in their 5-day program, providers should use this opportunity to provide support and empathy, as well as resources to the patient and family to follow up and seek additional support. There are several, national anti-bullying resources that can help to establish knowledge and a resource bank not just for providers, but also for direct victims and their parents. For example, the Cyberbullying Research Center provides links to not only report bullying on all major social media sites, but also information and resources to victims, nationwide [13]. StopBullying.gov also provides access to both information and links to both national phone number databanks, and links to local counselors [519]. Connectsafety.org [23] and Safekids.com [8] are two websites that promote internet safety guidelines and educate parents, educators, youths about online privacy, security and digital wellness. Resources should be available and accessible at all stages of patient-provider engagement, not just for clinicians, but also for patients, as they may not always disclose their whole experiences, and having access to these resources may aid them in the long run.

Limitations

The study has its own limitations. First of all, it is possible to miss latent signals or misinterpret elements of observed actions when shadowing. As the current workflow related practices, provider engagement, and related challenges around screening were primarily reported from the shadow observations, it is possible to overlook essential aspects or even incorporate unconscious bias during data analysis. To ensure that I addressed this limitation, I consulted with our clinical partners at Parkview Behavioral Health whenever I had questions throughout my data collection and analysis process. They reviewed my data as well as findings, suggested necessary adjustments (if needed), and provided additional information/explanation if I had any question. Furthermore, since I decided to perform a closed card sorting exercise with the providers, the strategy itself has some drawbacks. Closed card sort is criticized for measuring target participants' ability for classifying content into the "correct" bucket, but to users, it can resemble more of a puzzle than an intuitive way of matching content to categories [554]. While this strategy facilitates my investigation to explore providers' perception of how well a question fits into an existing category, it may not always reveal how a set of themes is understood by the providers. To address this limitation, I conducted a follow up interview with the providers right after the card sorting activity where they shared their thought process and concerns related to the screening questions as well as workflow that currently is in practice at PBH. Aside from these methodological challenges, there are additional content-related constraints that must be addressed. For example, even though the newly developed screening tool suggested in this chapter tries to encapsulate core concepts of cyberbully, majority of the questions are focused on the construct of cyberbully victimization, and not aggression. It is possible that the patients taking the screening are bully themselves. While past research has shown that cyberbullying victimization is positively related to cyberbullying perpetration [644, 484], the tool presented in this chapter does not necessarily screen for all the aspects of such behaviors and experiences. However, as there is a strong link between cyberbully victimization and perpetration, I have added this behavior as a coping strategy in the assessment, which will enable clinicians in screening individuals who are both victims and bullies.

Ethical Considerations

It was important that both clinical teams and patients at PBH felt comfortable and safe during our data collection, specifically through shadow observations. Because the youth inpatient facility includes children of all ages who are dealing with a variety of challenges, including suicidal ideation and self-harm, a clinical nurse or mental health professional was always present during our observations. Since my colleague and I were frequently close to the patients during our observations, we avoided interacting with them for the risk of triggering any mental, physical, or emotional breakdowns within them. Additionally, while we observed nurse practitioners and therapists interacting with patients one-on-one or in a group setting with other peers or their family members, we obtained permission from the providers as well as the patients/family to be present during the sessions and made sure not to interrupt or disrupt in any way. To ensure that the identities of the patients were not comprised, any information or conversation recorded between providers and patients were deidentified and representative exemplars of the actual content were created.

Conclusion

This study identifies several shortcomings in the current operationalization of cyberbully screening in clinical settings from the perspectives of tool implementation, data integration and accessibility in a clinical workflow. Based on the data collected from provider interviews, card sorting, and shadow observation, I recommend specific modifications to refine the existing screening tool for cyberbully experiences in adolescent patients. I also assist healthcare practitioners in assessing and addressing cyberbullying experiences in their younger patients by offering strategic and systematic design considerations that can improve current practices and clinical workflow in behavioral healthcare settings. The development of deeper knowledge and resources is crucial if we are to work toward more comprehensive and patient-centered clinical care that ensures better services and treatment from healthcare providers. This may be accomplished, for example, by creating assessments and treatments that take young, adolescent, and at-risk patients' digital activities into account in order to have a deeper understanding of mental illness and the activities that support them.

CHAPTER 8: FINAL CHAPTER

In this chapter, I will discuss the implications of my dissertation by summarizing the outcomes and contributions of each projects. This dissertation aimed to make contributions at the intersection of social computing and healthcare system where ***first***- I explore, understand and contextualize different social, cultural, mental and technical cues related to online harassment experienced by vulnerable populations from diverse contexts *(Chapter 2,3,4,5)*, then ***second***- I integrate these knowledge and connect digital signals about harassment into clinical practices to recommend approaches for better patient assessment and outcomes *(Chapter 6,7)*. The outcomes of this dissertation suggests recommendations for a refined screening tool and structured workflow to enhance screening practices around risky health behaviors online, like cyberbully, in clinical settings and integrate such interventions into patient's electronic health records. I will conclude this dissertation by identifying limitations in my work that point to future paths of research in this area.

Implications for Social Computing Research

In the United States, the use of internet has evolved from an "extra" in everyday communication (cyber utilization) to a "primary and fundamental" aspect of communication and entertainment (cyber immersion), particularly among adolescents [212, 439]. This rapid advancement of technology and the internet is not just restricted to the U.S; for many people in the global south, it has also become an inseparable part of daily interactions, self-presentation, and even workforce [529, 446]. The increased use of technology has changed how individuals connect online, as it enables them to express a range of harmful activities such as harassment, self-harm, sexual misconducts, life-threats- many of which are specifically targeted towards at-risk populations [477, 446, 39], particularly within adolescents [247]. Research in social computing domain has focused on understanding the prevalence of such negative experiences online [480, 439] and how youth reflect on their own online harassment and bullying [480, 633]. Other research has documented how various mobile app features might influence cyberbullying between various individuals [562]. Given that there is no universally accepted definition of what constitutes as cyberbullying, researchers studying this topic in the social computing domain frequently fail to take into account crucial contexts and factors that may have a harmful impact on victims, particularly children and adolescents. The outcomes of my research address this concern and identifies various social, cultural, mental, and technical indicators that are persistent to online harassment. By investigating these elements, I was also able to identify distinct design implications and recommendations that must be taken into account when developing more inclusive and safer technologies for vulnerable and at-risk communities worldwide.

For instance, a core concept of harassment is power [602]. **Chapter 2** and **3** in my dissertation specifically explore this imbalance of power from an identity perspective, focusing on how participants experienced frequent and severe online harassment based on their minority status, such as gender identity and sexual preferences [448, 446]. **Chapter 3** digs deeper and shows how often people from gender and sexually minor communities are ignored in the domain of social computing, as the negative experiences they face online are not always addressed from diverse contexts and incorporated in the platform design phase. It facilitates the power imbalance between mainstream populations and GSM users online leading them to suffer further from online harassment and identity crisis. This concept of power becomes more evident, as often it is paired with anonymity that the current technologies provide to its users. The outcomes from **Chapter 2** show how online anonymity through social media can lead to violence, aggression, trolling, hostile commenting, deception, sexual exploitation- acts that are illegal [333, 148, 384], and in cases more harmful, as the harassers can be someone victims know but technically invisible [449]. ASMs provides a safer way to break the invisible norms of society without being judged or scrutinized, which amplifies the instances of harassment. This psychological state of feeling unaccountable is known as de-indivisuation where an individual becomes a part of an anonymous crowd and displays more anti-normative and dis-inhibited behavior [502]. Some researchers call it cyber-disinhibition when this kind of behavior happens online [653]. Although previous research have studied anonymous harassment from different angles and online platforms [204, 107], explorations on how this cyber-disinhibition paired with anonymity are often targeted towards certain GSM populations have been very limited [104, 148] from a non-Western context. This study, thus, addresses this gap in knowledge and contributes to the existing literature by exploring such mental states and classifying different forms of anonymous harassment targeted towards GSM identities.

While chapter 2 talks about harassment through perceived anonymity within a known online network,**chapter 4** in my dissertation talks about social or group anonymity that may not come from the known personal online network, but rather is a part of the online community identity. Previous research has shown that social media platforms like Reddit, Twitter, and others can provide users with a false sense of anonymity, lessening social inhibition and encouraging them to be more aggressive in this form of communication [518]. As a result, some people may perceive their online conduct as harmless or as a right to free speech or concerning engagement but might be misinterpreted as online harassment. Outcomes of **chapter 4** show that such online harassment may not cause any physical damage initially, but may slowly trigger devastating psychological impacts including stress, anxiety, depression, and low self-esteem among the victims, and even encourage people to engage in risky health behaviors like eating disorder or suicidal ideation [444, 354]. To protect themselves from this harassment while maintaining their online safety and privacy, participants in my research adopted a variety of tactical approaches. For instance, [446]. This study advises designers to think more holistically about how marginalized users prefer to define their gender online and to provide more accessible and culturally appropriated privacy settings that can offer better safety to GSM users.

My research has also explored the presence of community and cultural influences that impact how vulnerable and at risk populations perceive harassment on online platforms and curate their own participation and involvement with that specific technology. **Chapter 3** shows how GSM users prioritize their community bonds and cultural values, which influence their adoption of specific technologies, online behaviors, and sense of what constitutes a safer and trustworthy online environment. This community based influence through online technology was also observed in **chapter 4**. My network analysis on Twitter eating disorder communities in **chapter 4** showed increased exposure to negative social influence and harmful information from influential users online raises the likelihood of greater levels of unhealthy adoption of lifestyle, particularly among general users with health concerns [444]. While this research contextualizes the presence of unhealthy lifestyle, like eating disorder (ED), in online communities through node-level participation and engagement, it also provides a granular understanding of prominent topics and contents within ED community online using multiple topic modeling algorithms and extends the current knowledge on online ED contents [444]. It also contextualizes emerging ED-related linguistic indicators (e.g., #meanspo) with known ED activities that are centered around self-harassment and online censorship [479], blurring the line between motivation and harassment. While harassment is frequently defined as an exterior act directed at another person [634, 637], my study demonstrated how it can also be internalized, with a person harassing themselves through self-injurious behaviors online known as digital self-harm or self-harassment/cyberbullying

[?, 470, 254].

So what do these findings mean for social computing research that is focused on detecting harassing and harmful contents online with an aim to serve victims who suffer a range of mental and behavioral consequences [108, 446, 477]? The current concept of addressing negative experiences such as online harassment or cyberbullying is restrictive in the social computing domain, since it frequently overlooks the different contextual and technical cues that are very important and play significant roles in encouraging the risky behaviors online that can lead to serious health concerns [478, 446, 39]. If platform-based interventions and potential clinical interventions are based on this paradigm, the risk for creating healthcare disparities is a real risk. We must incorporate these socio-technical knowledge of online anonymity, community and cultural influences, gender identity and sexual orientations, as well as technical skill, into the definition of online harassment or cyberbullying in addition to key elements like imbalance of power, intention, and frequency [269]. The knowledge of these factors will not only help researchers and platform designers to design more inclusive and safer platforms for the users, but also will be useful in clinical practices, as providers can target their therapeutic interventions, understand triggers and responses, and keep them abreast of the technical affordances/trends, which implicitly or explicitly impacts their patients.

Implications for Healthcare Systems

Implementing efficient assessment

It has been suggested that the effects of cyberbullying may be greater than the effects of traditional bullying because the attack can be viewed by a wider audience, who can access the material repeatedly and in turn share it to an untold number of people [605, 439]. Despite the fact that being the target of cyberbullying, or in general negative experiences, has serious mental and behavioral consequences on victims, it is rarely addressed and investigated by healthcare experts in clinical settings [399]. The high prevalence and the negative consequences of cyberbullying reveal the need for systematic assessments to detect and intervene in these situations having negative impacts on human development, thus requiring the use of assessment instruments [249].

As there are certain adolescents who are at a higher risk of being bullied, early detection can help the provider to identify patients who are at higher risk and require additional support and curated care from their providers [63]. For instance, using real patient data, outcomes from **chapter 5** in my dissertation revealed that gender had a big impact on the occurrence of most adverse experiences (e.g., sexual abuse, psychological abuse, substance misuse, mental illness etc.) among adolescent patients, and those experiences were considerably more prevalent among individuals who were cyberbullied. Female patients, who had past experiences of cyberbully, were found to be clinically diagnosed with depression or suicidal attempts/ideation more than male patients in the same sub-group, whereas male patients had higher instances of being diagnosed with ADD/ADHD and mood disorder. Similarly, **chapter 4** highlights the severity of risky health behaviors, like eating disorder, within individuals who get influenced through self-harassment that take place in online communities by the name of motivation or inspiration.

The outcomes of this study contribute to the discussion of incorporating these social and behavioral indicators into clinical practices, as they are often invisible and may not be detected without particular patient assessment [192]. The Ecological Systems Theory of Urie Bronfenbrenner is founded on the notion that a person's development is influenced by "nested" levels of their surroundings [124, 373]. Bronfenbrenner argued that a child's experiences are most powerful in moulding the trajectory of their psychological growth." [368]. Without screening the social and contextual influences surrounding patients, such as their interactions with peers, parents, teachers, it is hard to design appropriate interventions as these indicators can potentially influence the bullying experiences and consequential behavioral changes within a child. Using these patterns of influence and online interactions, providers can assess the triggers and perspectives of patients that potentially drive them towards adopting dangerous health behaviors, necessitating greater care during treatment [130].

It is typical practice for healthcare providers to provide each adolescent patient with individual time without their parents present in order to establish a safer and supportive setting for conversations about topics that may be more private or stigmatizing for adolescent patients [433]. However, physicians, psychologists, and nurses are still on the periphery of efforts to assess, prevent, educate, and manage cyberbullying within patients who may wish to share their experiences and seek specialized care from their healthcare providers [421]. Measuring cyberbullying in clinical setting is difficult because there are few valid and reliable instruments available that can measure important socio-cultural factors that contribute to different cyberbullying experiences. For instance, outcomes from **chapter 5** and **6** imply several shortcomings in the current operationalization of cyberbully screening in clinical settings. Using PBH patient data, the studies demonstrates that the quality of screening instruments, screened data, and how data is collected in hospitals are still not validated and reliable everywhere, and that faulty/invalidated screening instrument and data can result in misdiagnosis and misseddiagnosis of patients. Due to the confusion about the both conceptual and operational definition of cyberbully, there is a substantial gap in the assessment process of young patients in clinical settings [406]. Findings from **Chapter 6** also support this notion and address the existing screening instrument's inability to screen patients at PBH for critical indicators such as various sorts of verbal, sexual, and racial online bullies.

Within the mental and behavioral health space, the use of validated screeners for diagnostic purposes is common, but it varies from practice to practice and from disease to disease. Unfortunately, there are no specific screening tool(s) used by health care providers to assess adolescents' exposure to cyberbullying or cyberbullying victimization [121, 453]. Even though there are some existing screening scales that are frequently used in academic or some healthcare setting, they rarely consider core aspects of harassment, such as anonymity, cultural context, social norms, the broader audience etc. in the definition of cyberbullying [92]. Therefore, my outcomes in **Chapter 7** address these problems and make design recommendations that can improve the existing practice of screening adolescents for online risky behavior and experiences, such as cyberbullying, in clinical settings. More particularly, this study promotes patient-centered screening, where questions are structured around patients' readability level, mental development, and concerns around survey fatigue [365]. Patient-centered care puts special emphasis on the patient and their unique health requirements [457]. Cyberbullying can be a life-changing experience for many young teenagers who may not receive the necessary support from their surroundings. Often, their environment can exacerbate their struggle, increasing the severity of the behavioral and emotional effects they face.

Thus, it is important that an efficient assessment protocol should be in place that not only screens adolescent patients' cyberbully experiences by contextualizing them with different social, cultural, mental and technical cues that are around the patients, but also establishing safe patient-clinical relationship where patients can have a venue to share their expectations and experiences with the providers and received the expected care. Thus, rather than blindly accepting, shortening, or expanding a certain existing scale to satisfy the need for an efficient assessment of cyberbullying, in **chapter 7**, I chose to create a refined version of the cyberbully screening tool adapted from providers' recommendations, my own research, and current literature on existing tools to guarantee that the core concepts of cyberbullying were covered, making the tool more theoretically and empirically sound. This is significant because without a validated and conceptually sound screening instrument, healthcare providers will struggle to prevent the long-term health repercussions of youth bullying/cyberbullying in clinical settings [217, 172, 605].

