

The Digging Deep Project

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Completed Research

Clinical Trials

Shadow's Edge Impact on Cancer Survivors - Dec 2018 – Nov 2020
Lurie Children's Hospital / Feinberg School of Medicine

Summary

An independent team of researchers at Northwestern University and the Ann and Robert H. Lurie Children's Hospital of Chicago recently completed a randomized clinical trial to determine whether playing Shadow's Edge promoted resilience and well-being for teen and young adult cancer survivors. Many teens and young adults who have cancer early in life live with symptoms such as fatigue and ongoing pain as a result of their life-saving treatment. Having cancer can also interrupt friendships, affect school and work, and may become a significant part of survivors' identities. This study focused on how teen and young adult cancer survivors think about, and express, their life stories and whether playing Shadow's Edge – journaling, creating graffiti, and making connections with others – can help to improve their physical, social and emotional health following cancer. In our study, one hundred seventy-seven young people played Shadow's Edge for six weeks and completed surveys about their mood, body sensations, sense of personal identity, and resilience.

Objective

The overall goal of this Lurie Children's research program is to promote holistic wellness among adolescent and young adult cancer survivors through innovative programming relevant to their unique developmental and contextual needs. The specific aims of the study were to:

- Determine efficacy of Shadow's Edge in enhancing resilience (positive affect, benefit-finding, meaning and purpose), improving quality of life, promoting identity development and decreasing fatigue and pain
- Examine the impact of game use on participants' affect variability, incidents of extreme low mood and daily, temporal associations among positive and negative affect, pain and fatigue.
- Examine themes of participants' narratives

Background and Significance

This study by the team at Northwestern University is a significant contribution to science. It is one of the first and largest clinical trials examining the role of serious gaming and its outcome on the wellbeing on an adolescent and young adult chronic health population.

Method

The clinical trial has a randomized 2 arm-controlled waitlist design. 174 cancer patients age 14-24 year old in remission or final stages of cancer treatment participated in the trial. Participants were 50% male and 50% female, with no gender expansive identifying participants.

The intervention consisted in the completion of a baseline survey, followed by six weeks of playing the serious game Shadow's Edge and a final assessment. Self-report measures covered personal identity and growth, identity exploration, sense of life meaning purpose and worth, momentary positive affect, benefit finding or growth following a serious health condition.

Key Findings

Hypothesis: adolescent and young adult cancer survivors would report more adaptive identity status greater identity exploration, great positive affect, greater sense of life meaning and purpose, increased benefit finding compared to group who did not play the game.

Adolescents and young adults did endorse higher levels of personal or ideological identity exploration and social and interpersonal identity exploration. Playing the game moved them further along on the continuum of identity exploration of personal, career interests and social roles - which is appropriate for the developmental stage of this age group. There were no further outcomes immediately or post intervention.

According to the Lurie team, the findings are promising. Even with the relatively short identity formation Shadow's Edge may promote identity formation in youth – which is a critical aspect of wellbeing.

Further Research

The Lurie Team is interested to look at long term maintenance effects and positive wellbeing outcomes after playing the Shadow's Edge game. They are also interested in looking at the effect of gameplay on momentary coping and the impact on functioning on a day-to-day basis. In addition, the team is planning to dive deeper into engagement, looking at dose effects and performing a qualitative analysis of player journals to identify themes and how these potentially evolve over gameplay.

Publication of Research

This research was presented at the 7th IPPA World Congress for Positive Psychology in July 2021 and is being presented to various journals and conference. Full list to follow once dates are confirmed.

Psychological Studies

In their own words – Grounded theory analysis of Shadow’s Edge player video Interviews – January 2021

Kristi Pikiewicz PHD



Summary

The study used semi-structured interviews to speak with 25 young people ages 13-25 during the time period 24 July 2020 to 17 December 2020 about their gameplay experience with Shadow’s Edge, focusing on how gameplay affected their emotional lives, offline. Players found the game either through therapist recommendation through browsing the app store. Players reported dealing with depression, anxiety, social anxiety, autism or were exploring their identity or gender related topics. 25% of research participants had a history of childhood cancer. The methodology of Grounded Theory was used to discover “meaning units” from interview transcripts, describing the emergence of shared themes or experiences.

