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SOVA: Design of a stakeholder informed social media website for depressed adolescents and their parents

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Abstract

Two moderated social media websites were designed for increasing likelihood for mental health treatment engagement for depressed adolescents (sova.pitt.edu) and for parents (wisesova.pitt.edu). This paper describes iterative stakeholder interviews conducted with adolescents, young adults, parents, advocates, and clinicians and use of human computer interaction techniques to inform major design changes which: (1) underscored the role of online interaction to provide emotional support and information; (2) importance of anonymity; (3) desire to share positive media; and (4) need for frequent moderation. Future studies will examine acceptability and effectiveness of revised websites in helping depressed adolescents and their parents engage with treatment.

Keywords

patient-centered outcomes research; depression; anxiety; technology; social media; adolescents

INTRODUCTION

Technology interventions for behavioral health are effective (Cuijpers, Donker, van Straten, Li, & Andersson, 2010), but may not be adapted to engage target users (Eysenbach, 2005) prior to dissemination efforts. This potentially compromises their efficacy and can result in obstacles to widespread implementation and dissemination (Meyers, Durlak, & Wandersman, 2012). Integrating end users and other stakeholder feedback earlier in development may circumvent this problem (Czajkowski et al., 2015); funding agencies are increasingly encouraging stakeholder engaged intervention development (PCORI, 2012) to improve patient acceptance (Burke et al., 2013). Involving users prior to solidifying design

components is highly developed and employed in standard human computer interaction techniques (Goodman, 2012). Better understanding of how stakeholder engagement and human computer interaction user methods overlap in a way that increases the likelihood that effective behavioral health technology interventions will be implemented is vital.

Only one third of adolescents receive treatment for major depression (SAMSHA, 2014); interventions focusing on addressing negative health beliefs associated with this low uptake of treatment are needed for both adolescents and parents (Tanielian et al., 2009; Wahlin & Deane, 2012; Wu et al., 2001). This paper describes a stakeholder-informed user-centered approach to designing two websites (one for adolescents called SOVA or Supporting Our Valued Adolescents and one for parents called wiseSOVA) as a moderated online social media intervention for depressed adolescents and their parents. The websites aim to combine depression and anxiety psychoeducation - specifically addressing negative health beliefs - with peer support from an online community.

The NIH recommends the ORBIT (Obesity-Related Behavioral Intervention Trials) model for behavioral intervention development (Czajkowski et al., 2015). This model offers a progressive pathway to testing developmental stages leading up to an efficacy trial of a behavioral intervention, and overlaps well with human computer interaction design stages. We modified this pathway to include an additional technology preparatory study (2a), combine the pilot and proof-of-concept study (2b) and conduct an effectiveness as opposed to efficacy trial (phase 3) (Figure 1). This paper focuses on Phase 1 design and user-centered methods.

In this model, the first phase (Phase 1a Define) is the formulation of a hypothesis to investigate the mechanism of action of a proposed behavioral intervention. Methods used include a review of the literature and formative qualitative research with the target population. Similarly, a user-centered design development process begins with a formative analysis phase where the developer is involved in understanding the user's work and needs (Hartson & Pyla, 2012). This process informs the design and prototype which is then evaluated. Each of these steps: analysis, design, prototype development, and evaluation is iterative.

In the second phase (Phase 1b Refine), intervention components are clarified - the mode of delivery, dose, and duration, acceptability, and need for tailoring to ensure relevance for target populations (Burke et al., 2013). Methods used in this phase include single case designs, and again, formative qualitative research. To obtain this information for a technology intervention, user centered design employs prototype development (i.e. a template or low-tech version of the proposed intervention). User-centered methods include using Think Aloud protocols, usability surveys, and focus groups and interviews to evaluate the prototype.

METHODS

Stakeholder Engagement

A community based participatory research methods approach guided the process of stakeholder engagement (Burke et al., 2013).

The Stakeholder Communities—The stakeholder communities of interest included people impacted in life or work by adolescent depression, including adolescents and young adults with depression and their parents/caregivers, as well as primary care providers (PCPs), mental health clinicians, and local mental health advocacy groups.