Integrating Digital Signals into Clinical Practices

There is an ongoing debate about the most appropriate methodological approaches to implement screening in the clinical workflow. Many hospitals and medical practices fail to adequately incorporate screened data on patients' social and behavioral components into their EHR due to a lack of in-depth healthcare workflow analysis [68]. Good workflow design has significant (both anticipated and unanticipated) consequences on care delivery, and conscious workflow design has been shown to boost the efficiency of existing work processes [135, 134]. There are currently no standardized processes or workflow across health systems for treating extremely vulnerable individuals for social and behavioral domains such as cyberbullying or other similarly risky internet practices [599]. While clinical workflow can differ hospital to hospital, my research in **chapter 7** on PBH's inpatient facility in acute settings showed there are multiple process related concerns that limit the operationalization of cyberbully screening for adolescent patients.

Without a comprehensive protocol for implementing and integrating screening into the clinical setting, it becomes extremely difficult for providers to use the assessment during treatment planning. In **chapter 7**, I classify these limitations in the current clinical workflow as obstacles in information flow, time and behavioral constrains, and organizational limitations. Healthcare requires intricate processes that combine both clinical and administrative duties [457]. Research community has long been intrigued by the difficulties and complications that come up when handling patient related data in highly collaborative hospital systems and clinical teams [493]. The ability to use reliable data for collaborative decision making in healthcare to deliver the best and most informed treatment to patients with cyberbully concerns is currently limited. While healthcare system like electronic health records aid health workers (e.g., medical specialists, therapists, nurses) in making collaborative decisions on patient's health, it may also inherit internal biases [615] in analyzing observational health data without careful consideration to the patients and their contexts- a theme explored in SIGCHI [283, 285] and further discussed in my dissertation in **chapter 5** and **6**. Although the importance of addressing the needs of clinicians cannot be overstated, concentrating on patient requirements and assistance helps guarantee that newly developed workflow fully utilizes all possibilities of current information technology solutions [457]. Therefore, **chapter 7** aims to address this risk and improve treatment suggestions by advocating systematic and structural integration of critical cyberbully information into patients' online health records. I specifically suggest for incorporating strategic screening administration, streamlining information sharing and collaboration among care teams, and using advanced computational methods on structured/unstructured patient data that can extract high quality information on patients' cyberbully experiences. Outcomes in **chapter 5** report that in a clinical setting, it is possible to observe discrepancy between multiple data sources. Without combining multiple data sources during assessment, it is possible to produce faulty and erroneous information on patients. [540] presents insights into the integration of structured and unstructured data to automate clinical code assignment and found that such integration of data enhances the utility of the EHRs and improves the performance of computational methods during information extractions. Having an integrated EHR also allows patients to collaborate with clinicians during the decision-making process when there are trade-offs between treatment alternatives, ensuring that patient preferences and values are incorporated into the medical plan [216].

It is unfortunate that there are little efforts to systematically incorporate and utilize data on patients' social factors in patients' EHRs, which could potentially increase the system's usefulness, reduce patient and provider discomfort, and allow flexibility to address individual patient's specific social and clinical needs [243, 263, 264]. Producing quality information on patients' socio-technical and socio-cultural involvement that have detrimental impacts on their lifestyle and health will not be useful, if providers are not aware of how to address them clinically and timely within the treatment program. Even though use of different technologies, like social media has, been pervasive for over a decade, the education curriculum of health care professionals has not necessarily changed to reflect this, and, thus, some clinicians are not properly trained to address the impacts of such platforms on patients' health behaviors [444]. If social media data is to be integrated into the healthcare ecosystem, a more comprehensive understanding of how mental illness manifests itself in online social spaces is required. Thus, **chapter 7** discusses the significance of such education, training, and resources in healthcare settings and suggests that practitioners who administer screening or access the information need to be well-trained and well equipped with resources to comprehend the intended use of the screening tool and its psychometric properties, to be aware of its limitations, and to interpret results in the context of the child's life [162, 183]. In a larger scheme of quality of care, having resources available and easily accessible at all stages of patient-provider engagement—not just for clinicians but also for patients—will benefit both providers and patients by resolving the potential exclusion of those patients from the standard of care who might not disclose their negative experiences on online platforms to their providers during treatment but might still benefit from the resources.

Ethical Considerations

Aside from the focus of this body of work, I regularly dealt with key ethical tensions and challenges. In this section, I'll discuss the various ethical concerns I encountered while performing this research, as well as the decisions I made in each stage.

Many of my research include publicly accessible social media- a common theme in most other social computing work researching mental health aspects. I collected this data without user knowledge or consent – an accepted practice when dealing with public data [176, 478, 479]. Many social networks require members to agree to a worldwide, non-exclusive, royalty-free license in order to utilize the platform and share their material with the rest of the world [476]. It allowed me to obtained data without the knowledge or consent of the content creators. While this practice is prevalent in HCI, there are some assumptions that may be problematic. As suggested by [652], it is unethical for researchers to use any personal information obtained through social media if the data or information is restricted to a certain group of people or communities, even though in general sense they are public to that specific communities [446]. Keeping ethical considerations in mind, I only collected information on groups and pages via search phrases that were already openly public for everyone on social media platforms [229, 123] and were not limited to a specific community of users. Additionally, to ensure anonymity of the users in my dataset, me and my research team have replaced all actual usernames with pseudonyms. We have also used representative media and text examples and/or edited any direct quotes to ensure that the user-generated content reported in this paper cannot be searched and connected to the account that posted it.

During the research described in Chapter 3, it was critical that my participants were handled with the utmost respect and ethics. Obtaining access to a gender and sexually minor population with severe harassing experiences and discrimination was challenging, which is why I was extra precocious to ensure they feel comfortable during the data collection. When working with vulnerable populations, such as this one, and asking them to entrust you with sensitive information ranging from social media data to online sex work, additional procedures were taken that were vital. For example, a NGO worker was always present during all of the participant interviews to monitor the responsiveness of the participant and interject with a specific question if they felt the participant was becoming uncomfortable or noticeably impacted by the discussion taking place during the interview. As Hijra communities are run by these NGOs, this step was taken to ensure none of our participant gets in trouble to share their data.

As my dissertation is a combination of research that fall under the domains of social computing and healthcare system, I also had to take extensive precautions to address the safety and ethical concerns of working with patient data.In my study, all researchers who interacted directly with patients' data and performed provider interviews had to complete additional training beyond that generally required for working with human subjects. To ensure we regulated all the rules under HIPAA and PHI, we only collected a limited amount of demographic information (such as name, zip code, address, etc.) and deidentified all these information in order to lessen the potential consequences of a data spill. As data from patients' clinical notes often included very graphic details related to abuse, neglect, and general maltreatment of the youth patient, several safety provisions, like QPR [16] and ASIST [4], were enacted for the team. The clinical representatives including the nurse manager for the Parkview Behavioral Health In-Patient Youth Services Division and the Director of Community Services for Parkview Behavioral Health were also routinely confined to ensure the mechanism of collecting and analyzing patient data. It helped me to interpreter data without any researcher bias.

Future Work

There are several research directions that would be interesting to expand beyond the scope of this dissertation. For instance, my findings in this dissertation are restricted to populations which are not representative of humanity as a whole. While the first phase of my research attempts to break free from Western notions of online harassment and focuses primarily on at-risk populations from the global south, the implementations of such understandings in healthcare have primarily been explored within White or Caucasian populations majority of whom were from the same geographical area in the Midwest United States. While my work sought to establish diversity of gender and ethnicity within the participant pool, there is a compelling need to understand how people's interactions on online platforms impact their mental and behavioral health lifestyles in broader contexts and societies in the United States as well as in non-Western contexts.

Additionally, this dissertation has employed mixed methods approaches and integrated practices from both qualitative and quantitative research to create a holistic assessment tool and workflow to address cyberbully related concerns within adolescent patients in clinical context. While the refined tool I recommended was designed based on different social, cultural, clinical aspects that have an impact on how an individual experiences negative experiences online or through technology, it is important to analyze the reliability and validity of the tool. The validity of a measuring instrument relates to whether or not it measures what it is supposed to measure [604]. The main objective of this refined cyberbully tool is to screen patients who have experienced cyberbullying and are struggling with coping mechanisms or serious behavioral or mental health issues. Knowing more about these patients would not only enable healthcare providers to identify patients who require additional clinical and social assistance, but will also enable them to create more specialized treatment plans. Thus, it is crucial to test the reliability and validity of the tool.

There are multiple ways one can test the efficacy of the tool, such as using Kuder-Richardson coefficient method [604], Cronbach's alpha [628] and so on. Additionally, including assessments by independent subject matter experts (SME) on how well items represent the chosen topic can be a technique to confirm the tool's content validity [604]. To ensure this content validity and presentation of the screening, the proposed tool is currently under review by the leadership at Parkview Youth Behavioral Health Hospital, and there is an ongoing conversation going on to do a small pilot study to analyse the responses to the assessment and include the strategies and thought processes of individual patients. It may be possible to identify sources of consistency that are unrelated to the concept being measured by analyzing the variation in response patterns among various patient groups [401].

Additionally, as the scope of this dissertation did not include exploring traditional bullying or cyberbully from a perpetrators perspectives, future work can focus on these aspects and can design extension of the current proposed tool for more holistic exploration. Despite systemic difficulties, such investigations can yield valuable knowledge on patients' mental and behavioral health, enabling healthcare professionals to make better treatment recommendations. For instance, future research can develop systematic recommendations on patients' treatment interventions and suggests new channels of discourse between provider-patient during treatments by extending my design recommendations on assessment protocols to other youth-based behavioral domains like cyberbullying aggression, substance abuse, suicidal ideation, or other adverse childhood events [376, 192].

Conducting social computing research and linking the findings to healthcare practices is interesting, meaningful, and essential. Connecting social computing research with healthcare has opened new avenue of knowledge that take advantage of technology mediated interactions with mental health concerns [110]. My research has shown that the healthcare industry, particularly the mental and behavioral health sector, is becoming more dependent on different aspects of human computer interactions, interactive health technologies, and data analytics techniques that can assist patients and providers in creating individualized treatment plans. Even though there are benefits to combining social computing research methodologies and outcomes with health informatics and healthcare systems, not often we see such systematic collaboration in the field of behavioral health, particularly among at-risk populations. To optimize the diagnostic categorization of social events, like cyberbullying, digital self-harm, and adverse childhood experiences, assessed by quantitative models in healthcare, it is crucial that researchers and system designers in the social computing and HCI domains must work with psychometricians in the healthcare domain. The primary focus of psychometricians in healthcare is on creating and validating models or tests that evaluate intricate psychological concepts or constructs, such as a person's drive, rage, attitude, or personality [515]. As my research in chapter 5,6, and 7 show cyberbullying and trauma in youths continue to rise or change forms and implementation of efficient assessment tools is paramount. Complementing Machine Learning-based analysis with the analytical workflow of psychometric approaches will maximize accurate collaborative decision making on patient assessment and appropriate treatment process [266, 498, 504]. However, is there any established protocol that dictates how and which health-related variables should be included in computational models to predict or identify impacts of socio-cultural and socio-technical influences within patients? Moreover, how can we better reform incentive structures to establish systematic collaboration between researchers and healthcare providers in the domain of mental and behavioral health?.

Conclusion

My research focuses on defining how online risky activities and behaviors like online harassment and cyberbullying can lead to clinical manifestations of mental and behavioral health concerns within youths. For my research, I have employed mixed methods approaches and integrate practices from both qualitative and quantitative research. It is imperative to incorporate different methods to deeply study socio-technical systems that are embedded in a complex healthcare domain. Developing and incorporating different sources of information also helps the researchers understand the social, and cultural contexts within which the concept of cyberbully is situated as well as design holistic solutions that offer high utility and improve the nature of practice in healthcare system. The findings and design frame proposed in this dissertation not only suggest structured interventions against cyberbullying in healthcare domains, but also emphasize the importance of using such holistic prevention strategies both in technical and clinical settings that address multiple, not just one, risky online behaviors during adolescence. Mental health professionals working with adolescents with problematic internet use should explicitly evaluate the presence of other associated risky online behaviors, and adapting this proposed tool and workflow can be beneficial during such evaluation.

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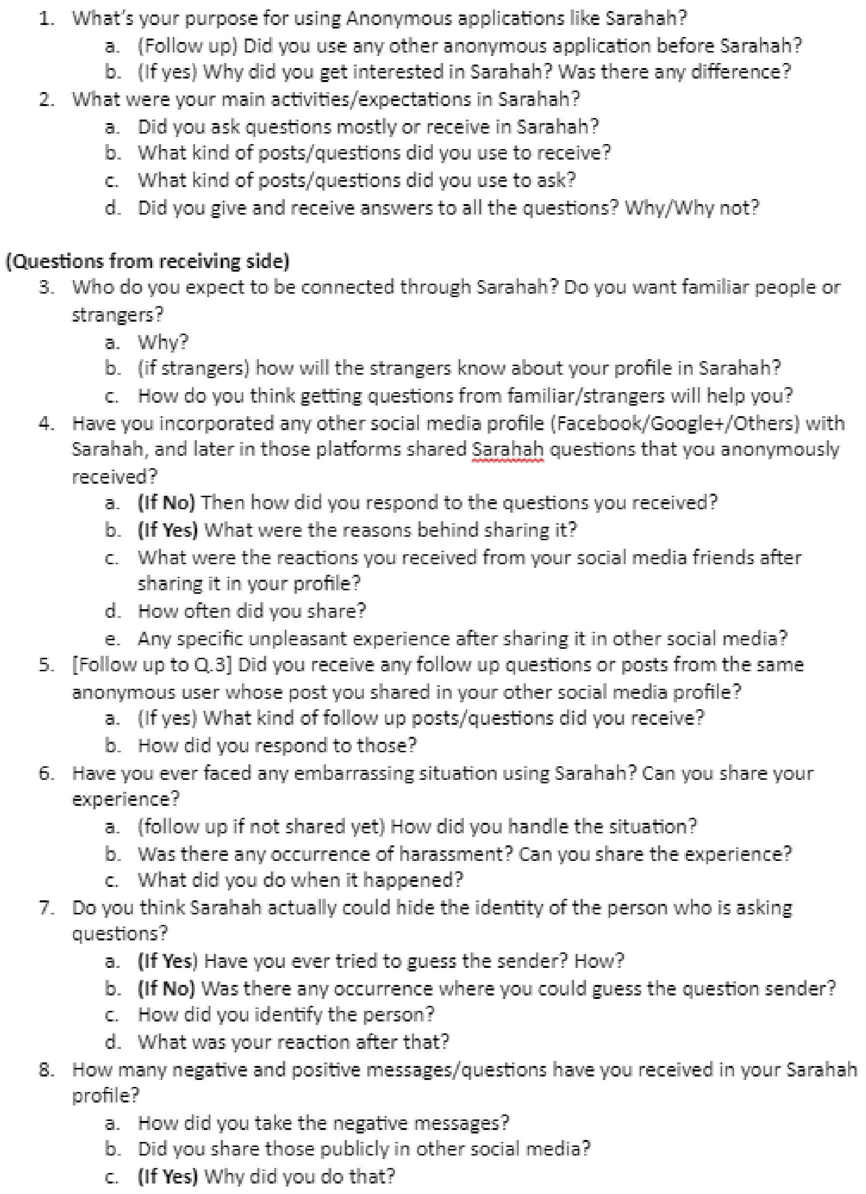
APPENDIX A. ANONYMOUS APP USE

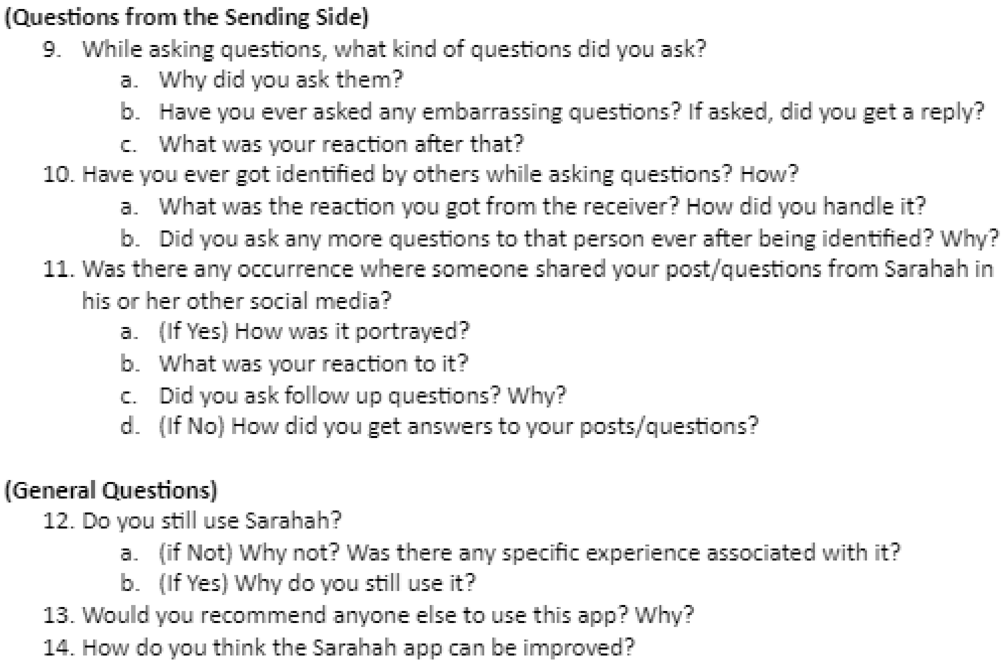
A1. Questionnaires for Interview



1. What's your purpose for using Anonymous applications like Sarahah?
    a. (Follow up) Did you use any other anonymous application before Sarahah?
    b. (If yes) Why did you get interested in Sarahah? Was there any difference?
2. What were your main activities/expectations in Sarahah?
    a. Did you ask questions mostly or receive in Sarahah?
    b. What kind of posts/questions did you use to receive?
    c. What kind of posts/questions did you use to ask?
    d. Did you give and receive answers to all the questions? Why/Why not?