Objective & Key Research Questions

- Understand how long- term and engaged Shadow’s Edge players are motivated to play the game and how they take advantage of various features within the game and what they are missing in the game experience.
- Identify other techniques they use how to support themselves when going through challenges and how their lives have changed through playing Shadow’s Edge

Key questions include:

- What drives players to look for support in a digital experience?
- What is the impact of playing Shadow’s Edge in the words of long-term players?
- What is their gameplay experience, what do they like, what would they change?
- What do players learn from the game and translate into their real life? What other forms of mental health support are they looking for?

Background and Significance

Unfortunately, many teens lack access to traditional modes of support through family and peer interactions or through work with professionals (due to lack of resources, scheduling and transportation concerns, the stigma of seeking help, and more). With this recognized need for emotional health support, many technology, healthcare and mental health organizations have experimented with mental and emotional health applications, resulting in products meant to increase coping skills such as mindfulness and meditation to treat conditions including

depression, anxiety and PTSD. For example, the app *Calm* provides guided breathing and relaxation exercises to accompany meditation, with the companion *Calm Kids* offering support for younger users. Similarly, companies are leveraging wearable technologies such as smartwatches or activity-monitoring devices such as FitBit to promote movement and healthy sleep patterns (e.g., Whoop, Withings, etc.), and wearables such as TouchPoints offer stimulation meant to decrease stress. However, very few of these apps are “game-ified” in a way that makes teens want to interact with the platform for the long term. The goal of the mobile app *Shadow’s Edge* is to provide this needed support in a form accessible to and preferred by teens. Very basically, the app, which is made free through philanthropy for download at the App Store and Google Play, uses art and journaling to guide users through stages of Disruption, Disillusionment and Discovery as they work through life challenges. Now the current research seeks to create a preliminary understanding of outcomes associated with *Shadow’s Edge* gameplay.

Key Findings

Overall, the interview-based research reaffirmed that many young people feel stuck in the “now” of challenges including depression, anxiety, gender identity and loneliness. However, this also presents an opportunity: Due to the influence of the prefrontal cortex leading young people to live largely in the present, each moment is a chance to chart a new path.

Throughout this project, teens expressed the desire to understand their experiences as a way to move forward. They were hungry for change and support, and were motivated to explore tools to help them progress. As one participant said, “Getting stuck isn’t healthy. You need to find a positive outlet so you can process your emotions.” For many of these teens, the world of *Shadow’s Edge* provided this outlet.

Mental/Emotional Health Support: Teens in this study overwhelmingly expressed their need for supportive tools and their frustration with the lack of tools or lack of access to tools to support emotional health. Participants also spoke about the ways in which *Shadow’s Edge* offered this support (e.g. “SE really gives me that benefit factor of like being able to be in tune with my emotions and express myself in new ways”). Participants’ ideas coalesced into the following categories: Expression, Reflection, Processing Emotions, Mental Health Knowledge/Facts, Mindfulness, Support Around Transitions and Escape. Figure 1 presents participants’ sample interview material coded as per these categories.

Gameplay Preferences: Participants were overwhelmingly drawn to the introspective writing activities embedded in the app, and expressed their appreciation for unexpected and/or surprising game features, including pigeons that offer wisdom and other non-expected interactive features. Consensus for possible areas of improvement include increased ability to monitor and track progress toward goals and a more individualized experience in which self-discovery content is tailored to players’ personal needs and goals. Additionally, participants identified an opportunity to augment the app’s educational function, stating their preference for more mental-health related information and knowledge.

Why is this research relevant: The Teen Brain is a Work in Progress

Especially in teens and young adults, there is a significant difference in influence between their powerful and highly sensitive emotions and their ability to make mature decisions. In large part, this is driven by brain development. The brain structure known as the amygdala drives emotions and emotional responses, and while the amygdala is fully formed in young people, its natural balance, the prefrontal cortex, is not fully formed until age 25. The prefrontal cortex is the home of *executive function*, which includes the ability to see oneself in the future and thus make decisions informed not only by present conditions, but by how these decisions will influence the future self.