Identifying mental health advocates was relatively easy, but recruiting PCPs and adolescents and young adults with depression and their parents/caregivers was more challenging. Adolescents and young adults with mental illness are a vulnerable population and may be reluctant to trust the research community especially with privacy and confidentiality concerns related to stigma (Gulliver, Griffiths, & Christensen, 2010). Community PCPs are often interested in research findings, but wary of being involved in studies due to time commitment and interruptions to clinic flow associated with conducting research activities. One way we addressed recruitment challenges was by using community members as bridges. For example, a mental health advocate who had been involved in the conception of the SOVA project helped arrange meetings to develop relationships with other advocates who helped recruit interested young people and parents. Similarly, we worked with Pediatric PittNet, (CTSI, 2016) a practice-based research network that works to involve pediatric primary care practices in research relevant to them. As a trusted ally who identifies research studies most relevant and feasible for PCPs, Pediatric PittNet's support was key to having opportunities to meet with PCPs and mental health clinicians in the community.

Specifically, for Phase 1a, we used individual stakeholder dyads: adolescents ages 13-21 who had a physician diagnosis of depressive disorder currently receiving treatment, and their parents. Although the final intervention plans to target adolescents who are initially diagnosed with depression or anxiety and offered treatment, we knew this group may have difficulty conceptualizing how a technology intervention could be helpful if they had not yet fully accepted a depression diagnosis. For this reason, and because the intervention also planned to include peer advisors experienced in depression treatment, we recruited a sample who had received treatment already. This sample was recruited during 2013-4 by clinicians treating patients at an academic adolescent medicine clinic and at a specialty psychiatry clinic for teens with depression and suicidality. For Phase 1b, there were several key informant samples used (Groups described in Figure 2). The adolescent and parent samples were a convenience sample, and were already active in advisory roles within the Division of Adolescent and Young Adult Medicine. Group 1 included 8 adolescents and young adults serving on a youth research advisory board (Navratil, McCauley, Marmol, Barone, & Miller, 2015). This group focused one of their monthly meetings to review research on specifics of this study. Group 2 consisted of 4 adolescents and young adults serving on the youth advisory board and 3 parents involved in advocacy within the division. This group participated in individual in-depth reviews of the website called "Think Alouds." Group 3 consisted of the SOVA Advisory Board; the participants at the April 2015 meeting consisted

of 3 parents and 1 young adult. Group 4 included 3 separate clinician focus groups: two equal number PCP groups (7 PCPs and 1 nurse practitioner) and one behavioral health clinician group (11 therapists and 1 child psychiatrist).

Prior to meeting with stakeholders, we identified strengths and potential challenges to working with this community. Strengths included adolescents and young adults with depression and parent/caregivers offer an insider's view on unique experiences with mental health. As depression is a complex emotional and physical problem underdiscussed publicly due to stigma, this perspective from end users is critical for informing content and design. To build on these assets, we asked directed questions to elicit feedback during meetings and reiterated everyone's point of view was valuable. Based on prior work with mental health advocates we identified important characteristics about this group which may impact their ability and willingness to provide feedback. These included: being listened to, feeling included, and not being judged for unconventional thoughts or opinions. We anticipated potential challenges of working with this group may be: experiencing worsening in symptoms which could impair participation or feeling emotionally triggered by discussions. For this reason, when conducting stakeholder meetings, we employed flexibility and patience, anticipating absences, cancellations, and turnover due to other priorities.

Although groups of individuals with mental illness are challenging to engage as stakeholders, they are frequent internet users (Ybarra, Alexander, & Mitchell, 2005). For this reason, in addition to live meetings, we also developed a study website, sovaproject.pitt.edu. The mission of this website included sharing research progress, findings, and events, introducing the study team, and being an outward representation of the study to the community. We also included a password-protected area for collaboration. The purpose of this was to reduce the influence of power differentials between stakeholders which may occur at a live meeting and to allow for collaboration between group meetings. This area of the site was under-utilized as advisory board members preferred in-person discussions.

Most meetings with community members focused on research. The lead investigator also offered to discuss current needs important to the community. She presented to community PCPs about social media and adolescent depression, and assisted members of the advisory board with career opportunities which combined professional goals with personal interests in mental health advocacy (e.g. writing letters of recommendation).

Stakeholder Engagement Plan—Based on work by Burke et al (Burke et al., 2013), we developed a stakeholder engagement plan with different types of stakeholders varying in level of involvement (Table 1). Advisory board members received frequent updates on research progress and provided regular feedback through organized meetings or intermittently communicating with the lead investigator. Community supporter/organization members and individual stakeholders were contacted periodically for specific feedback.