(Questions from receiving side)

3. Who do you expect to be connected through Sarahah? Do you want familiar people or strangers?
    a. Why?
    b. (if strangers) how will the strangers know about your profile in Sarahah?
    c. How do you think getting questions from familiar/strangers will help you?
4. Have you incorporated any other social media profile (Facebook/Google+/Others) with Sarahah, and later in those platforms shared Sarahah questions that you anonymously received?
    a. **(If No)** Then how did you respond to the questions you received?
    b. **(If Yes)** What were the reasons behind sharing it?
    c. What were the reactions you received from your social media friends after sharing it in your profile?
    d. How often did you share?
    e. Any specific unpleasant experience after sharing it in other social media?
5. [Follow up to Q.3] Did you receive any follow up questions or posts from the same anonymous user whose post you shared in your other social media profile?
    a. (If yes) What kind of follow up posts/questions did you receive?
    b. How did you respond to those?
6. Have you ever faced any embarrassing situation using Sarahah? Can you share your experience?
    a. (follow up if not shared yet) How did you handle the situation?
    b. Was there any occurrence of harassment? Can you share the experience?
    c. What did you do when it happened?
7. Do you think Sarahah actually could hide the identity of the person who is asking questions?
    a. **(If Yes)** Have you ever tried to guess the sender? How?
    b. **(If No)** Was there any occurrence where you could guess the question sender?
    c. How did you identify the person?
    d. What was your reaction after that?
8. How many negative and positive messages/questions have you received in your Sarahah profile?
    a. How did you take the negative messages?
    b. Did you share those publicly in other social media?
    c. **(If Yes)** Why did you do that?



(Questions from the Sending Side)

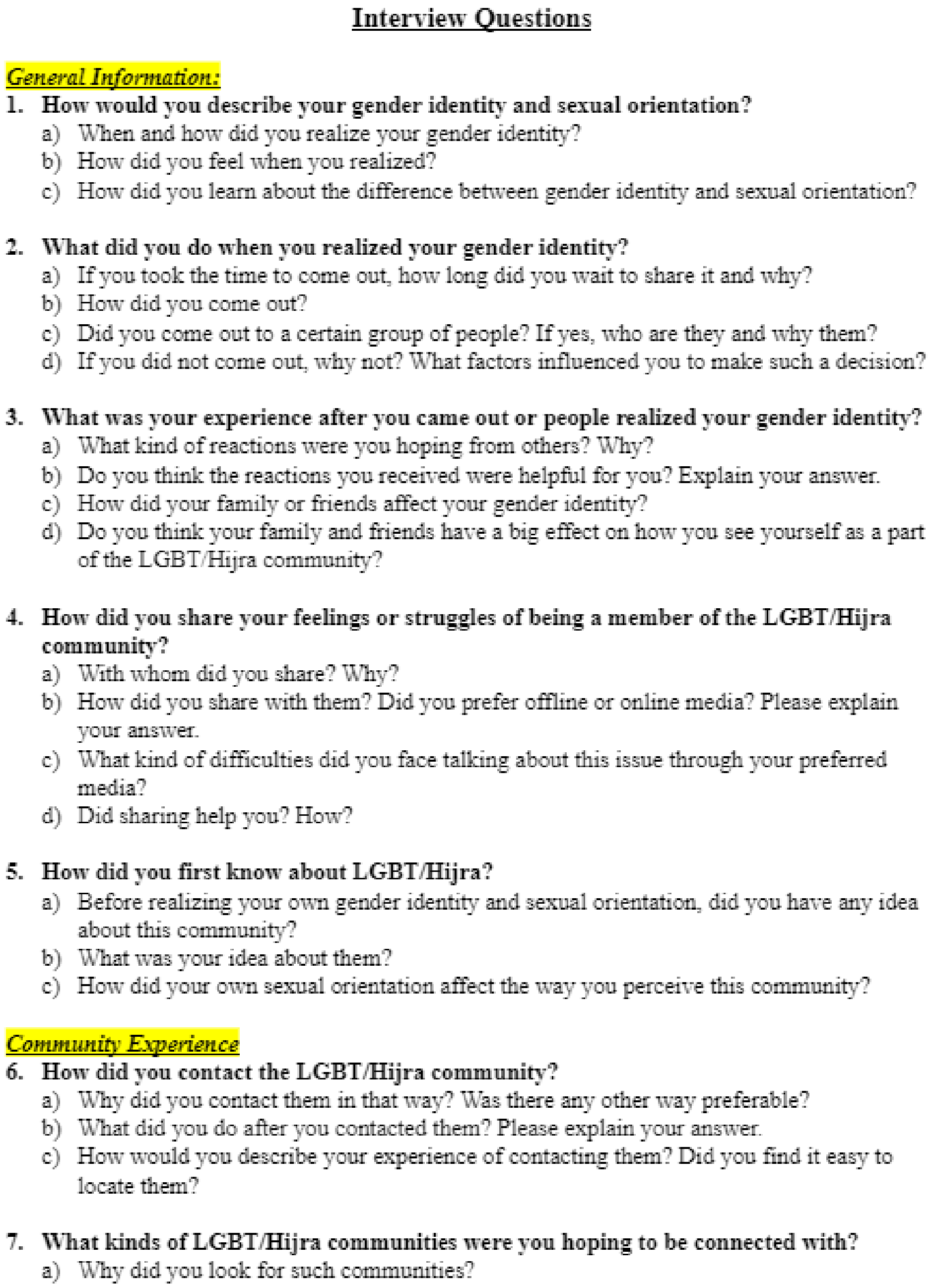
9. While asking questions, what kind of questions did you ask?
    a. Why did you ask them?
    b. Have you ever asked any embarrassing questions? If asked, did you get a reply?
    c. What was your reaction after that?
10. Have you ever got identified by others while asking questions? How?
    a. What was the reaction you got from the receiver? How did you handle it?
    b. Did you ask any more questions to that person ever after being identified? Why?
11. Was there any occurrence where someone shared your post/questions from Sarahah in his or her other social media?
    a. (If Yes) How was it portrayed?
    b. What was your reaction to it?
    c. Did you ask follow up questions? Why?
    d. (If No) How did you get answers to your posts/questions?

(General Questions)

12. Do you still use Sarahah?
    a. (if Not) Why not? Was there any specific experience associated with it?
    b. (If Yes) Why do you still use it?
13. Would you recommend anyone else to use this app? Why?
14. How do you think the Sarahah app can be improved?

APPENDIX B. HIJRA INTERVIEW & GROUP ACTIVITY

B1. Questionnaires for Interview and Group Discussions



Interview Questions

General Information:

1. **How would you describe your gender identity and sexual orientation?**
    a) When and how did you realize your gender identity?
    b) How did you feel when you realized?
    c) How did you learn about the difference between gender identity and sexual orientation?

2. **What did you do when you realized your gender identity?**
    a) If you took the time to come out, how long did you wait to share it and why?
    b) How did you come out?
    c) Did you come out to a certain group of people? If yes, who are they and why them?
    d) If you did not come out, why not? What factors influenced you to make such a decision?

3. **What was your experience after you came out or people realized your gender identity?**
    a) What kind of reactions were you hoping from others? Why?
    b) Do you think the reactions you received were helpful for you? Explain your answer.
    c) How did your family or friends affect your gender identity?
    d) Do you think your family and friends have a big effect on how you see yourself as a part of the LGBT/Hijra community?

4. **How did you share your feelings or struggles of being a member of the LGBT/Hijra community?**
    a) With whom did you share? Why?
    b) How did you share with them? Did you prefer offline or online media? Please explain your answer.
    c) What kind of difficulties did you face talking about this issue through your preferred media?
    d) Did sharing help you? How?

5. **How did you first know about LGBT/Hijra?**
    a) Before realizing your own gender identity and sexual orientation, did you have any idea about this community?
    b) What was your idea about them?
    c) How did your own sexual orientation affect the way you perceive this community?

Community Experience

6. **How did you contact the LGBT/Hijra community?**
    a) Why did you contact them in that way? Was there any other way preferable?
    b) What did you do after you contacted them? Please explain your answer.
    c) How would you describe your experience of contacting them? Did you find it easy to locate them?

7. **What kinds of LGBT/Hijra communities were you hoping to be connected with?**
    a) Why did you look for such communities?

b) How did you or do you prefer to be connected with your preferred community?
c) What factors did work behind your preference?
d) Did your gender identity and sexual orientation influence your decision to find communities to be connected with?
e) Do you think the way you searched for your preferred community has any influence on the functioning of that community?
f) Did you find what you were looking for in a community? Please elaborate on your answer.
g) How do you think your preferred community will help you in life?

8. What was your preference while locating a preferred group online?
a) Did you have enough preferable LGBT/Hijra community representation online? Why do you think it is like this?
b) Did you maintain communication only with the LGBT/Hijra community or did you have other preferences?
c) Do you have any specific language/words/similes/metaphors/phrases that as a member of this community you use within the group online? What are they?
d) Do you have or know of any secret online group for LGBT/Hijra community in Bangladesh? If yes, how did you get to know about them?
e) How are they different compared to public communities online?
f) How efficient do you think it is to communicate in a secret online group than in public online group for Hijras/Transgender people?
g) Do you think anonymity and privacy are big concerns for LGBT/Hijra populations? Why?
h) How would you maintain it?

9. How would you describe your participation in the offline LGBT/Hijra Community?
a) Are you an active member of that community? How often do you meet them or communicate?
b) What are the preferred ways of communication?
c) Did you face issues maintaining your participation in the community offline? How?
d) How would you describe the group dynamics of that community? What do they promote?
e) Do you support group dynamics? Please elaborate on your answer.
f) Have you ever felt “not belonging” as a part of that group? Why so?
g) What kind of information/communication/help did you expect from those group?
h) How did the community meet your expectations of being a part of it?

10. How would you describe your participation in the online LGBT/Hijra Community?
a) Are you a part of any public online group/platform where only LGBT/Hijras communicate or share with each other?
b) If yes, what is the name of that group? How did you learn about it/them?
c) Are you an active member of that community? How often do you communicate with each other? justify
d) How would you describe the group dynamics of that community? What do they promote? How many members do they have?

e) Do you support group dynamics? Please elaborate on your answer.
f) Have you ever felt "not belonging" is a part of that group? Why so?
g) What kind of information/communication/help did you expect from those groups?
h) How did your expectations meet the realities? Please explain your answer.

11. **How do you think online communities differ from offline communities in terms of rules, diversity, mentality, resources, accessibility and so on?**
    a) Were there different diversified groups in the LGBT/Hijra Community when you met Online? What are the groups?
    b) Were there rules to follow to be a part of that online community? If yes, can you mention some?
    c) Were there outsiders in the online community? If yes, how would you define them as outsiders?
    d) What kind of communications did you maintain with outsiders?

12. **How did your online participation influence your offline activities?**
    a) Did you always maintain online communications or did you prefer both platforms?
    b) Did your online participation influence you to meet people offline? How often did you do so?
    c) How did your online participation influence you to uphold your gender/sexual identify offline?
    d) Did you take part or arrange any offline activist event for LGBT/Hijra community that was initiated through online platforms? Can you share your experience?
    e) How do the activities of your online communities' shape/reshape the way your offline communities work or function?

13. **How was your experience of being a part of online communities?**
    a) How often did you find it useful to be a part of that online community? How so?
    b) What are the challenges you or someone you know faced being a part of the online communities?
    c) Have you or anyone you know ever been a victim of unwanted experiences or harassment of any kind on these online platforms? Can you share the incident?
    d) Who was responsible for such an incident? Was it someone outsider or insider?
    e) Why do you think the incident happened?
    f) Did you face similar incidents in offline communities? How did you handle those?
    g) How easier or harder do you think it is to handle such situations online than offline?
    h) What kind of social support do you get?

14. **How do you think LGBT/Hijra community is mostly received by others on online platforms?**
    a) Do you think in Bangladesh LGBT/Hijra people have enough representation on online platforms?
    b) Among all the LGBT/Hijra communities, who has the least amount of representation on social media in Bangladesh?
    c) Why do you think it is like that?

d) Does it affect you individually or as a part of that community?
e) How does it affect you?
f) How do you think the situation of LGBT/Hijras can be improved both offline and online?
g) How much do you think it is important to have proper representation of LGBT/Hijra community online?

Individual Preferences:

15. As an LGBT/Hijra, have you used any online platforms/mobile applications for one to one communications?

a) What are those applications?
b) How did you get familiar with such applications?
c) What kind of communications did you maintain there?

16. How did you manage your identity while using the online platform?

a) Did you disclose your true gender/sexual identity?
b) What challenges or advantages did you face for your identity?
c) How did you trust others while disclosing about your gender/sexual identity?
d) Did you have multiple IDs? Why?

17. How difficult is it for you to maintain your identity online?

a) How comfortable are you to post such posts online (both a personal profile and online group)? Do you post anonymously or with your own identity?
b) Why do you do so?
c) What kind of challenges do you think you face as a sexual minority?
d) Have you ever been threatened/felt unsafe/harassed to post something online because of your gender/sexual identity? Can you elaborate?
e) Do you regularly post about your personal emotions/feelings/thoughts online? How do people react to it?
f) Have you ever felt threatened for your own identity online? Can you elaborate?
g) How do you deal with harassment online?

18. What kind of relationship did you build or prefer to build through those platforms?

a) How did you build up relations there?
b) Did the online platform influence your real life in any way?
c) Do you consider those relationships valuable and impactful?

19. What kind of issues do you personally think is important to be discussed in the LGBT/Hijra community?

a) Why do you think those are important to discuss?
b) How often are they properly discussed in offline communities? Elaborate your answer.
c) How often are they properly discussed in online communities? Elaborate your answer.
d) How different are the experiences for you?

20. What kind of posts do you post online?

a) Why do you post them?

b) How often do you post them?
c) Do you use multiple online platforms for multiple purposes? For example, Bigo for private conversation, Facebook for group conversation and so on. Can you explain your answer?
d) Do you use your personal profile to post them?
e) What kind of responses do you get?
f) How often do you post those in an online group?
g) How different is the experience of posting those in your personal profile vs. online communities?
h) Have you ever used an online platform for dating purposes/impression management/social support/being vocal about your sexuality etc.? Can you elaborate on your answer?
i) How was it different from your offline communication?