“Because the prefrontal cortex is still developing, teenagers might rely on a part of the brain called the amygdala to make decisions and solve problems more than adults do. The amygdala is associated with emotions, impulses, aggression and instinctive behaviour,” writes the Center for Adolescent Health.

In other words, teenagers *feel* deeply and *reason* more superficially, with the rational part of their brain a big step behind the impulsive part, leading teens to make most of their decisions based on emotions and instincts.

This push and pull between feeling and thinking was obvious in the current research, with teens and young adults reporting primarily their experiences of the present, for example current and immediate feelings of anxiety, depression and confusion; but at the same time, the research also shows the *desire* of these young people to move toward a more mature understanding of their decisions, actions and emotions.

Overall, it was as if research participants were trapped in the present but wanted to move through that stage to create more mature future selves. Interacting with the Shadow’s Edge app provided guidance for self discovery as well as an outlet for expressing difficult emotions.

Conclusion and Future Directions

The current research demonstrated that participants recognized their need for mental health support, identified the difficulty in finding this support in existing systems, and found significant benefit in the support provided by *Shadow’s Edge* (see Figure 1). Additionally, the support provided by Shadow’s Edge is multifaceted, with participants pointing to a range of coping strategies guided by the app, allowing teens to take from the experience strategies that are individualized to their needs, goals and preferences. For example, some teens preferred the simple distraction of escape into a virtual world, while others preferred the guided growth of self-discovery. These expressions of benefit from *Shadow’s Edge* gameplay suggest the app could be a useful tool to support teen mental health either in an independent setting or between sessions with a mental health professional.

The project also highlights the need for additional research to further describe the lived experience of teens undergoing emotional and mental health challenges, exploring important questions such as the prevalence or lack of support, the current strategies teens use to manage mental health, and opportunities to augment mental and emotional health support in ways that are both effective and practical for use.

The Impact of playing Shadow's Edge on Emotional Resilience – Aug – Oct 2017

Shadow's Edge design team and PIP Advice of University Twente



Summary

The study investigates the impact of a self-led, narrative therapy-based game (Shadow's Edge) on player resiliency. Fifty-five teenagers and young adults facing a serious or chronic illness were given an opportunity to play Shadow's Edge during the game's beta-test period. The study comprised a pre- and post-assessment on seven factors of resilience over six weeks, with an opportunity to provide qualitative comments during the post-assessment. Results showed a positive impact on all seven factors contributing to emotional resilience, with a significant impact on emotional regulation, optimism and positive self-identity.

Objective

- Investigate how players assess the impact of game play on seven factors contributing to emotional resilience derived from literature:
 1. *Proactive Coping*: dealing in a future-oriented way with difficult situations and setting realistic goals
 2. *Mindfulness & Acceptance*: creating a nonjudgmental focus on, and acceptance of, present moment experiences
 3. *Optimism*: developing a mental and emotional attitude that “future conditions will work out for the best”
 4. *Emotional Regulation*: building the capacity to allow and deal with strong emotions
 5. *Derived Meaning*: creating a sense of purpose from one's current context
 6. *Positive Self Identity*: having a sense of self-worth
 7. *Connectedness*: Feeling supported and able to reach out for help

Background and significance

This was one of the initial studies focusing on the impact of serious gaming on teens and young adults facing serious or chronic disease.

Method

Players signed up to play over a period of four weeks for 20 – 30 minutes per day. Before starting to play they completed a baseline survey asking them to self-assess their capacity against the seven factors influencing emotional resilience. At the end of the four weeks, they answered a series of questions about their game play experience and repeated the emotional resilience questionnaire.

Participants were 55 players, between 13 and 22 years old, mainly from the US (90%) and Europe (10%) that were recruited via online support groups and through a mailing to hospitals and health related foundations. 50% of the players were dealing with a physical illness, 20% with mental illness and 30% chose not to disclose what kind of health challenge they were facing. Players reported a variety of conditions they are dealing with, including: cancer, chronic Lyme's disease, brain tumor, kidney disease, organ transplants and depression. Players received an online voucher of USD 75 for completing the required gameplay and both surveys.