User-Centered Approach

Phase 1a: Defining the Intervention: Interviews with Depressed Adolescents and their Parents—Of 31 adolescents and 30 parents who filled out an interest form

about the study, 8 adolescents and 7 parents were not able to be reached for interview, leaving 23 adolescents and 23 parents that completed the study. The lead investigator conducted all interviews and introduced herself as a University of Pittsburgh researcher and physician specializing in Adolescent Medicine. Interviews took place over telephone or inperson in a private patient room. Interviews were semi-structured and individual (parents interviewed separately from adolescents). Verbal informed consent was obtained from parents and assent from adolescents (consent if over 18). Interviews lasted 60 to 90 minutes, were conducted in English, and no safety concerns or distress occurred. In addition to demographics, participants were asked open ended questions about the main research question regarding online interaction with others who have depression (or whose child has depression); specifically what their experience with this was and thoughts about what would make this interaction acceptable. Interviews were audio-recorded, transcribed, and qualitatively coded for major themes, using qualitative content analysis through an iterative process (Morgan, 1993).

Phase 1b: Refining the Intervention: Think Alouds, Advisory Boards, and Clinician Focus Groups—As shown in Figure 2, groups reviewed prototypes of different stages of the intervention design to facilitate discussion (Table 2). Think Aloud interviews were semi-structured and conducted individually (Group 2), and other groups involved focus group discussions. Advisory boards participated as part of normal operations (Groups 1 and 3). The Think Aloud group signed consent for video recording. Verbal informed consent was obtained from clinicians. Individual interviews lasted 60 to 90 minutes and focus groups lasted 45 minutes. All were conducted in English and no safety concerns emerged.

The website intervention was modified prior to each subsequent group and also between different Think Aloud participants (Group 2). While Group 1 was presented with PowerPoint slides showcasing possible component ideas, Groups 3 and 4 in addition were guided through the current stage of the website and its features including those for social interaction and thoughts on moderator involvement and safety concerns. The advisory board groups (1, 3) were not audio-recorded and two note takers from the research team took notes of meeting proceedings. Group 4 (clinician focus groups) were audio-recorded and interviews were transcribed to extract main points and summarize key provider concerns.

The group 2 individual interviews used a Think Aloud protocol which is an empirical human computer interaction technique used to gather data for usability testing and product development. (Goodman, 2012) In the first part of the Think Aloud, participants received instructions to complete specific tasks while "thinking aloud" or verbalizing their concrete thoughts about steps they were taking to complete the task. The specific tasks were: a) register for the site and log-in; b) create a user profile; c) post a comment in the discussion board; and d) contribute to a story using a wiki tool. Metrics to evaluate tasks included ability to complete a) and b) without error, find c) and d) in less than 30 seconds and complete the task with less than 2 errors. After reviewing the site, participants completed an adapted version of the Post-Study System Usability Questionnaire (PSSUQ) (Fruhling & Lee, 2005) and Ease of Use (USE) Questionnaire (Lund, 2001) and one question about ease of navigation. Users' scores were averaged and a mean score was calculated with 1 (strongly disagree) as least usable and 5 (strongly agree) as most usable. Participants were asked for

feedback on positive aspects, improvements to make, and whether their experience felt secure or private. These were video and audio-recorded in entirety, and computer screen actions were tracked using screen recorder software (Studio). Interviews were transcribed verbatim, reviewed for major themes, and feedback was summarized. Final sample size was determined by a goal of at least 3 Think Aloud participants per group which generally results in finding at least 75% of major usability problems (Nielsen & Landauer, 1993).

The University of Pittsburgh IRB approved all study procedures. For Phase 1a, adolescents received as compensation a book about adolescent depression (Dequincy & Brent, 2008) and parents a book about having a child with depression (Evans & Andrews, 2005). For Phase 1b, all groups were compensated with a prepaid debit card.

RESULTS

Phase 1a: Defining the Intervention: Interviews with Depressed Adolescents and their Parents

The sample consisted of 23 adolescents, with mean age 16 (SD=2.3) and 23 parents with a mean age of 46 (SD=6.8). Most adolescents were female (N=18) and Caucasian (N=20) as were most parents (female: N=19, Caucasian: N=21). Almost all adolescents used social media (N=22) and most used it several times a day (N=18). Many parents reported using social media (N=19); for those who did not, they were asked their opinion about using social media to connect with other parents of depressed adolescents.