21. What kind of posts do you prefer to read online?
a) Why do you prefer them?
b) How often do you see these kinds of posts?
c) How do you respond to those posts?
d) Do you think it is easier to share experiences or opinions on issues like sexuality, gender identity, political/religious stance regarding Transgender/Hijra people in these online groups/platforms than offline platforms? Why so?

22. Is there a social movement going on in regards to the Hijra/LGBT community online?
a) What kind of movement? Can you elaborate?
b) Are you actively participating in it?
c) Which side are you on? Why?

23. How do you think, as a part of the LGBT/Hijra Community, online platforms contribute compared to offline platforms in your life to maintain your lifestyle?
a) What are the reasons behind your such preference?

Demographics
24. Please mention your age, level of education, occupation, tentative monthly/annual income, religion, and location.

APPENDIX C. ED CONTENT ANALYSIS

C1. ED Related Hashtag Categories

Categories	**Details**	**Tag Examples**
Inspiration (27.6%)	Terms associated with ED-specific support and other forms of empowerment. Includes pop culture related inspiration, people of color related inspiration, male/ female inspiration as well	#thinspo, #pocthinspo, #kpopthinspo
General Eating Disorders (ED) (29%)	Terms associated with general tweets elated to eating disorder	#EDtwt, #edthings, #eatingdisorder
Anorexia (19.2%)	All terms associated specifically with Anorexia are captured in this category	#anorexia, #proana, #anorexia
Bulimia (3.03%)	All terms associated specifically with Bulimia are captured in this category. Unlike Anorexia, this category also includes central behaviors and activities crucial to the disease of bulimia like binging and purging.	#bulimia, #promia, #mia
Body Part (2.27%)	This category encompasses all terms associated with anatomical parts of the human body. It also includes terms related to desire to see bones, such as bonespo.	#legspo, #ribcage, #bonespo
Body Image (4.36%)	This category encompasses all terms associated with the physical state or body image of the individuals, such as fat, skinny, thin, etc.	#skinny, #slimspo, #FlatTummy

Coach and Tips (0.48%)	All terms related to finding coaching and tips for ED motivations	#coaching, #proanacoach, #proanatips
Emotional/ Mental State (0.1%)	Emotional terms associated with sadness, depression, anxiety, or behaviors associated with these sentiments. These sentiments could be reflective of oneself, the community, or the world	#depressed, #anxiety, #mentalillness
Diet/Food (0.25%)	Food and beverage-related terminology as well as diet related terms and charts are included here	#fasting, #safefood, #abcdiet
Grunge/Goth (0.05%)	This category encompasses gothic and grunge terms associated with eating disorder lifestyle	#grunge, #goth, #darkgrunge
Meanspo (4.54%)	This category encompasses only the terms specifically related to the "mean" way of inspiration. These inspiration/motivation could be reflective of oneself, the community, or the world	#meanspo, #mean, #Meanspo
Suicide/Self-Harm (0.12%)	Explicit and implicit suicidal or self-harm related ideation is included in this category	#proselfharm, #selfharm, #suicide
Viral Platforms (0.2%)	This category includes terms individuals used to connect their ED motivations from other social media platforms. Platforms like Tiktok, Douyin, Instagram, Tumblr , Onlyfans are included here	#douyin, #tiktok, #onlyfansgirls

C2. LDA Primary and Secondary Topics

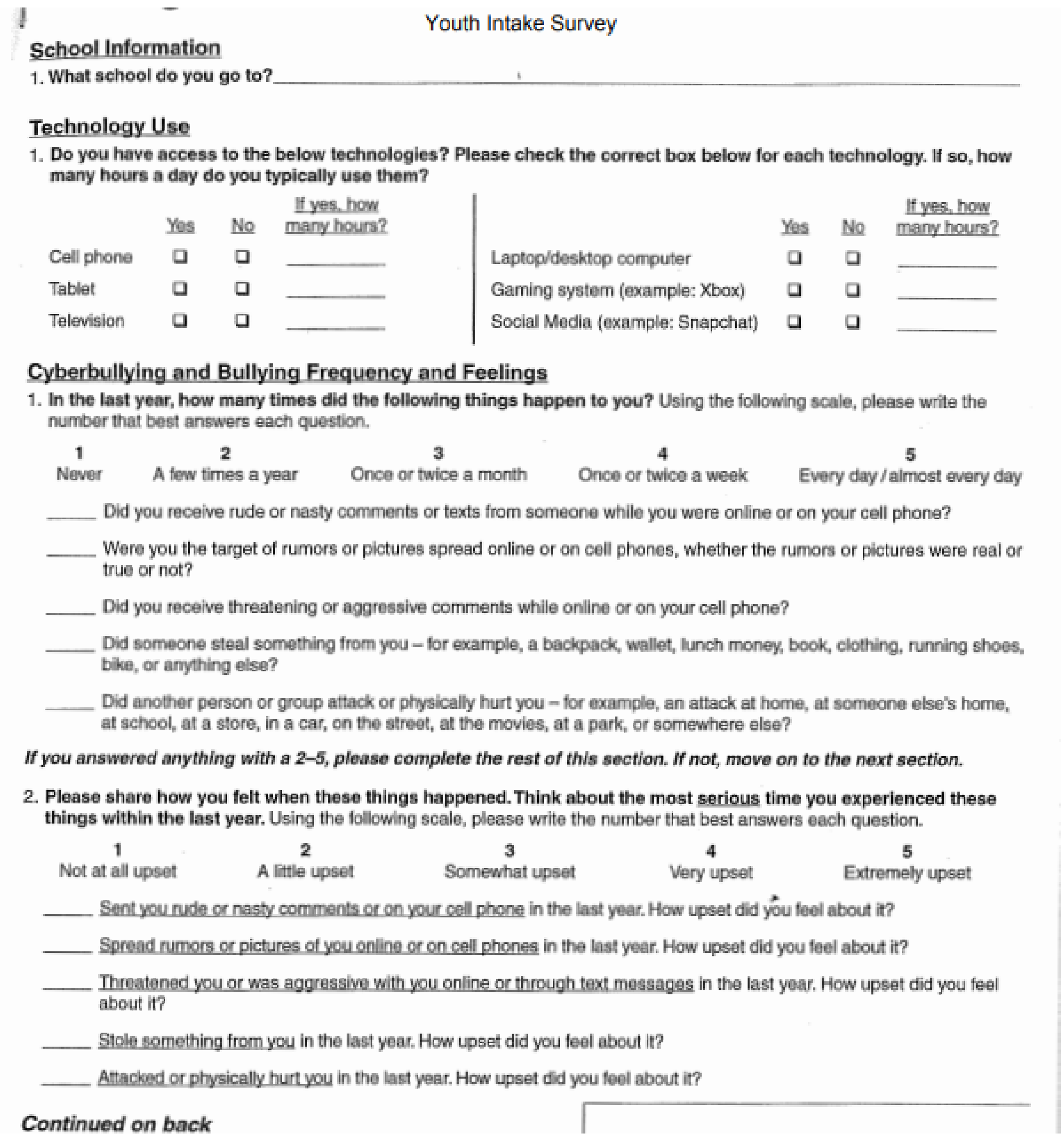
Primary Theme	**Secondary Theme(s)**	**Representative Keywords**
Community Build/ Maintenance	-Motivational conversation -Coping mechanism	edtwt, retweet, motivation, friend, anorexia
Best Practices and plans	-Sharing best practices (e.g., melatonin to stay asleep so can't eat; laxatives for IBS; fasting tips) -Daily updates/Plan	group, feel, tips, binge, today
Specific ED Inspiration	-Desired ideals/Longing for desired actions/ Celebrity idolization - Malespo/gender specific inspiration	body, goal, malespo, wanna, wait
Weight loss setting/status	-Accountability/status -Weight loss	weight, lose, pound, goal, loss
Thought Processes during active ED	-Antagonistic rhetoric/ negative thought process (Struggle, Meanspo) -Self-realization/feelings	Fuck, hungry, look, disgust, feel
Presentation of (ED) self	-Outwards exhibitions of diet, meal-prep and status -Negative reflections of others to build up oneself -Gender/ethnicity (internal and external)	eat, starve, hate, self, people
Fitness/Diet (Diary type discussions related to process of fitness diet; more intrinsic)	-Fitness Regime -Seeking Advice/Q/A -Resource sharing (including specific social media content providers)	calorie, water, workout, fast, know
Personal reflection on body image	-Tone (Neutral, sad, frustrated, defeated) -Specific body traits	skinni, want, imagine, thigh, leg
Engagement with sub-communities	-Reaching sub-communities for ED (international and known sub-communities) - ED journey (withdraws/ relapse) - Impacts with community (toxicity/disorder)	bslyw, abwtb, waniliowemleko, disorder, toxic
ED experiences and values	-Mis-category of ED hashtags -Ed related memes -Valuing ED lifestyle (Earning/deserving)	edtwt, edmem, deserve, hard, food

C3. NMF Primary and Secondary Topics

Primary Theme	Secondary Theme(s)	Representative Keywords
Community based characteristics and curating	- Community gate -keeping/building between Twitter to Tiktok -General thinspo	edtwt, mutuals, dailythin, calorie, workout
Popularity of major community member	-User has been suspended and content analysis can't be conducted	TikTokDiets, block, instagram, leave
Disorder specific community engagement	-Proana Thinspo -Proana diet/fasting (calorie counting/exercise)	proana, promia, anorexia, edtwitt, diet
Community building	-Membership status (active/inactive) -Expanding the community (new-connections/new-additions)	like, mutual, follow, friend, active
ED related Aspiration	-Body traits (including Malespo/poc inspiration/ clothing) -Diet/fast updates -Personal reflections/ accountability	skinni, thinspir, edtwitt, girl, leg
Weight Loss	-Community support/tips (motivations) -Updates (struggle/status/ plan)	lose, weight, pound, goal, know
Support/Motivations during active ED	-Criticism/Meanspo (inward/outward) -Motivation/support (inward/outward) -Seeking meanspo	meanspo, send, edtwitt, motivation, need
Targeted engagements and presentations of ED journey	-Specific components of ED (Body traits/clothing/ disciplinary motivations) -Group chat (social media/ fasting groups)	group, friend, toxic, fast, chat
ED specific reflections	-Daily ED reflections (emotions/events) -Comparison reflecting ED self (outward-celebrity/ personal relationships) -ED memes -(Positive) Encouragement/ tips (outwards)	think, edmem, funnier, everytim, feel
Desired ED lifestyle	-Tone (frustration/self-hate) -Extreme idealization of ED values (extreme: hard work/ goal) - Celebrity Idolization/goal	body, fuck, hate, kill, wish

APPENDIX D. INTAKE SCREENING TOOLS

D1. Youth Intake Screening Tool



Youth Intake Survey

School Information

1. **What school do you go to?**______________________________

Technology Use

1. **Do you have access to the below technologies? Please check the correct box below for each technology. If so, how many hours a day do you typically use them?**

	Yes	No	If yes, how many hours?		Yes	No	If yes, how many hours?
Cell phone	☐	☐	________	Laptop/desktop computer	☐	☐	________
Tablet	☐	☐	________	Gaming system (example: Xbox)	☐	☐	________
Television	☐	☐	________	Social Media (example: Snapchat)	☐	☐	________

Cyberbullying and Bullying Frequency and Feelings

1. **In the last year, how many times did the following things happen to you?** Using the following scale, please write the number that best answers each question.

1	2	3	4	5
Never	A few times a year	Once or twice a month	Once or twice a week	Every day / almost every day

_____ Did you receive rude or nasty comments or texts from someone while you were online or on your cell phone?

_____ Were you the target of rumors or pictures spread online or on cell phones, whether the rumors or pictures were real or true or not?

_____ Did you receive threatening or aggressive comments while online or on your cell phone?

_____ Did someone steal something from you – for example, a backpack, wallet, lunch money, book, clothing, running shoes, bike, or anything else?

_____ Did another person or group attack or physically hurt you – for example, an attack at home, at someone else's home, at school, at a store, in a car, on the street, at the movies, at a park, or somewhere else?

If you answered anything with a 2–5, please complete the rest of this section. If not, move on to the next section.

2. **Please share how you felt when these things happened. Think about the most serious time you experienced these things within the last year.** Using the following scale, please write the number that best answers each question.

1	2	3	4	5
Not at all upset	A little upset	Somewhat upset	Very upset	Extremely upset

_____ Sent you rude or nasty comments or on your cell phone in the last year. How upset did you feel about it?

_____ Spread rumors or pictures of you online or on cell phones in the last year. How upset did you feel about it?

_____ Threatened you or was aggressive with you online or through text messages in the last year. How upset did you feel about it?

_____ Stole something from you in the last year. How upset did you feel about it?

_____ Attacked or physically hurt you in the last year. How upset did you feel about it?

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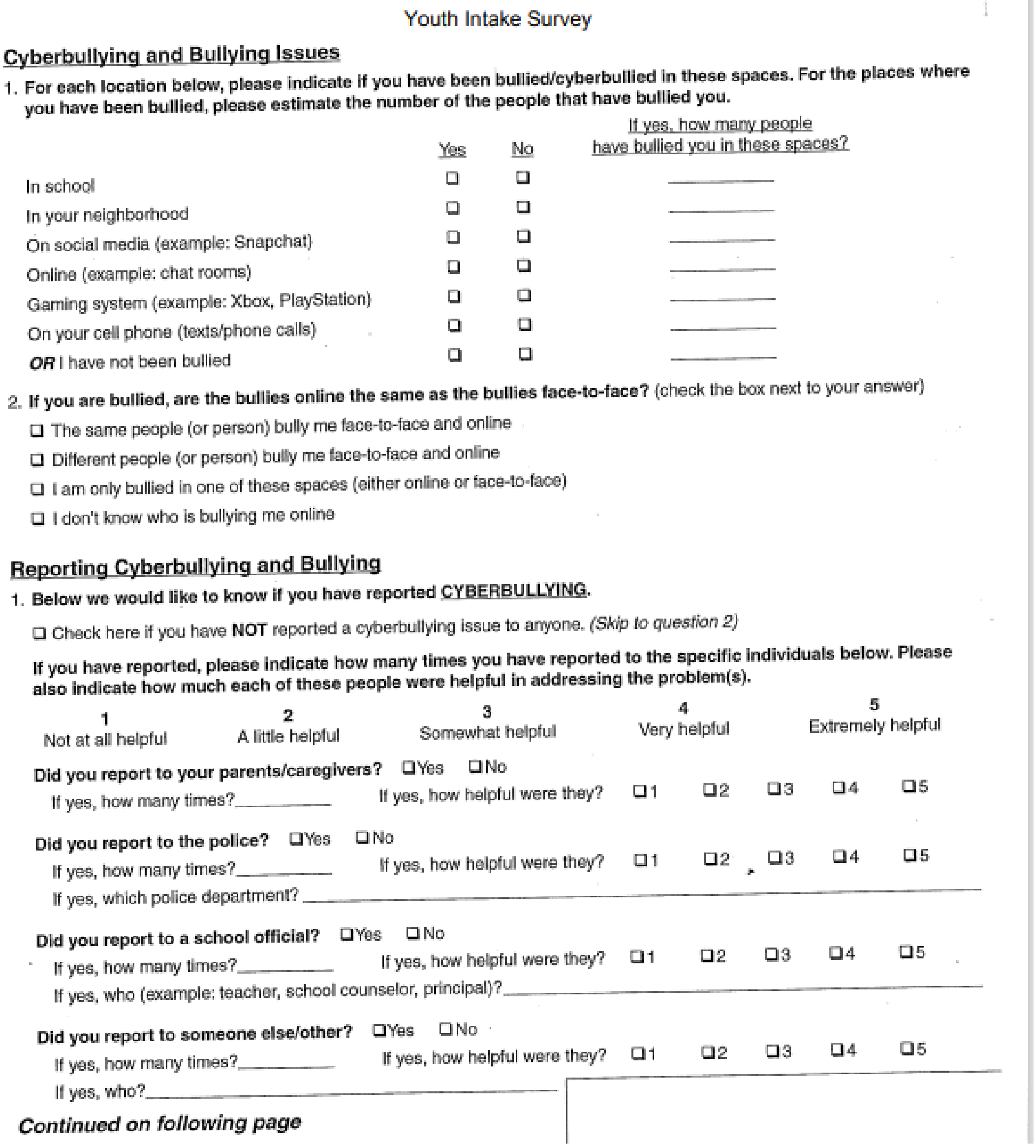

Youth Intake Survey

Cyberbullying and Bullying Issues

1. **For each location below, please indicate if you have been bullied/cyberbullied in these spaces. For the places where you have been bullied, please estimate the number of the people that have bullied you.**

	Yes	No	If yes, how many people have bullied you in these spaces?
In school	☐	☐	________
In your neighborhood	☐	☐	________
On social media (example: Snapchat)	☐	☐	________
Online (example: chat rooms)	☐	☐	________
Gaming system (example: Xbox, PlayStation)	☐	☐	________
On your cell phone (texts/phone calls)	☐	☐	________
OR I have not been bullied	☐	☐	________

2. **If you are bullied, are the bullies online the same as the bullies face-to-face?** (check the box next to your answer)
   - ☐ The same people (or person) bully me face-to-face and online
   - ☐ Different people (or person) bully me face-to-face and online
   - ☐ I am only bullied in one of these spaces (either online or face-to-face)
   - ☐ I don't know who is bullying me online

Reporting Cyberbullying and Bullying

1. **Below we would like to know if you have reported CYBERBULLYING.**

☐ Check here if you have **NOT** reported a cyberbullying issue to anyone. *(Skip to question 2)*

If you have reported, please indicate how many times you have reported to the specific individuals below. Please also indicate how much each of these people were helpful in addressing the problem(s).