Key Findings

Results indicated a positive impact on all seven factors of emotional resilience, with a significant impact on positive self-identity, emotional regulation and optimism.

In addition, the follow-up survey asked open questions on their game experience. Many players described a shift in how they relate to their current situation:

- *“The game does make you expose your feelings if you are honest and challenges you to continue to believe healing does come.”* – David (14)
- *“The game did give my mind some sense of peace, especially when I had the thought of reviving a devastated city. Revitalizing a lost word makes me feel happy and fulfilled.”* – Joshua, 13+
- *“The game helped me relieve stress, cope with new challenges, and makes me feel less alone in my struggles. I loved being able to process ideas directly related to my situation. I felt like the journal prompts were written just for me!”* – Katrina, 23

Future Research, Limitations of the Study

This was an internally- led study without a randomized sample and control group. Also the team used a proprietary combination of scales. For better comparability with other studies, a future version of the study will work with PROMIS health measure scales.

Publication

In-house study published on website.

Product Design Studies

Shadow's Edge Player Centric Design Approach - October 2017 to present

Kevyn Eva Norton, MSC/Little Chicken Games Company

Summary

Since its inception, the Shadow's Edge game project has been driven by user research. Game design started with our founder, Sheri Brisson who is a long-term survivor of young adult brain cancer. Sheri's first-hand experience with illness and her 24 years of clinical experience in health psychology working directly with young people dealing with illness issues shaped the game purpose and narrative. We then worked closely with health and mental health professionals to design the metaphors and interventions within the game's worlds, characters, and narration. We collaborated with pediatric psychologists, child life specialists, palliative care teams, art therapists, social workers, and educators to create a truly interdisciplinary product. We complimented this with desk and literature research, collected concept feedback via focus groups, surveys and interviews, ran prototype playtests and player observations and conducted a formal beta-test. We are continuing with these practices for every subsequent release.

We have recorded input from more than 400 players in various formats that include interview transcripts, focus group recordings, survey results, design feedback session and playtest recordings. Additionally, we have analyzed in-game analytics from more than 37,000 downloads. While in the early development phase, we worked primarily with new players; today, we are working with a combination of new users as well as players who have extensively played the game.

Objectives

- Understand player context, motivations and key player needs.
- Integrate player ideas and feedback into the design of the product.
- Validate design decisions and usability through observing players using the game.
- Build a player community.

Method

We have worked directly with more than 400 young people using various research approaches. We have recruited players via patient and youth organizations and directly via social media and online forums. To recognize their contribution to the game, we pay players between USD 20 – 50 in gift vouchers to participate in research depending on the type of study. Players have come from North and South America, Europe, Asia and Australia, with the majority from the US, the Netherlands and Switzerland. To support this research, we use

- Video interviews, Focus groups, surveys
- Personas / Patient journeys / Job stories
- Direct design feedback through in-person interviews or surveys regarding the game world, backstory, characters, game objectives and game progression design

- Continuous validation of game mechanics and usability via prototypes and MVP tests combining exploratory interviews and player observations
- In-house playtests with released versions, using individuals and pairs, incorporating facial and screen recording
- Player diaries

Key Findings

The data from the most recent player interactions during the summer 2020 with 75 Shadow's Edge players shows that Shadow's Edge players are between 13 and 34 years old, with the majority between 16 and 24. This age range is older than we expected when we originally designed the game. Players look for a game like Shadow's Edge when they are in phases of transition - from school to high school, from high school to job, unemployment, wrestling with identity questions around gender or profession, or dealing with depression and anxiety. About half of the instances of depression and anxiety are related to a serious or chronic illness. The majority of these players find the game based on a recommendation from their doctor or therapist.

Players that found the game organically typically search the app store and were looking for graffiti, journaling or art apps or for mental health apps. They already use writing or art as a form of relaxation or self-help, however are not familiar with the concept of narrative therapy. About half the players who signed up for playtests with us have been diagnosed with a mental health issue, most commonly ADHD or ADD, depression or chronic anxiety.