Adolescents shared a desire to provide online peer support to other adolescents experiencing depressive symptoms to pay forward help they felt they had received. They described how their experience with depression provided them with expertise on how to help others "in their shoes," and gave examples of sharing and receiving online peer support. This included positive messages (i.e. pictures, quotes, advice), crisis resources, and even guidance on thought restructuring based on cognitive behavioral skills they had learned. Adolescents frequently mentioned blogs as a preferred format for sharing online support, with Tumblr described as having a robust online depressed adolescent community. Adolescents did raise several concerns about interacting with other depressed youth online, including being unaware of local crisis resources to provide someone from another location, sharing advice which is not accepted, co-ruminating, emotional attachment, decreasing their own mood, misinterpretation and negative comments or bullying, and privacy. Some expressed these concerns could be modified with the presence of a moderator.

As opposed to adolescents, parents had little experience communicating online with other parents and had not found many online resources. Parents did relate that they imagine hearing stories about how other parents handled difficult situations would be helpful, but they felt strongly about ensuring their own and their child's privacy and would want an anonymous environment. On the other hand, some parents felt that in an anonymous environment, they would be unsure whether they could trust the authenticity of comments or advice from others. Information named as potentially useful included how to communicate with and monitor their child, how to facilitate school accommodations, and reduce isolation. Parents also related that sharing positive quotes online was a desirable way to use social

media. Frequently, parents mentioned their concerns that their children needed more guidance on using social media and that they themselves would like more education on how to provide this guidance. This feedback and concerns informed this intervention's need for anonymity and moderation for both parents and adolescents. Parents greatly emphasized a need for privacy for themselves and for their children: they preferred an anonymous site, but did mention that anonymous content can be difficult to trust and would benefit by being screened by a moderator with mental health experience. Adolescents were not very worried about their privacy but preferred anonymity to decrease the risk of negative consequences such as bullying. Quotes describing these themes and how the SOVA design was informed by them can be found in Table 3.

Phase 1b: Refining the Intervention: Think Alouds, Advisory Boards, and Clinician Focus Groups

After Phase 1a, a prototype of the website was developed which was presented to groups. After each round of stakeholder interviews, changes were made to the design (Figure 2). Suggestions from the youth research advisory board included using lighter topics such as positive quotes or humor (versus an entire website focusing on depression) to help youth feel more comfortable. An option to rate comments posted by others using a "like" button was removed as youth strongly expressed rating features made them feel worse if their comment or post was not "liked."

Further changes were made during the Think Aloud interviews, including removing a "wiki" option where multiple users could contribute to and edit a story. One adolescent expressed, "See I would rather – read about other people's experiences - that's how you feel support - versus 'we're creating this together'. If you cut something out that was, especially this is so personal, because it's my experience." Out of the 7 participants, all were able to complete the requested Think-Aloud tasks, except one parent who was unable to create a user-profile without error. The story contribution option ("wiki") was removed due to dislike of and confusion over how to use this function. The mean adapted Post-Study System Usability Questionnaire and USE survey score (with 1 being least usable and 5 most useable) for the 7 participants was $4.5 \, (SD = .31)$. Additionally, of the 3 parents who participated, all strongly agreed they felt other parents would be able to use the site without difficulty.

DISCUSSION

Multiple interviews with stakeholder groups informed iterative adaptations in the design of an online behavioral intervention focusing on depressed adolescents and their parents. Design challenges included creating two sites for different audiences (adolescents and parents) with similar content and leveraging the benefits of social media tools (user profiles, user interaction) with the preferences of a depressed adolescent and parent population. Our research team needed to balance our project aims (i.e. to transmit knowledge about negative mental health beliefs and depression and anxiety education in a supportive and moderated online community) with the options and capabilities provided by the technology we were using (i.e. Wordpress) and satisfy stakeholder preferences in a feasible way which was within our budget.

Throughout the design process, there were many seemingly small and large decisions that needed to be made -- from background color of the sites to how anonymous the sites should be. Without the stakeholder input described in this study, we would have needed to make major assumptions, which if incorrect, may compromise the future uptake of our intervention. Some of the findings, such as the importance of moderation and anonymity, had been hypothesized as being important, although we were unaware of how critical anonymity and privacy would be for adolescents in addition to their parents. We also became cognizant of specifics to anonymity such as the need to balance sharing individuality (through user-picked avatars and profile information) while concealing identity. We also had not predicted the wide range of comfort with technology among parents; what we learned led us to use a theme for the parent site which was simpler with fewer options and easier to navigate. We also did not anticipate the extent to which the parent and clinicians feedback would inform the development of the adolescent website. Parents' concerns about children's social media use influenced us to add education about using social media to both sites. Clinicians' concerns about adolescents' high online activity occurring late at night led us to update our moderating procedure to include using overnight notification procedures.