1	2	3	4	5
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

Did you report to your parents/caregivers? ☐Yes ☐No
If yes, how many times?________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5

Did you report to the police? ☐Yes ☐No
If yes, how many times?________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, which police department?________________________________

Did you report to a school official? ☐Yes ☐No
If yes, how many times?________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who (example: teacher, school counselor, principal)?________________________

Did you report to someone else/other? ☐Yes ☐No
If yes, how many times?________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who?________________________

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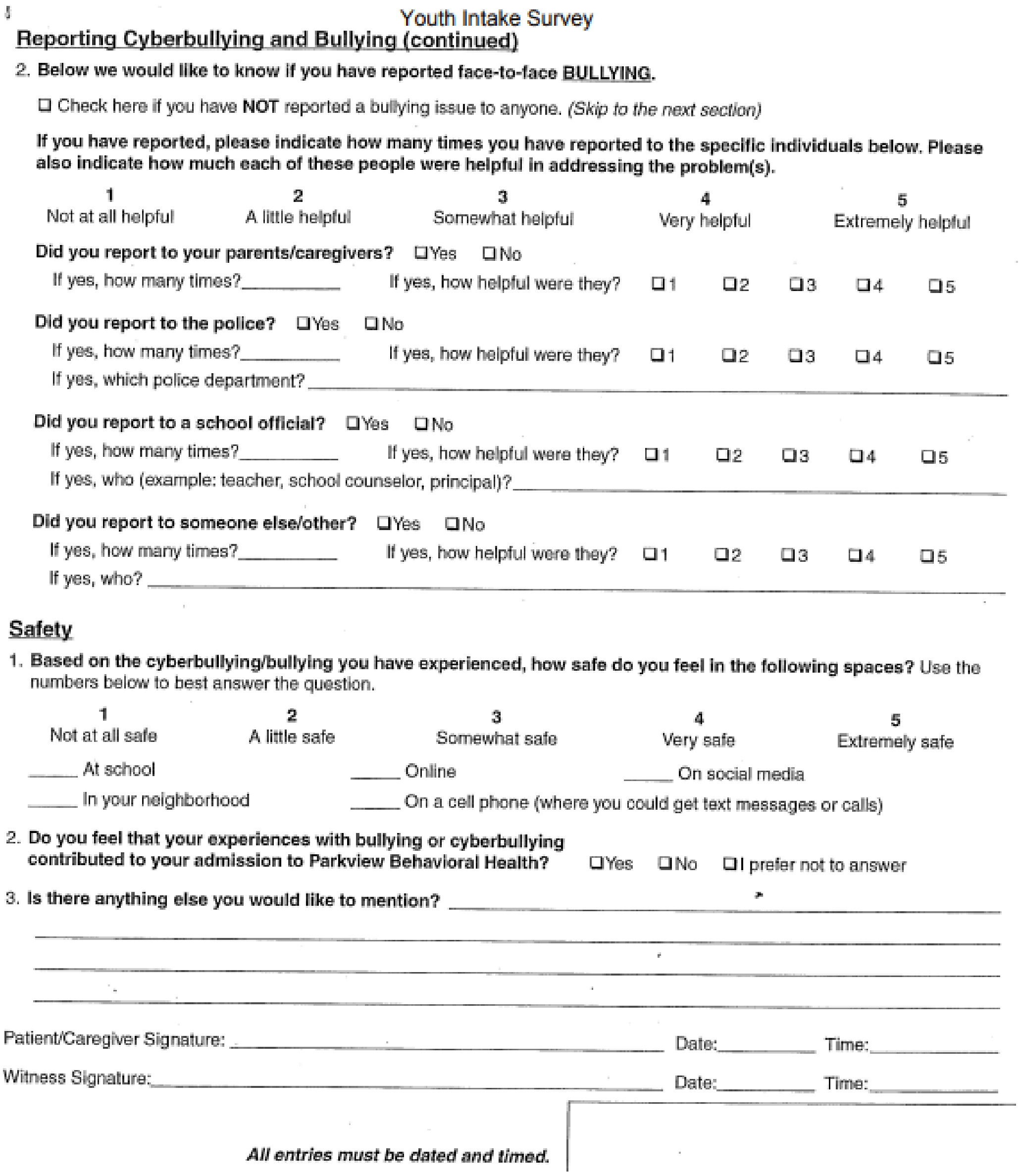


Youth Intake Survey

Reporting Cyberbullying and Bullying (continued)

2. **Below we would like to know if you have reported face-to-face BULLYING.**

☐ Check here if you have **NOT** reported a bullying issue to anyone. *(Skip to the next section)*

If you have reported, please indicate how many times you have reported to the specific individuals below. Please also indicate how much each of these people were helpful in addressing the problem(s).

1	2	3	4	5
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

Did you report to your parents/caregivers? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5

Did you report to the police? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, which police department? ____

Did you report to a school official? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who (example: teacher, school counselor, principal)?______________________

Did you report to someone else/other? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who? ____

Safety

1. **Based on the cyberbullying/bullying you have experienced, how safe do you feel in the following spaces?** Use the numbers below to best answer the question.

1	2	3	4	5
Not at all safe	A little safe	Somewhat safe	Very safe	Extremely safe

_____ At school _____ Online _____ On social media
_____ In your neighborhood _____ On a cell phone (where you could get text messages or calls)

2. **Do you feel that your experiences with bullying or cyberbullying contributed to your admission to Parkview Behavioral Health?** ☐Yes ☐No ☐I prefer not to answer

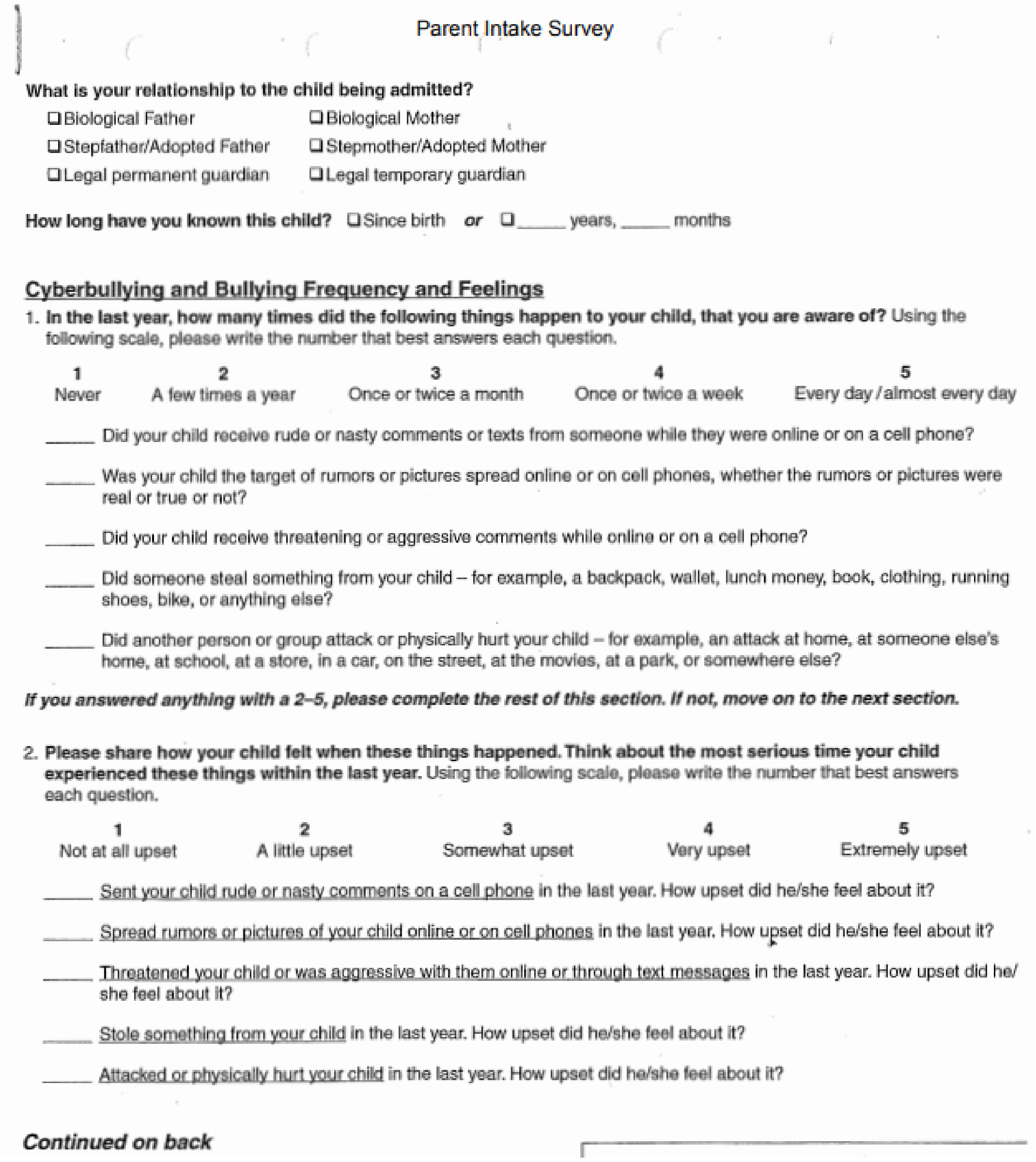
3. **Is there anything else you would like to mention?** ______________________________
____
____
____

Patient/Caregiver Signature: ______________________ Date:__________ Time:__________

Witness Signature:______________________ Date:__________ Time:__________

All entries must be dated and timed.

D2. Parent Intake Screening Tool



Parent Intake Survey

What is your relationship to the child being admitted?

☐ Biological Father ☐ Biological Mother
☐ Stepfather/Adopted Father ☐ Stepmother/Adopted Mother
☐ Legal permanent guardian ☐ Legal temporary guardian

How long have you known this child? ☐ Since birth ***or*** ☐ _____ years, _____ months

Cyberbullying and Bullying Frequency and Feelings

1. **In the last year, how many times did the following things happen to your child, that you are aware of?** Using the following scale, please write the number that best answers each question.

1	2	3	4	5
Never	A few times a year	Once or twice a month	Once or twice a week	Every day / almost every day

_____ Did your child receive rude or nasty comments or texts from someone while they were online or on a cell phone?

_____ Was your child the target of rumors or pictures spread online or on cell phones, whether the rumors or pictures were real or true or not?

_____ Did your child receive threatening or aggressive comments while online or on a cell phone?

_____ Did someone steal something from your child – for example, a backpack, wallet, lunch money, book, clothing, running shoes, bike, or anything else?

_____ Did another person or group attack or physically hurt your child – for example, an attack at home, at someone else's home, at school, at a store, in a car, on the street, at the movies, at a park, or somewhere else?

If you answered anything with a 2–5, please complete the rest of this section. If not, move on to the next section.

2. **Please share how your child felt when these things happened. Think about the most serious time your child experienced these things within the last year.** Using the following scale, please write the number that best answers each question.

1	2	3	4	5
Not at all upset	A little upset	Somewhat upset	Very upset	Extremely upset

_____ Sent your child rude or nasty comments on a cell phone in the last year. How upset did he/she feel about it?

_____ Spread rumors or pictures of your child online or on cell phones in the last year. How upset did he/she feel about it?

_____ Threatened your child or was aggressive with them online or through text messages in the last year. How upset did he/she feel about it?

_____ Stole something from your child in the last year. How upset did he/she feel about it?

_____ Attacked or physically hurt your child in the last year. How upset did he/she feel about it?

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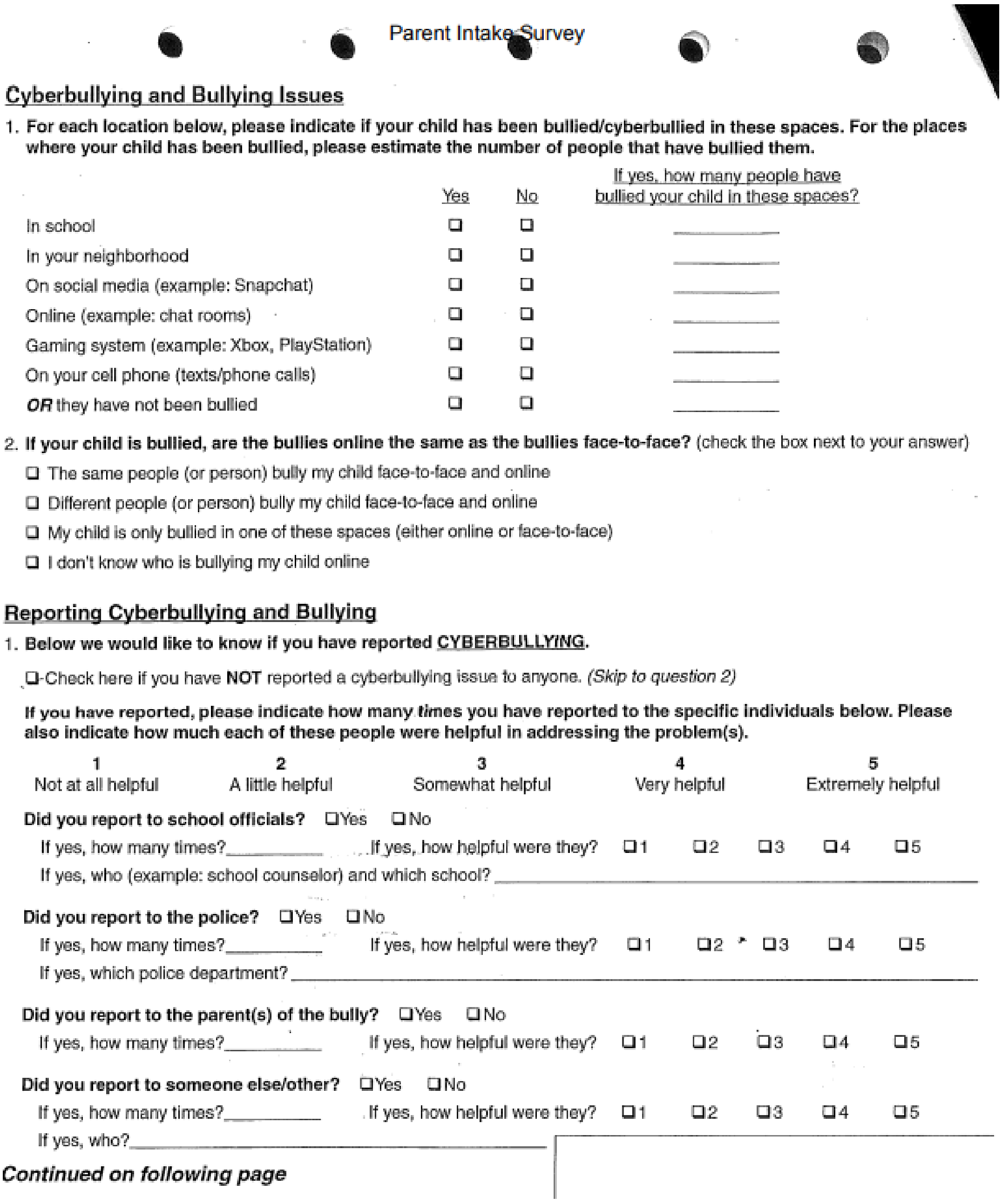

Parent Intake Survey

Cyberbullying and Bullying Issues

1. **For each location below, please indicate if your child has been bullied/cyberbullied in these spaces. For the places where your child has been bullied, please estimate the number of people that have bullied them.**

	Yes	No	If yes, how many people have bullied your child in these spaces?
In school	☐	☐	______
In your neighborhood	☐	☐	______
On social media (example: Snapchat)	☐	☐	______
Online (example: chat rooms)	☐	☐	______
Gaming system (example: Xbox, PlayStation)	☐	☐	______
On your cell phone (texts/phone calls)	☐	☐	______
OR they have not been bullied	☐	☐	______

2. **If your child is bullied, are the bullies online the same as the bullies face-to-face?** (check the box next to your answer)
   - ☐ The same people (or person) bully my child face-to-face and online
   - ☐ Different people (or person) bully my child face-to-face and online
   - ☐ My child is only bullied in one of these spaces (either online or face-to-face)
   - ☐ I don't know who is bullying my child online

Reporting Cyberbullying and Bullying

1. **Below we would like to know if you have reported CYBERBULLYING.**

☐-Check here if you have **NOT** reported a cyberbullying issue to anyone. *(Skip to question 2)*

If you have reported, please indicate how many times you have reported to the specific individuals below. Please also indicate how much each of these people were helpful in addressing the problem(s).