Most players used the game in the morning after waking up or at night before going to bed. Fewer players played the game during breaks on their jobs or in common areas while spending time with their families. For some players Shadow's Edge was a companion over several months, other players played the game through in two to three days.

Key benefits players reported from playing were: a new perspective on themselves, relaxation, building a journaling practice, and having a new approach to art as a way of processing events. Not all players used the sharing features, as for some, a key benefit of the game was having a personal space where they could express things before they were ready to share with anyone else and learned new ways to communicate and build connection with others.

Players appreciated the journal questions. This resulted in 33,000 journal entries which we started analyzing in late 2020. There is an untapped opportunity here to interact with players based on their journal content via artificial intelligence that we will investigate in the future releases.

Based on the findings of the study, a number of changes were made to the game. This included a My Progress section, a set of discovery, writing and art missions and a messaging app within the game. Players also asked for additional backstory. The game characters now serve up more of this and provide mini writing and art exercises to support players as warm-ups for the narrative and expressive therapy exercises. The latest round of playtests also highlighted the need for a more personalized journey depending on the issues they are facing, more information on the

therapeutic background of the game, and a desire for more mini-games and puzzles within the game.

Further Research

- Upcoming releases in Columbia
- Work with game facilitators – i.e. therapists and teachers in the SEL space

Publication of Research

Article “What we learned from over 400 player conversations with young people between 13 and 34 years old” in a non-academic psychological magazine.

Shadow's Edge Journal Data Exploration – Dec 2020 - March 2021

Navot Naor, PHD



Summary

This study explores the journaling behavior, themes and sentiment contained in 21,000 anonymized journal entries of Shadow's Edge players using natural language processing techniques.

Objective & Key Research Questions

The objective of this research is to understand the journaling habits of Shadow's Edge players and the topics and sentiment they express in their journal entries.

Key questions we will be exploring are:

- What is the distribution of journal entries across different player's segmentations and through our different sections of the game.
- How does the journaling behavior change over time with gameplay?
- What are the emotions, main themes and sentiments conveyed in the journals?
- Do the players only write when prompted or do they also use the free journaling option?

Background and Significance

This research will deepen the understanding of how adolescents engage with a digital writing intervention that asks them to self-reflect. Understanding which prompts entice players to write a lot vs. which ones do not encourage answers can be valuable input for the design of therapeutic interventions. The themes and sentiment and range of emotions in the journal entries can give insight into the psychological process the game supports. Understanding what issues players are dealing allows us to understand which group of people and what they are dealing with benefits most from the game. This information will also allow us to personalize the experience to be most meaningful for the individual.

Method

This project is using Natural Language Processing (NLP) to analyze 14,000 journal entries by 700 players. Among the tools and tests that will be used for the data exploration are:

- Tools: Pandas, Numpy, Matplotlib, Seaborn, Scikit-learn
- Tests: T-testing, Pearson correlation, Paired-T or Wilcoxon test, linear regression, Analysis of Variance.
- NLTK or SparkNLP

Key Findings

Findings for data exploration and sentiment analysis; thematic analysis still in progress.

A number of key findings emerged from the initial exploratory NLP analysis. First, by exploring the distribution of number of words used by players throughout all their journaling entries, and the number of journaling entries it is evident that close to 40% of players journaled only once. As such it is out hypothesis that there are at least two distinct types of player types, writers, and non-writers. We furthermore assume that within the non-writers group a distinct artist group would emerge.

The majority of journal entries is below 50 words, with an average of 15 words – making them comparable to tweets or messages rather than prose. These are followed by a high number journal entries between 50 and 100 words, and a series of outlier journal entries with more than 100 words up to 300 words. The journal entries that invite most writing are in the Disruption phase of the game and talk about dealing with anger, numbing out and relating with others in the changed situation and being difficult. The overall most popular prompt is “Blessings” in the Discovery phase which invites players to describe their learnings and blessings from their difficulties.