Limitations

Some limitations of this process include that individuals participating in the Think Alouds were mostly above age 18 and may not be representative of a younger adolescent sample. Additionally, due to the qualitative nature of designing this intervention, our samples were small, convenience samples which may not be generalizable to other settings. However, using this community partnered, participatory approach to develop this intervention allowed for the rich detail that informed website refinements.

Implications

This paper describes a framework and process for how multiple types of stakeholder groups providing iterative feedback using concepts of user-centered design can result in incremental tailoring of a technology behavioral intervention for adolescents and their parents. Stakeholder engagement methods allowed us to have a sample of invested adolescents, parents, and clinicians who provided iterative feedback on our evolving intervention. Using this strategy of combining stakeholder engagement methods and human computer interaction techniques may increase the likelihood of acceptance of technology interventions for health in adolescents. Next steps include a preparatory study to refine the SOVA intervention and determine its usability using beta testing (Figure 1, Phase 2a).

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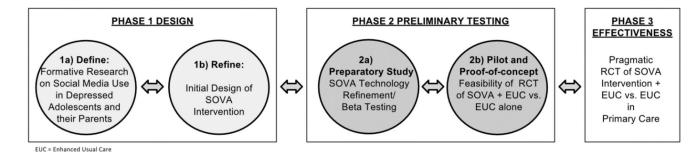


Figure 1.
SOVA (Supporting Our Valued Adolescents) Behavioral Intervention Development Model

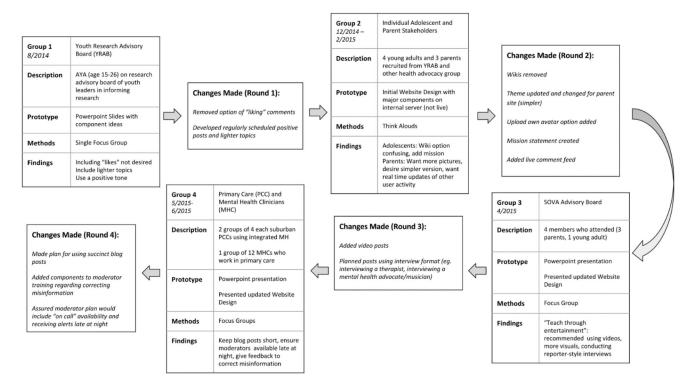


Figure 2. SOVA Design Iterations

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Stakeholder Engagement Plan

Table 1

Stakeholder Types	Level of Involvement	Frequency of Contact	Criteria	Areas/Type of Involvement	Member I	Member Description
Advisory Board Member	High	at least monthly	- history of depression/ anxiety in self, lovel love or involved in	intervention design website content recruitment strategy	1	Senior in high school involved in mental health advocacy
			involved in advocacy or clinically with patients who have depression/ anxiety	- conceptual framework - analysis plan (choosing measures which are patient- centered)	7	Freshman in college with several chronic medical conditions and mental health advocate
			- denies current symptoms conflicting with ability to participate	 study design (future) translation dissemination 	ဇ	PhD candidate in education, mental health advocate with a history of bipolar disorder
			willing to maintain regular contact and contribute ideas and		4	Parent of child with complex medical conditions and mental health advocate
			feedback		w	Parent of a child who had mental illness and died from overdose
					9	Parent of children with history of depression
					7	Pediatric Primary Care Provider
					œ	Behavioral Health Clinician Researcher
Community Supporter/Organization Member	Medium	as needed		same as above but more limited specific feedback	1	A youth research advisory board (YRAB) organized by Division of Adolescent and Young Adult
			- avanabinty at least quarterly		7	Members from mental health

Radovic et al.