1	2	3	4	5
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

Did you report to school officials? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who (example: school counselor) and which school? ______________________________

Did you report to the police? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, which police department? ______________________________

Did you report to the parent(s) of the bully? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5

Did you report to someone else/other? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who?______________________________

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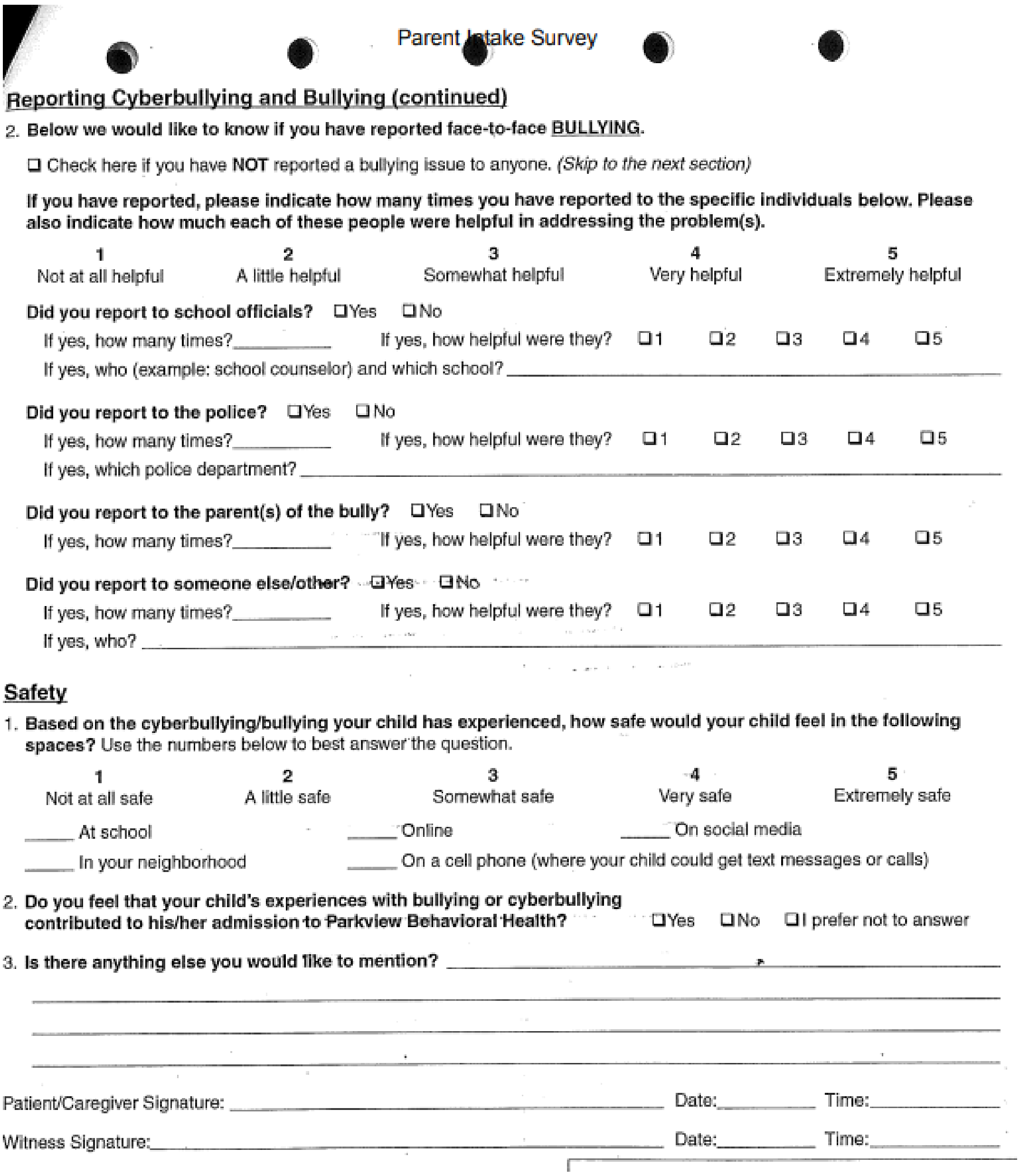


Parent Intake Survey

Reporting Cyberbullying and Bullying (continued)

2. **Below we would like to know if you have reported face-to-face BULLYING.**

☐ Check here if you have **NOT** reported a bullying issue to anyone. *(Skip to the next section)*

If you have reported, please indicate how many times you have reported to the specific individuals below. Please also indicate how much each of these people were helpful in addressing the problem(s).

1	2	3	4	5
Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful

Did you report to school officials? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who (example: school counselor) and which school? ____________________

Did you report to the police? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, which police department? ____________________

Did you report to the parent(s) of the bully? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5

Did you report to someone else/other? ☐Yes ☐No
If yes, how many times?__________ If yes, how helpful were they? ☐1 ☐2 ☐3 ☐4 ☐5
If yes, who? ____________________

Safety

1. **Based on the cyberbullying/bullying your child has experienced, how safe would your child feel in the following spaces?** Use the numbers below to best answer the question.

1	2	3	4	5
Not at all safe	A little safe	Somewhat safe	Very safe	Extremely safe

_____ At school _____ Online _____ On social media
_____ In your neighborhood _____ On a cell phone (where your child could get text messages or calls)

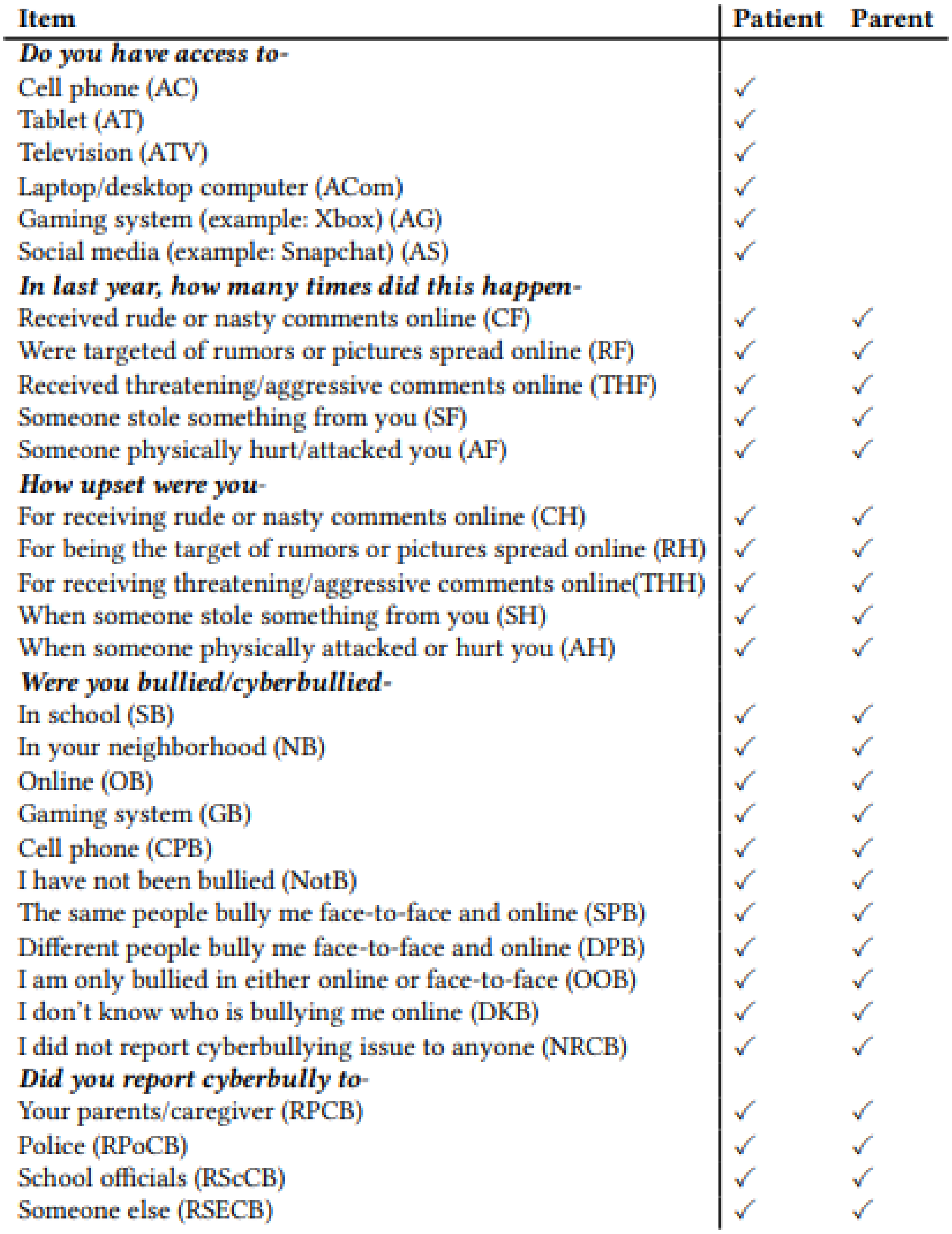
2. **Do you feel that your child's experiences with bullying or cyberbullying contributed to his/her admission to Parkview Behavioral Health?** ☐Yes ☐No ☐I prefer not to answer

3. **Is there anything else you would like to mention?** ____________________

Patient/Caregiver Signature: ____________________ Date:__________ Time:__________

Witness Signature:____________________ Date:__________ Time:__________

D3. Item Acronyms and Tool Comparison

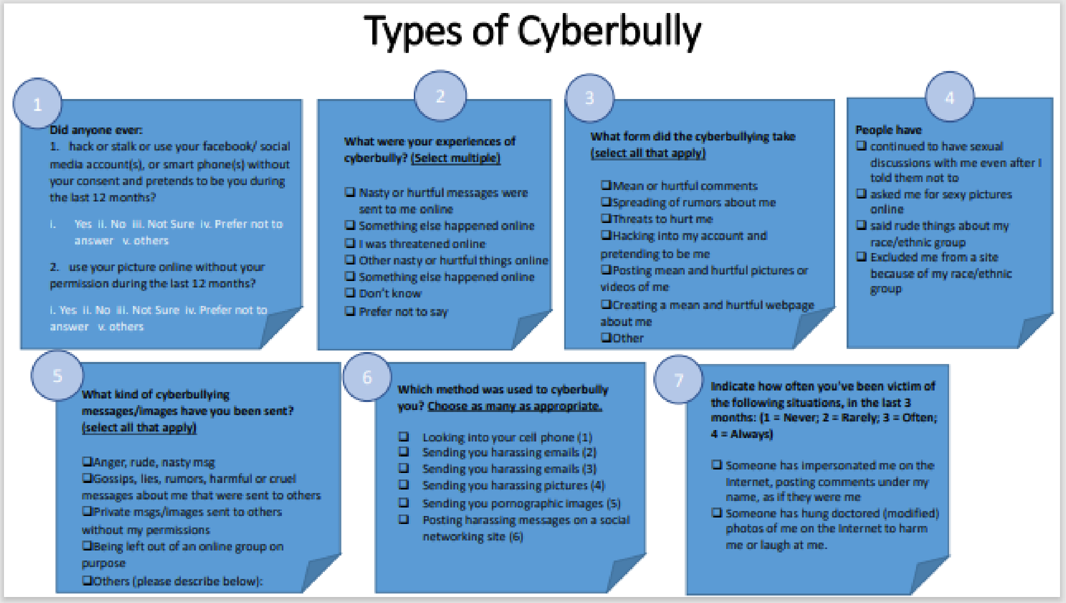


Item	Patient	Parent
Do you have access to-		
Cell phone (AC)	✓	
Tablet (AT)	✓	
Television (ATV)	✓	
Laptop/desktop computer (ACom)	✓	
Gaming system (example: Xbox) (AG)	✓	
Social media (example: Snapchat) (AS)	✓	
In last year, how many times did this happen-		
Received rude or nasty comments online (CF)	✓	✓
Were targeted of rumors or pictures spread online (RF)	✓	✓
Received threatening/aggressive comments online (THF)	✓	✓
Someone stole something from you (SF)	✓	✓
Someone physically hurt/attacked you (AF)	✓	✓
How upset were you-		
For receiving rude or nasty comments online (CH)	✓	✓
For being the target of rumors or pictures spread online (RH)	✓	✓
For receiving threatening/aggressive comments online(THH)	✓	✓
When someone stole something from you (SH)	✓	✓
When someone physically attacked or hurt you (AH)	✓	✓
Were you bullied/cyberbullied-		
In school (SB)	✓	✓
In your neighborhood (NB)	✓	✓
Online (OB)	✓	✓
Gaming system (GB)	✓	✓
Cell phone (CPB)	✓	✓
I have not been bullied (NotB)	✓	✓
The same people bully me face-to-face and online (SPB)	✓	✓
Different people bully me face-to-face and online (DPB)	✓	✓
I am only bullied in either online or face-to-face (OOB)	✓	✓
I don't know who is bullying me online (DKB)	✓	✓
I did not report cyberbullying issue to anyone (NRCB)	✓	✓
Did you report cyberbully to-		
Your parents/caregiver (RPCB)	✓	✓
Police (RPoCB)	✓	✓
School officials (RScCB)	✓	✓
Someone else (RSECB)	✓	✓

I did not report bullying issue to anyone (NRB)	✓	✓
Did you report bullying to-		
Your parents/caregiver (RPB)	✓	✓
Police (RPoB)	✓	✓
School officials (RScB)	✓	✓
Someone else (RSEB)	✓	✓
How safe do you feel-		
At school (SS)	✓	✓
Online (OS)	✓	✓
Social media (SMS)	✓	✓
Neighborhood (NS)	✓	✓
Cell phone (CPS)	✓	✓
Bullying/cyberbullying contributed to admission (BC)	✓	✓

APPENDIX E. PBH PROVIDER ACTIVITY & REFORMED TOOL

E1. Card Sorting Activity



Types of Cyberbully

1

Did anyone ever:

1. hack or stalk or use your facebook/ social media account(s), or smart phone(s) without your consent and pretends to be you during the last 12 months?

i. Yes ii. No iii. Not Sure iv. Prefer not to answer v. others

2. use your picture online without your permission during the last 12 months?