Following the exploratory NLP analysis, VADAR dictionary was used to score each text affective level on two axes: positive vs negative, and emotional intensity. VADAR was used as it is trained on social media texts, such as tweets and thus is suited for short text inputs. From the output of the analysis, it is evident that the intensity of positive is stronger than that of negative emotions. Examples of words that are most frequent on the positive side are friends, think, proud and love. Examples of most frequent words on the negative side are feel, sad, pain and miss. Interestingly the most prominent word on both sides is people – which indicates how connection with others is a key driver of wellbeing or not wellbeing. Furthermore, the ratio of positive to negative entries increases drastically as players transition through the game’s phases. These findings, however, should be further examined as the overall number of journal entries declines after the “Disruption” phase.

Future Research

What are the themes included in the journal entries? Are the findings changing over time when we re-run the algorithms? What is the correlation between art making and journal writing? Can we define distinct player groups? Which player group is most likely to develop engagement with the game? Can the machine learning models we develop be used for further emotion recognition analysis?

Publication of Research

In-house only

Science of wellbeing studies

Serious and Chronic Illness online engagement – Apr - June 2018

Summary

For many youths facing serious or chronic illness, online conversations are a key means to interact with others. Often, these individuals are looking to others online to gather insights about their condition, the impact of their condition on their lives and – when feeling better or having emotionally come to terms with their situation – give back through encouragement and advice to others facing similar conditions.

Using an innovative toolset including machine learning and big data analytics to search postings on social networks, message boards, patient communities, and topical sites, our partner, Culturintel, performed a large-scale qualitative analysis using over 13 million online conversations of teens and young adults facing chronic or serious disease. The data shows there are many more questions around living with serious and chronic disease than answers online. It also highlights an emotional journey from desperation to hope and the importance for patients to share and give back once they are feeling better. This indicates an opportunity and need to include young patients in meaningful real-life conversations about their illness, provide facts and ways to collaborate with others online and support youth who are looking for agency in dealing with the situations they are facing.

Objectives

- Understand the online behavior, needs and opportunities for teens and young adults facing serious or chronic illness when they engage with each other online.
- Investigate how these differ among these different groups of young people and how they change over the course of their patient journeys.
- Highlight opportunities to improve young people's online experiences.

Background and Significance

This study makes use of the power of online interaction by mining public online conversations to listen to what people are saying in ways that are completely unsolicited, spontaneous, and without any interviewer or researcher bias. It seeks to understand which of the young people's needs are being met and which are lacking.

Method

A total of 9.3 million conversations of teens and young adults facing serious disease and 4.6 million conversations from teens and young adults with chronic disease were analyzed over a period of 12 months on topical sites, forums, social networks and blogs. This AI-driven research combined a series of text-mining tools to examine: sources, sentiment, topics of discussion, priorities and needs discussed, mindset and decision paths.

Key Findings

For these young people, the majority of online conversations happen on topical sites or message boards vs. social networks. Young adults with serious disease were the most engaged, followed by teens with serious disease (+45% for young adults). About two-thirds of conversations revolved around their medical condition and were driven by the uncertainty about their future and their desperation regarding their condition.

There were more questions than answers online for teens and young adults facing serious illness. This data is significant because if patients are asking questions and no one is answering, this gap can create a feeling of being let down or being isolated in their struggles. For teens and young adults with chronic disease, the online experience has become more of a platform to support each other by answering questions and sharing experiences with others. For these groups, there is an even distribution between asking questions, providing answers and sharing insights. Conversations are directly about their medical condition, followed by the impact of their condition on their lives and sharing advice with others. From these conversations we see that the journey navigating through illness and coping emotionally with the impact is as important as understanding their medical condition itself. Young adults with chronic disease overall express a more negative sentiment, likely the result of living with their condition long-term.

Our data shows a strong driver of positivity is the emotional stage the person is in, not whether they are physically better. 25% of the sentiment expressed online for patients with chronic illness is positive when they share ways they have come to terms with their situation. The data also shows that young people are taking an active role in learning about, and managing, their conditions by turning to the Internet to better understand their conditions. But simply receiving information on the internet, which at times may be incomplete, confusing, and in the worst-case, may unduly frighten patients. By including patients in important real-life conversations about both the medical aspects of their illnesses and the impact these illnesses are having, builds patients' confidence in their ability to play an active role in their lives.