Stakeholder Types	Level of Involvement	Frequency of Contact	Criteria	Areas/Type of Involvement	Member Description
			- willing to provide feedback		advocacy organizations (e.g. Mental Health America, National Alliance on Mental Illness) contacted through relationship with Advisory Board Member #3
					3 Community Primary Care Providers 4 Behavioral Health Clinicians
Individual Stakeholder	Medium (specific timeframe)	as needed or per individual interest	history of depression or anxiety in self or in child willing to provide feedback	intervention design and user testing website content contribution form a peer based network	14–26 age adolescents and young adults with history of symptoms of depression or anxiety Parents who have had a child with depression or anxiety

Page 13

Table 2

Iterative Groups

Group 1	Youth Research Advisory Board		
Group 2	Individual Adolescents and Parent Stakeholders		
Group 3	SOVA Advisory Board		
Group 4	Primary Care Providers and Mental Health Clinicians		

Radovic et al. Page 15

 Table 3

 Themes Informing Intervention Design from Interviews with Depressed Adolescents and their Parents

Theme	Adolescent Quote	Parent Quote	How SOVA Design Informed
Feeling Online Peer Support would help and willingness to provide peer support	"It's good because you would be talking to someone probably feeling the same way as you and can sympathize." Teen ID 23 "After posting statuses calling for help, but no one took it that way because they thought it was just calling attention - now every time I see someone sad or posting I'm going to kill myself, even if for attention, I will contact or message them, and say whatever I can to help." Teen ID 28	"It would be helpful to know there are other people going through it. I'm sure I'm not the only parent with a 13 year-old daughter who is confused or doesn't know which direction to go, I might find insightful information." Parent ID 3 "[My child] has given permission to tell my friends she's been depressed, and she's taking Zoloft. I know some of my friends' kids have taken it, so we've talked a lot about that, openly." Parent ID 11	Emphasize online peer support Validated adolescents with depression desire to provide peer support to other young people Validated parents are willing to share their knowledge gained through experience
Sharing Positive Content	"I posted this inspirational quote and they said that helped them and they needed to see something positive." <i>Teen ID 20</i>	"If it's a poem that touches the heartstrings, I'll repost it." Parent ID 13	Include regular positive content (e.g. inspirational quotes, humor, videos, photography)
Sharing Crisis Resources	"I'll comment hotline numbers and give them someone who can actually help. There's a lot of resources kids don't know how to use, or that it exists." Teen ID 15	-	Include a crisis resources section (e.g. national hotlines, crisis text lines)
Sharing Coping Skills	"it does have similarities to group [therapy]. You're in a room with people who are depressed who've come up with mechanisms that make them feel better like meditation." Teen ID 4	"Three of us could sit and say, 'You know, here's what we're going through, and here's this issue with school. It is helpful when you can have that." <i>Parent ID 4</i>	At bottom of posts include discussion questions to elicit coping mechanisms others have used
Preference for Anonymity/Privacy Concerns	"not knowing who they are, keeping them nameless in Facebook makes you see it from a different perspective and makes the person who is posting feel a little bit more comfortable and confident in what they're posting and they don't feel embarrassed about sharing." Teen ID 10	"I'm a very private person and I think you can be more open and honest with somebody who's a anonymous." Parent ID 22 "I wouldn't want a potential employer or somebody she's going to date doing the Google search and finding all of that out." Parent ID 7	Anonymity (i.e. avoid identifying usernames/profiles, use avatars as profile picture) Require users agree to ground rules to uphold anonymity Use profiles to establish authenticity without compromising anonymity
Blogs as Preferred Format	"I know a lot of people on [Tumblr] are depressed, which is a different side of that website. And there are	"I like to read other people's experiences. When you've gone through it you learn	Use a content management system designed primarily

Radovic et al.

How SOVA Design Theme **Adolescent Quote Parent Quote** Informed people who post a bunch things not to do, the for a blog format of stuff about-how they things that did work. (Wordpress) feel, like if they're feeling Reading other people's Encourage users to depressed and they'll be stories is the most write blog posts able to recognize that beneficial thing I've within, like, 'I felt so empty that I was a waste of themselves found. Forums are nice, but sometimes can be sporadic and chaotic." oxygen." Teen ID 4 Parent ID 25 Uncertainty re: identity, Sharing negative coping Define Moderator information Role: promote "I would private message positive peer interactions; screen "I'm more worried them and talk to them about it: 'If you ever need about: what I'm looking content for safety; anything, I'm here.' And at, is it truthful? Am I offer guidance if they would: 'Oh, the really talking to the negative coping, same.' And then, we person that I'm talking highly emotional would just start talking, to? Is this person wellcontent shared; **Concerns about Online** and it would lead to bad qualified to be giving me intervene on Interactions, Need for conversations. Like, advice?" Parent ID 13 cyberbullying Moderation suicide, cutting, self-hate, Sharing negative coping anorexia sometimes." Teen Include information on moderator role, "It would have to be background in something that was behavioral health, strictly monitored, not and supervision by just by one person. And principal by people who are licensed." Parent ID 6 investigator

Page 16