i. Yes ii. No iii. Not Sure iv. Prefer not to answer v. others

2

What were your experiences of cyberbully? (Select multiple)

☐ Nasty or hurtful messages were sent to me online
☐ Something else happened online
☐ I was threatened online
☐ Other nasty or hurtful things online
☐ Something else happened online
☐ Don't know
☐ Prefer not to say

3

What form did the cyberbullying take (select all that apply)

☐Mean or hurtful comments
☐Spreading of rumors about me
☐Threats to hurt me
☐Hacking into my account and pretending to be me
☐Posting mean and hurtful pictures or videos of me
☐Creating a mean and hurtful webpage about me
☐Other

4

People have

☐ continued to have sexual discussions with me even after I told them not to
☐ asked me for sexy pictures online
☐ said rude things about my race/ethnic group
☐ Excluded me from a site because of my race/ethnic group

5

What kind of cyberbullying messages/images have you been sent? (select all that apply)

☐Anger, rude, nasty msg
☐Gossips, lies, rumors, harmful or cruel messages about me that were sent to others
☐Private msgs/images sent to others without my permissions
☐Being left out of an online group on purpose
☐Others (please describe below):

6

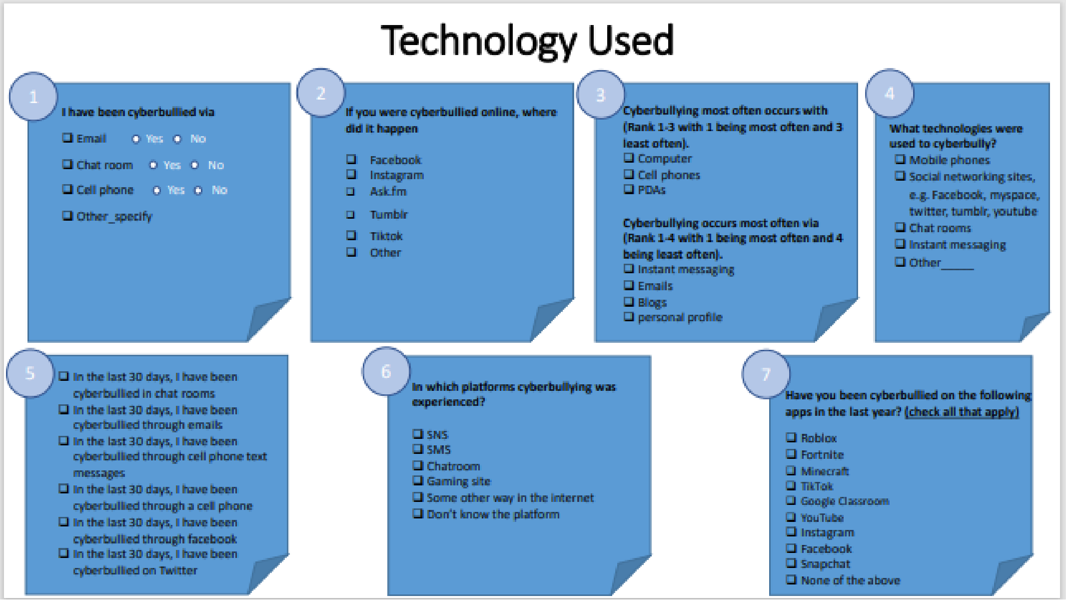
Which method was used to cyberbully you? Choose as many as appropriate.

☐ Looking into your cell phone (1)
☐ Sending you harassing emails (2)
☐ Sending you harassing emails (3)
☐ Sending you harassing pictures (4)
☐ Sending you pornographic images (5)
☐ Posting harassing messages on a social networking site (6)

7

Indicate how often you've been victim of the following situations, in the last 3 months: (1 = Never; 2 = Rarely; 3 = Often; 4 = Always)

☐ Someone has impersonated me on the Internet, posting comments under my name, as if they were me
☐ Someone has hung doctored (modified) photos of me on the Internet to harm me or laugh at me.



Technology Used

1

I have been cyberbullied via

☐ Email ○ Yes ○ No
☐ Chat room ○ Yes ○ No
☐ Cell phone ○ Yes ○ No
☐ Other_specify

2

If you were cyberbullied online, where did it happen

☐ Facebook
☐ Instagram
☐ Ask.fm
☐ Tumblr
☐ Tiktok
☐ Other

3

Cyberbullying most often occurs with (Rank 1-3 with 1 being most often and 3 least often).

☐ Computer
☐ Cell phones
☐ PDAs

Cyberbullying occurs most often via (Rank 1-4 with 1 being most often and 4 being least often).

☐ Instant messaging
☐ Emails
☐ Blogs
☐ personal profile

4

What technologies were used to cyberbully?

☐ Mobile phones
☐ Social networking sites, e.g. Facebook, myspace, twitter, tumblr, youtube
☐ Chat rooms
☐ Instant messaging
☐ Other_____

5

☐ In the last 30 days, I have been cyberbullied in chat rooms
☐ In the last 30 days, I have been cyberbullied through emails
☐ In the last 30 days, I have been cyberbullied through cell phone text messages
☐ In the last 30 days, I have been cyberbullied through a cell phone
☐ In the last 30 days, I have been cyberbullied through facebook
☐ In the last 30 days, I have been cyberbullied on Twitter

6

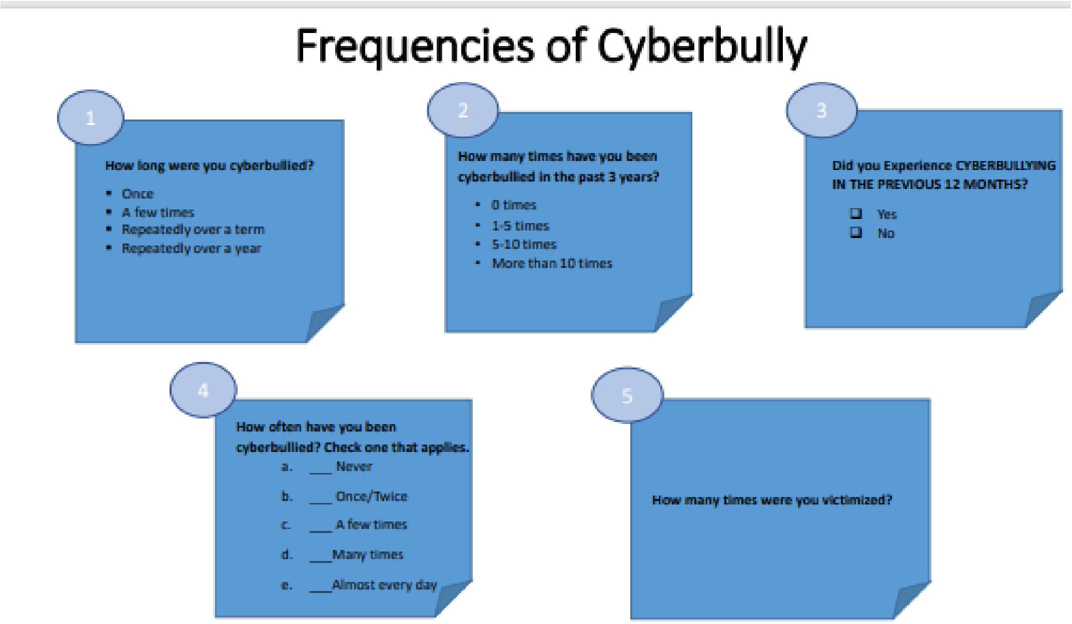
In which platforms cyberbullying was experienced?

☐ SNS
☐ SMS
☐ Chatroom
☐ Gaming site
☐ Some other way in the internet
☐ Don't know the platform

7

Have you been cyberbullied on the following apps in the last year? (check all that apply)

☐ Roblox
☐ Fortnite
☐ Minecraft
☐ TikTok
☐ Google Classroom
☐ YouTube
☐ Instagram
☐ Facebook
☐ Snapchat
☐ None of the above



Frequencies of Cyberbully

1

How long were you cyberbullied?

- Once
- A few times
- Repeatedly over a term
- Repeatedly over a year

2

How many times have you been cyberbullied in the past 3 years?

- 0 times
- 1-5 times
- 5-10 times
- More than 10 times

3

Did you Experience CYBERBULLYING IN THE PREVIOUS 12 MONTHS?

☐ Yes
☐ No

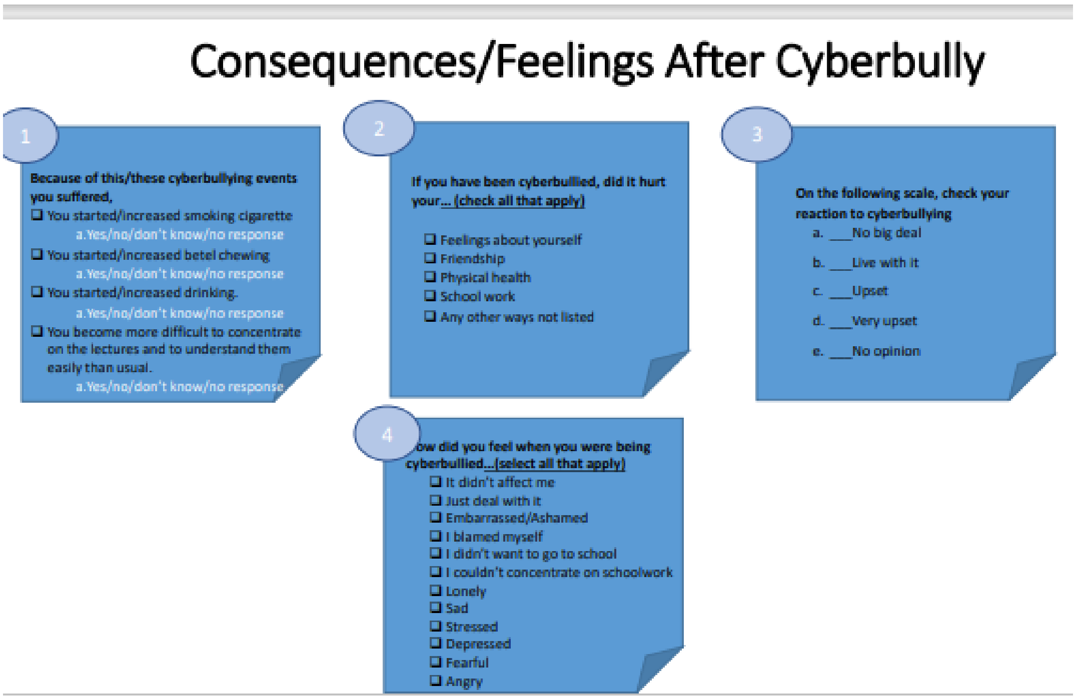
4

How often have you been cyberbullied? Check one that applies.

a. ___ Never
b. ___ Once/Twice
c. ___ A few times
d. ___Many times
e. ___Almost every day

5

How many times were you victimized?



Consequences/Feelings After Cyberbully

1

Because of this/these cyberbullying events you suffered,

☐ You started/increased smoking cigarette
a.Yes/no/don't know/no response
☐ You started/increased betel chewing
a.Yes/no/don't know/no response
☐ You started/increased drinking.
a.Yes/no/don't know/no response
☐ You become more difficult to concentrate on the lectures and to understand them easily than usual.
a.Yes/no/don't know/no response

2

If you have been cyberbullied, did it hurt your... (check all that apply)

☐ Feelings about yourself
☐ Friendship
☐ Physical health
☐ School work
☐ Any other ways not listed

3

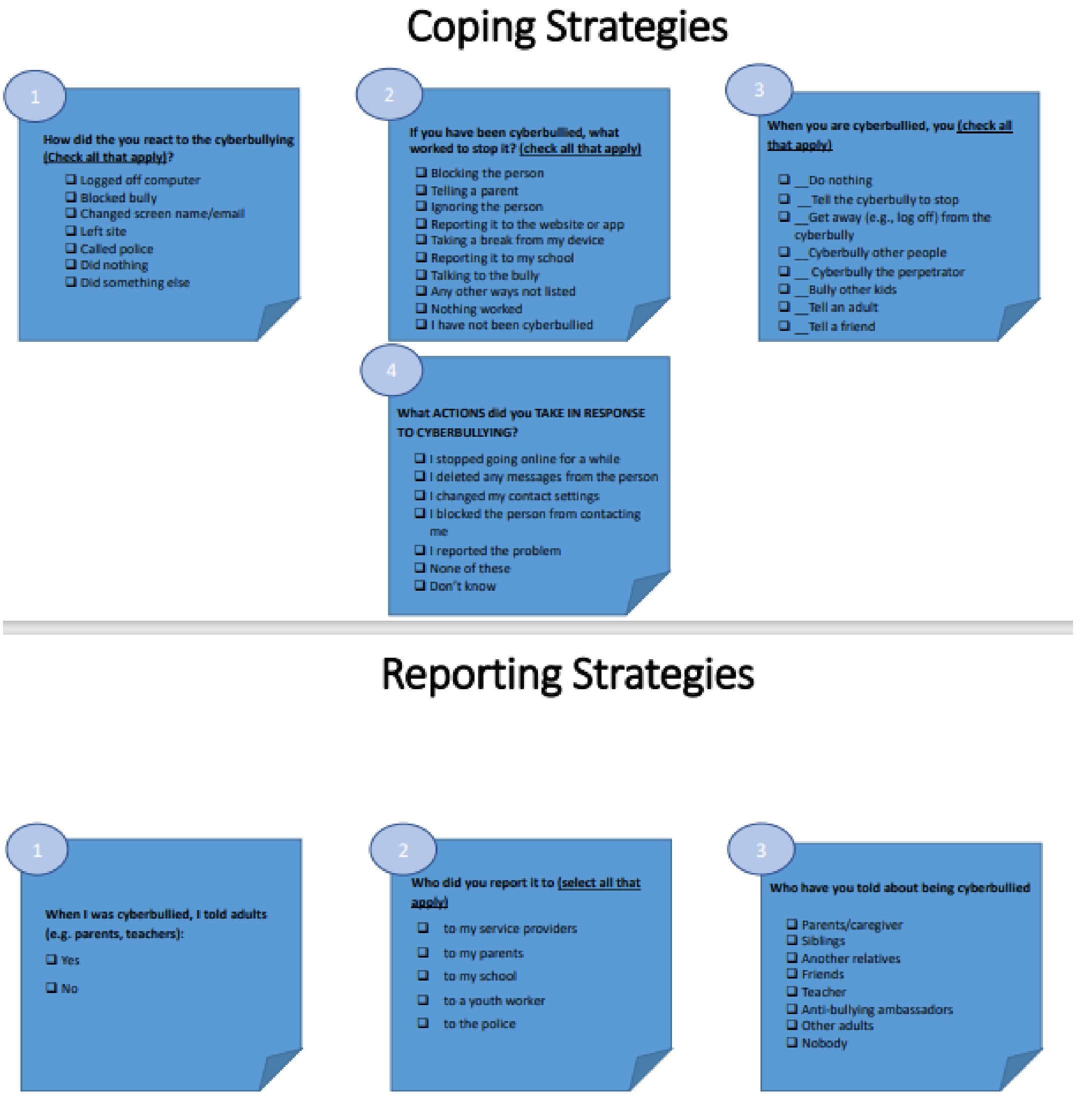
On the following scale, check your reaction to cyberbullying

a. ___No big deal
b. ___Live with it
c. ___Upset
d. ___Very upset
e. ___No opinion

4

ow did you feel when you were being cyberbullied...(select all that apply)

☐ It didn't affect me
☐ Just deal with it
☐ Embarrassed/Ashamed
☐ I blamed myself
☐ I didn't want to go to school
☐ I couldn't concentrate on schoolwork
☐ Lonely
☐ Sad
☐ Stressed
☐ Depressed
☐ Fearful
☐ Angry



Coping Strategies

①

How did the you react to the cyberbullying <u>(Check all that apply)</u>?

