How young adults with mental health conditions use the internet to access mental health information and support

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The Overwhelming Majority of Young Adults Use the Internet

- Among young adults (18-29)
  - 93% go online
  - 72% use social networking
  - 72% looked for health information online
    - 33% looked up information about mental health
    - 38% access information on medications
    - 34% look up alternative treatments

- “Every day, more people go online for medical advice than actually visit health care professionals”

People Use the Internet to Guide Their Health Decisions

• 68% of health information seekers state that the information they find online has an impact on their healthcare decisions

• 18% of adults have gone online to diagnose or treat a medical condition on their own, without consulting their doctor

• About half of online adult online health information seekers have read someone else's commentary or experience about health or medical issues

• We hypothesize these numbers are higher for young adults specifically

The General Quality of Online Mental Health Information is Poor

- The overall quality of online information on:
  - Depression (Griffiths & Christensen, 2000)
  - Social phobia (Khazaal, Fernandez, Cochand, Reboh, & Zullino, 2008)
  - Substance addictions (e.g., Khazaal, Chatton, Cochland, & Zullino, 2008)

is low!
Our Study

• How do transition-aged youth with serious mental health conditions use the internet for information and support regarding their mental health?

• Three focus groups (N= 27)
  – Three different parts of Oregon
  – Three different samples
  • Craigslist
  • Youth advocacy group
  • Residential treatment center
Sample Focus Group Questions

• What sorts of information do you need in order to best manage your mental health?
• Where you like to get information about your mental health?
• What web sites have you gone to in order to get information about mental health?
• How useful have these web sites been in answering your questions?
• What would make these web sites more useful for you?
• Categories of analysis
  – Topics searched for
  – Motivations for information seeking
  – Characteristics of desirable mental health websites
  – Barriers to successful searching
Results: Topics

• Diagnosis
• Access to health care (i.e., insurance information, places to go)
• Medications
• Treatment Options
• Support and Resources related to transition
• Diagnosis: “What is wrong with me?”
• Self diagnose online by looking up symptoms and finding a diagnosis that fits their experience.
  – They sometimes do this because they feel like they have nowhere else to turn when they aren’t feeling “right.”
• Access to health care: “Where can I go to get care?”
  – Look for places that accept clients without insurance or are low-cost.
  – Look up doctor ratings or backgrounds.
  – Look up information to prepare for a health visit.
Results: Topics

• Medication: “What does this medication do?”
• Young people are very concerned about medications. They want to know:
  – the side effects
  – the symptoms they are supposed to treat
  – the diagnosis associated with the medication.
• Treatment Options: What is the best treatment for me?
  – Young people want to be in charge of their health and treatment and want to know all the options.
  – They look up information on different approaches to treatment, often outside of medication.
Results: Topics

- Support and Resources: *How can I manage on my own?*
  - Young people look up strategies for living more independently – everything from how to develop good coping skills to where to get food stamps.
  - The internet provides information on how to successfully transition to adulthood and meet the challenges associated with living more independently.
Results: Motivations

- Finding out more
- To prepare for a mental health visit
- Community
- Nowhere else to go
- Anonymity
Results: Motivations

• Finding out more:
  – I like that you can look up the prescription that your psychiatrist is writing you. Because when you get a new psychiatrist or you have a new one or a crazy one, you can’t trust. They are just like “take this, this is what you need.” So I just like that you can look it up and it will tell you all the side-effects and then you can go back to him and say “why do you think that I am psychotic?”
Results: Motivations

• To prepare for a mental health visit:
  – [Online] I can learn about the breadth of information [about my mental health] at least so when I see a doctor and someone tells me what I have I at least have a basis of foundation for what is going on. So I think that for young people are getting diagnosed these days I bet that 50 percent or 75 percent of them already have some information about what is going on with themselves.
Results: Motivations

• Community:
  – *I trust the people who I have met who have had similar experiences. I had never met anyone who was bipolar before I met them on the internet and they told me their experiences personally.*
• Nowhere else to go:
  – *When I turned 18 I stopped [getting mental health care] and went to one therapy session because I didn’t have my mom’s insurance anymore. So suddenly it became about what resources I had access to myself, so from the medical field of mental health to the internet field of mental health – that was my transition.*
Results: Motivations

• Anonymity
  – The internet is private, there is no one there questioning me or what I’m looking up. Its personal and totally under my control.
Results: Desirable website

- Specific features (message board, interactive diagnoses assessment)
- Ease of navigation
- Accessible language
Results: Desirable website

• Specific features
  
  – *It has a mixture of mediums not just video and text but an availability of live chat with other people: that shows real dedication.*
Results: Desirable website

• Ease of navigation
  – I just won’t use Web MD because I cannot navigate that site. It is not user friendly. It is all blue and green and I just don’t know what to push. So, I’m like f____ this.
• Accessible language
  – KG: What would make some of these websites more useful to you?
  – Definitely youth friendly terms. I feel like in the search engines if I want to type in something, like, oh I don’t know, I just can’t take acronyms. Just youth friendly terms. I can’t take those 13-syllable medical terms.
Results: Desirable website

• Other wishes
  – Targeted audience (youth, dx specific)
  – Presentation “look and feel”
  – Quality indicators (cited sources, research, credible)
Results: Barriers

• Accuracy of information
• Too much information: overwhelmed/irrelevant
• Personal struggles vs. abstract possibility
• Accuracy of information
  – I don’t really trust those things [message boards]... people would say irrelevant things. They contradict. They are putting their two cents in and its only worth a half cent.
Results: Barriers

• Too much information
  – if you have a search engine like google or something like that you type one thing in say “schizophrenia” to see what the symptoms are and you got to that it might show a bunch of things with schizophrenia in the title and it might have a whole paper on what the symptoms of schizophrenia are and then you click on another and it might bring up a you-tube video of a dude freaking out. It gets really hard to make it specific, and that’s for anything on the internet and its what frustrates me so much about it when I use the computer.
Next Phases

• Collected data from 28 youth on information searching strategies and quality of websites accessed;
• Developed an online curriculum to teach how to search for accurate mental health information online.
  – Module 1 = Search strategies
  – Module 2 = Assessing the quality of information
  – Currently being piloted
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