

Ethical Issues in internet research

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Overview

- Study Background
- Ethical considerations
- Study one- YouTube
 - Recruitment
 - Data collection
 - Results
- Study two- Message boards/support sites
 - Recruitment
 - Data collection
 - Results

Study Background

- The lived experience of individuals who self-harm and use internet support: An Interpretative Phenomenological Analysis
- Study conducted in two stages
 - YouTube
 - Self-harm support sites/message boards

Study Background- Inclusion Criteria

- Females between the ages of 18-35
- Self-harm free for a year
- YouTube- posted more than one video with the recent post in the previous month
- Message boards- Registered for at least a year and had to be active user.
- Speak English

Ethical Issues

- Informed consent: Yes/No Format
- Confidentiality:
 - Password protected files
- Minimizing harm
 - Free web-based counselling services
 - Follow-up emails
 - Checking with participant throughout interview

Study One- YouTube

- Over 2000 videos of self-harm.
- Types: Character and non-character videos (Lewis et.al, 2011)
- Aims: To better understand the purpose and content of self-harm videos on YouTube

Recruitment

- Potential participants screened for inclusion criteria and contacted via YouTube message providing basic information about purpose of study.
- Interested participants provided with Plain Language Statement and Consent form

Issues?

- Did not meet self-harm free criteria
- Study modified to download videos instead of conducting interviews

Participant

- Mel, 22 years old and lives in Canada
- Been active on YouTube since 2007
- Posted over a 100 (at the time of data collection) videos on varied topics including struggle with self-harm, eating disorders, Borderline Personality disorder and experiences treatment and life in general.

Data Collection- YouTube

- 31 videos downloaded over a period of one year
- Content making explicit reference to self-harm, mental illness or recovery/treatment
- E.g.
<http://www.youtube.com/watch?v=jvOhhwGmCko>

Results- YouTube

- Theme one: Struggle with self-harm and mental illness
- Theme two: Treatment experience
 - Negative interactions with professionals and staff
- Theme three: Experience of posting videos
 - Benefits for self – sharing thoughts and feelings with users thus connecting with and forming virtual social networks
 - Negative aspects of the internet

Study Two- Self-harm support sites/message boards

- Self-harm message boards
- Moderation levels and types
 - Low moderation v/s high moderation
 - Over 700 message boards
- Aim : Understand and Explore from the participants perspective the experience of using self-harm message boards

Interview Schedule

- Three researcher determined categories
 - Circumstances leading to self-harm
 - Treatment experiences
 - Experiences of using message boards

Recruitment

- Moderators contacted directly to request permission
- Plain Language Statement and Informed consent posted on forum



Data Collection-message boards

Options offered

- Email
- Messenger
- Skype

Participants

- Lostwithoutwords, 26, UK
- StillFighting, 22, Poland
- Hathor, 33, UK
- Twyla, 25, Canada
- Frankie, 20, UK

Issues

- Verifying age
 - Profile page used to determine age

- Time zones
 - Interviews conducted at participants convenience

Results- Message boards/support sites

Origins of and experience of self-harm and mental illness	Treatment experiences	Role of internet
Theme one: Family dynamics, disrupted attachments and traumatic events leading to self-harm	Theme four: Help seeking, expectations and positive experiences of therapy	Theme seven: Helpful experiences of websites Three stages 1) Lurking 2) Actively posting 3) Less active use coinciding with recovery
Theme two: Nature of self-injury cycle and its functions	Theme five: Negative experiences in the mental health system and therapy	Theme eight: Harmful aspects of websites
Theme three: Struggle with self-injury	Theme six: Perceived factors in recovery	



Thank You