- ☐ Logged off computer
- ☐ Blocked bully
- ☐ Changed screen name/email
- ☐ Left site
- ☐ Called police
- ☐ Did nothing
- ☐ Did something else

②

If you have been cyberbullied, what worked to stop it? <u>(check all that apply)</u>

- ☐ Blocking the person
- ☐ Telling a parent
- ☐ Ignoring the person
- ☐ Reporting it to the website or app
- ☐ Taking a break from my device
- ☐ Reporting it to my school
- ☐ Talking to the bully
- ☐ Any other ways not listed
- ☐ Nothing worked
- ☐ I have not been cyberbullied

③

When you are cyberbullied, you <u>(check all that apply)</u>

- ☐ __Do nothing
- ☐ __Tell the cyberbully to stop
- ☐ __Get away (e.g., log off) from the cyberbully
- ☐ __Cyberbully other people
- ☐ __ Cyberbully the perpetrator
- ☐ __Bully other kids
- ☐ __Tell an adult
- ☐ __Tell a friend

④

What ACTIONS did you TAKE IN RESPONSE TO CYBERBULLYING?

- ☐ I stopped going online for a while
- ☐ I deleted any messages from the person
- ☐ I changed my contact settings
- ☐ I blocked the person from contacting me
- ☐ I reported the problem
- ☐ None of these
- ☐ Don't know

Reporting Strategies

①

When I was cyberbullied, I told adults (e.g. parents, teachers):

- ☐ Yes
- ☐ No

②

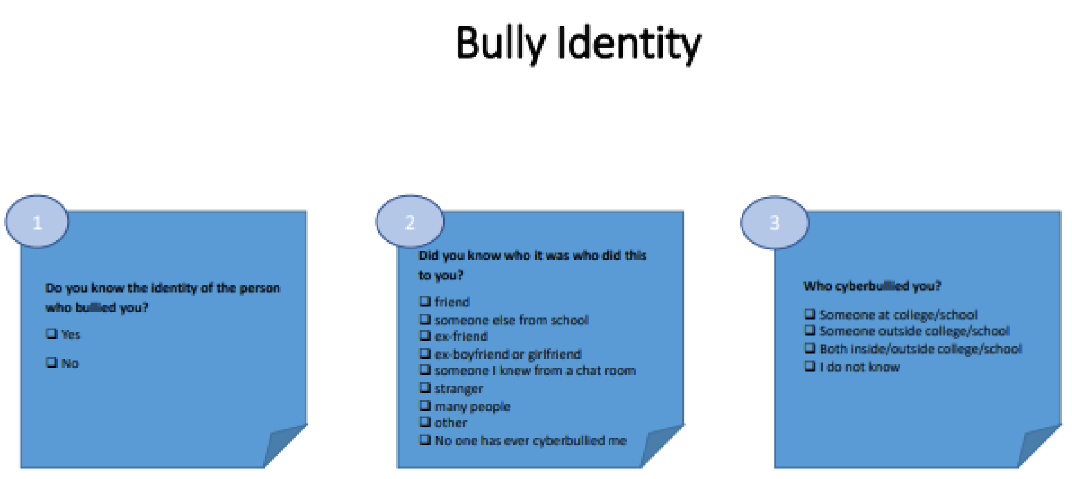
Who did you report it to <u>(select all that apply)</u>

- ☐ to my service providers
- ☐ to my parents
- ☐ to my school
- ☐ to a youth worker
- ☐ to the police

③

Who have you told about being cyberbullied

- ☐ Parents/caregiver
- ☐ Siblings
- ☐ Another relatives
- ☐ Friends
- ☐ Teacher
- ☐ Anti-bullying ambassadors
- ☐ Other adults
- ☐ Nobody



Bully Identity

1

Do you know the identity of the person who bullied you?

☐ Yes

☐ No

2

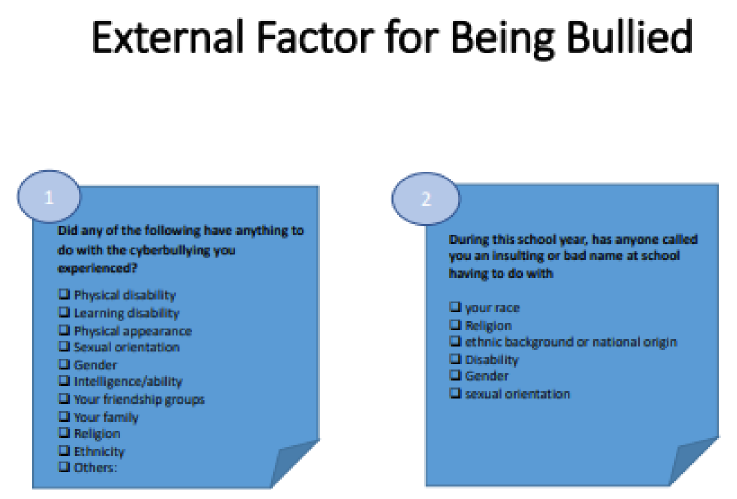
Did you know who it was who did this to you?

☐ friend
☐ someone else from school
☐ ex-friend
☐ ex-boyfriend or girlfriend
☐ someone I knew from a chat room
☐ stranger
☐ many people
☐ other
☐ No one has ever cyberbullied me

3

Who cyberbullied you?

☐ Someone at college/school
☐ Someone outside college/school
☐ Both inside/outside college/school
☐ I do not know



External Factor for Being Bullied

1

Did any of the following have anything to do with the cyberbullying you experienced?

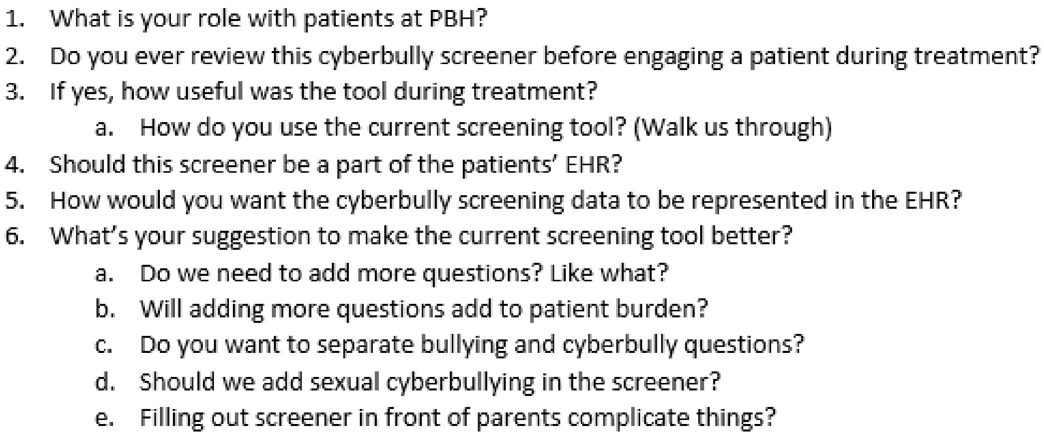
☐ Physical disability
☐ Learning disability
☐ Physical appearance
☐ Sexual orientation
☐ Gender
☐ Intelligence/ability
☐ Your friendship groups
☐ Your family
☐ Religion
☐ Ethnicity
☐ Others:

2

During this school year, has anyone called you an insulting or bad name at school having to do with

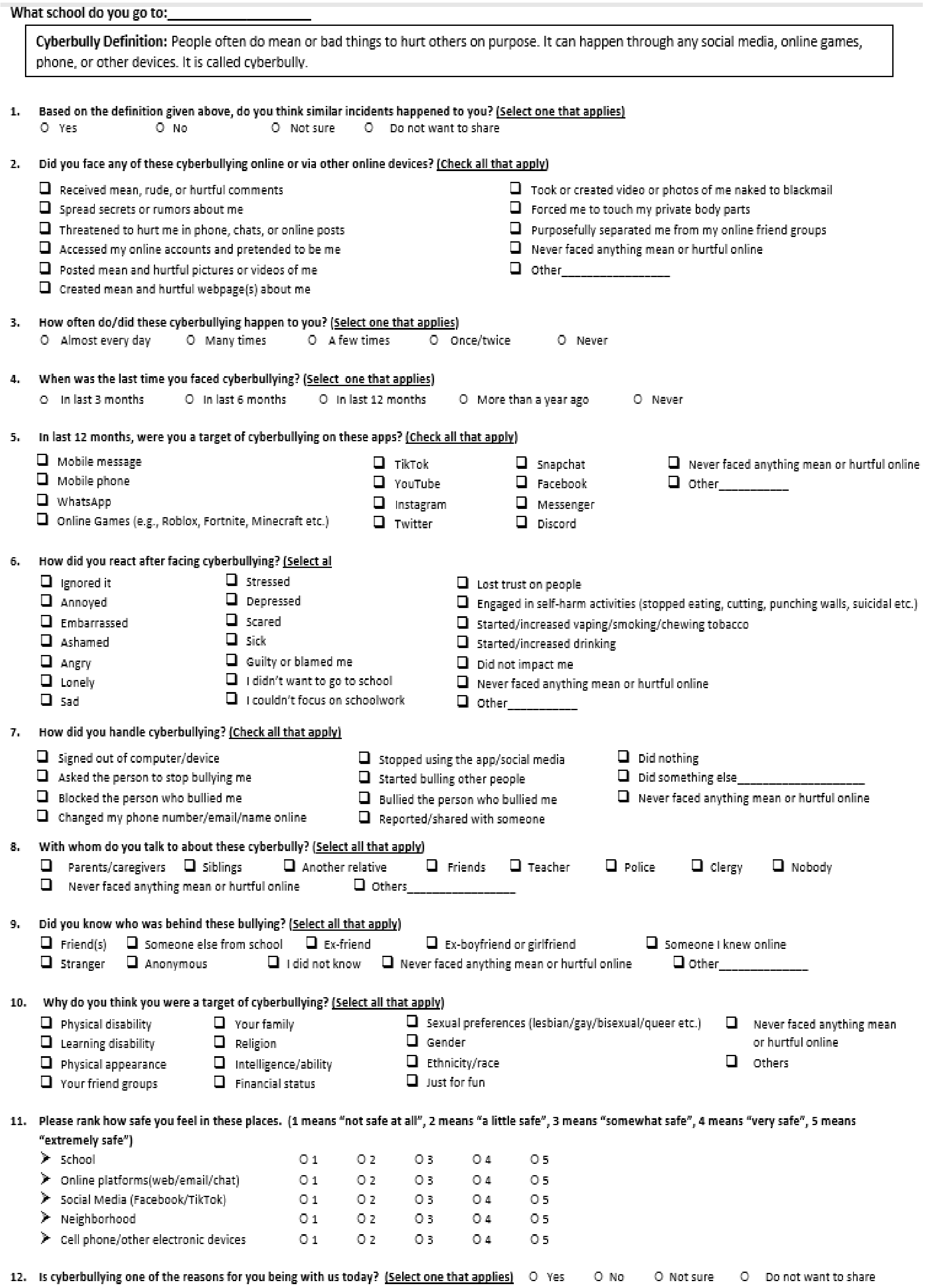
☐ your race
☐ Religion
☐ ethnic background or national origin
☐ Disability
☐ Gender
☐ sexual orientation

E2. Provider Interview Questions



1. What is your role with patients at PBH?
2. Do you ever review this cyberbully screener before engaging a patient during treatment?
3. If yes, how useful was the tool during treatment?
    a. How do you use the current screening tool? (Walk us through)
4. Should this screener be a part of the patients' EHR?
5. How would you want the cyberbully screening data to be represented in the EHR?
6. What's your suggestion to make the current screening tool better?
    a. Do we need to add more questions? Like what?
    b. Will adding more questions add to patient burden?
    c. Do you want to separate bullying and cyberbully questions?
    d. Should we add sexual cyberbullying in the screener?
    e. Filling out screener in front of parents complicate things?

E3. Modified Cyberbully Youth Intake Form



What school do you go to:____________________

Cyberbully Definition: People often do mean or bad things to hurt others on purpose. It can happen through any social media, online games, phone, or other devices. It is called cyberbully.

1. **Based on the definition given above, do you think similar incidents happened to you? (Select one that applies)**
○ Yes ○ No ○ Not sure ○ Do not want to share

2. **Did you face any of these cyberbullying online or via other online devices? (Check all that apply)**
☐ Received mean, rude, or hurtful comments
☐ Spread secrets or rumors about me
☐ Threatened to hurt me in phone, chats, or online posts
☐ Accessed my online accounts and pretended to be me
☐ Posted mean and hurtful pictures or videos of me
☐ Created mean and hurtful webpage(s) about me
☐ Took or created video or photos of me naked to blackmail
☐ Forced me to touch my private body parts
☐ Purposefully separated me from my online friend groups
☐ Never faced anything mean or hurtful online
☐ Other_______________

3. **How often do/did these cyberbullying happen to you? (Select one that applies)**
○ Almost every day ○ Many times ○ A few times ○ Once/twice ○ Never

4. **When was the last time you faced cyberbullying? (Select one that applies)**
○ In last 3 months ○ In last 6 months ○ In last 12 months ○ More than a year ago ○ Never

5. **In last 12 months, were you a target of cyberbullying on these apps? (Check all that apply)**
☐ Mobile message
☐ Mobile phone
☐ WhatsApp
☐ Online Games (e.g., Roblox, Fortnite, Minecraft etc.)
☐ TikTok
☐ YouTube
☐ Instagram
☐ Twitter
☐ Snapchat
☐ Facebook
☐ Messenger
☐ Discord
☐ Never faced anything mean or hurtful online
☐ Other__________

6. **How did you react after facing cyberbullying? (Select al**
☐ Ignored it
☐ Annoyed
☐ Embarrassed
☐ Ashamed
☐ Angry
☐ Lonely
☐ Sad
☐ Stressed
☐ Depressed
☐ Scared
☐ Sick
☐ Guilty or blamed me
☐ I didn't want to go to school
☐ I couldn't focus on schoolwork
☐ Lost trust on people
☐ Engaged in self-harm activities (stopped eating, cutting, punching walls, suicidal etc.)
☐ Started/increased vaping/smoking/chewing tobacco
☐ Started/increased drinking
☐ Did not impact me
☐ Never faced anything mean or hurtful online
☐ Other__________

7. **How did you handle cyberbullying? (Check all that apply)**
☐ Signed out of computer/device
☐ Asked the person to stop bullying me
☐ Blocked the person who bullied me
☐ Changed my phone number/email/name online
☐ Stopped using the app/social media
☐ Started bulling other people
☐ Bullied the person who bullied me
☐ Reported/shared with someone
☐ Did nothing
☐ Did something else__________________
☐ Never faced anything mean or hurtful online

8. **With whom do you talk to about these cyberbully? (Select all that apply)**
☐ Parents/caregivers ☐ Siblings ☐ Another relative ☐ Friends ☐ Teacher ☐ Police ☐ Clergy ☐ Nobody
☐ Never faced anything mean or hurtful online ☐ Others_______________

9. **Did you know who was behind these bullying? (Select all that apply)**
☐ Friend(s) ☐ Someone else from school ☐ Ex-friend ☐ Ex-boyfriend or girlfriend ☐ Someone I knew online
☐ Stranger ☐ Anonymous ☐ I did not know ☐ Never faced anything mean or hurtful online ☐ Other____________

10. **Why do you think you were a target of cyberbullying? (Select all that apply)**
☐ Physical disability
☐ Learning disability
☐ Physical appearance
☐ Your friend groups
☐ Your family
☐ Religion
☐ Intelligence/ability
☐ Financial status
☐ Sexual preferences (lesbian/gay/bisexual/queer etc.)
☐ Gender
☐ Ethnicity/race
☐ Just for fun
☐ Never faced anything mean or hurtful online
☐ Others

11. **Please rank how safe you feel in these places. (1 means "not safe at all", 2 means "a little safe", 3 means "somewhat safe", 4 means "very safe", 5 means "extremely safe")**

➤ School	○ 1	○ 2	○ 3	○ 4	○ 5
➤ Online platforms(web/email/chat)	○ 1	○ 2	○ 3	○ 4	○ 5
➤ Social Media (Facebook/TikTok)	○ 1	○ 2	○ 3	○ 4	○ 5
➤ Neighborhood	○ 1	○ 2	○ 3	○ 4	○ 5
➤ Cell phone/other electronic devices	○ 1	○ 2	○ 3	○ 4	○ 5

12. **Is cyberbullying one of the reasons for you being with us today? (Select one that applies)** ○ Yes ○ No ○ Not sure ○ Do not want to share