There is an opportunity to both develop content that is issue-based, common to anyone struggling with illness, such as returning to school, changed physical abilities, frustration of uncertainty, and placing it generally on the Internet, rather than developing content to specifically place, for example, on a cancer site, or a Lyme disease site.

Further Research

Re-run the study to understand the impact COVID has had on young people facing serious or chronic disease.

Publication of Research

Sheri Sobrato Brisson and Dr Kristi Pikiwicz presented the results of this study at the American Child Life Conference in April 2019.

Teen & young adult perception of wellbeing, mental health and self-care – May 2020

Summary

For many youths, wellbeing and mental health are becoming increasingly important in view of the many individual and global challenges they are facing. These challenges including the COVID-19 pandemic, economic uncertainty, and climate change have led to an increase in anxiety and depression globally in teenagers and young adults. Using an innovative toolset, including machine learning and big data analytics to search postings on social networks, message boards, online communities, and topical sites, our partner, Culturintel, performed a large-scale qualitative analysis mining over 11.5 million online conversations of teens and young adults around three key topics: wellness/wellbeing, mental health and self-care. The data highlights that young people are actively looking for ways to take their wellbeing/wellness and mental health into their hands. The study highlights a deficit in answers compared to the many questions young people have around all three topics. The areas where content is most lacking are: dealing with emotions, creating a sense of agency in adverse circumstances, the social impact of mental health issues and guidance and tools for self-care.

Objective

- Understand the online behavior, definitions, needs and gains for teens and young adults around wellbeing, mental health and self-care
- Identify opportunities in content and tools that can help young people to support themselves better to meet their needs

Background and Significance

This study makes use of the power of online interaction by mining public online conversations to listen to what people are saying in ways that are completely unsolicited, spontaneous and without any interviewer or researcher bias. It seeks to understand which of the young people's needs are being met and which are lacking.

Method

A total of 5.8 million online conversations around wellbeing / wellness, 6.9 around mental health, 4.1 million conversations around self-care by teens and young adults were analyzed over a period of three months on topical sites, forums, social networks and blogs. This AI-driven research combined a series of text-mining tools to examine: sources, sentiment, topics of discussion, priorities and needs discussed, mindset and decision paths.

Key Findings

For all three areas – wellbeing, mental health and self-care – 65% of conversations happened on message boards and topical sites, versus 10% on blogs and 25% on social networks or content sharing sites such as Youtube. Online conversations around wellness centered around four key topics: physical, emotional, social and circumstantial wellbeing. For mental health the topics discussed were personal issues, searching for resources and solutions, discussing social impact

and looking for support and connection. When individuals discussed self-care, they referred to both the physical and emotional dimension of taking care of yourself.

The data around wellness/wellbeing highlighted that youth define wellbeing as having four key components: physical, emotional, social and circumstantial. Attaining and maintaining physical wellbeing seems less challenging than emotional, social and circumstantial wellness, which are correlated with more difficult sentiments and lack of information and support.

In the area of mental health, positive drivers included finding or receiving effective help and social support, while negative drivers were losing connection, a lack of resources and the sense of being a burden. The data suggest a strong need for support to address the social impact of mental health issues. The analysis around the third topic, self-care, showed young people taking an active approach to self-care on both the physical and emotional levels.

For all three key dimensions there are more questions than answers online. There is a need for content that supports individuals dealing with strong emotions and provides them with tools to gain a sense of agency in adverse circumstances. Another key need are approaches for dealing with the social impact of mental health issues and the need to de-personalize challenges to make it easier to reach out for help without aggravating the sense of being a burden on others. As the overall sentiment towards self-help is positive, there is a great opportunity for additional content around positive self-care behaviors and guidance on self-care practices, especially in the emotional space.

Further Research

Re-run study as a Post-COVID analysis to understand the impact of COVID on wellbeing, mental health and self-care as perceived by young people.

Publication of Research

The study was aimed to be presented at SXSW 2020. The conference was canceled so no publications have been developed at this time.