Panel: Quantitative and Ethnographic Methods

Visual and digital anthropological methods to study illness visual narratives

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Fundación BBVA
RESEARCH PROJECT: SHARING PAIN AND GRIEF ONLINE

THE SELF-REFERENTIAL DIGITAL IMAGE OF ILLNESS AND DEATH AS A MEANS OF DESTIGMATIZATION, CONNECTION, VISIBILIZATION AND COPRESENCE

- Interdisciplinary exploration of the depiction of pain and grief in the domain of the digital image and humanities
- Specific object of study: the self-referential image of illness and death shared online.
- We analyze the new practices, narratives and formats emerging in their regard on the Internet and in social networks, along with their cultural significance.
- Focused in Illness Narratives, specially those related with mental illnesses and cancer.
- “New” methodologies from different fields have been acquired and hybridized as new tools of evaluation, analysis and verification of data necessary for research needs
RESEARCH QUESTIONS

- What kind of visual narratives of illness are emerging online?
- What are the objectives or the meaning of those practices?
- What are the differences between illnesses and "authors" that can be identified within those practices?
- Which are the reasons to share those images online?
- What kind of relationships are created through those images?
- What is the meaning or the role of family images and selfies in this field?
In my first stages while doing my PhD in the Art Faculty, I used only qualitative methodologies as:

- Participant Observation
- Case Studies
- Artistic experimentation
- Bibliography revision and analysis

PhD thesis about self-referential visual artworks based on family album and domestic films since 1970 till the end of the Thesis (2012). Most of the artist and artworks were related with a chronical, terminal or degenerative illness.

The methodologies I was using were insufficient to analyze that phenomena.
QUALITATIVE METHODOLOGIES II

Master degree in Anthropology and ethnography = some new methodologies.

First of all, it was necessary to focus to be able to apply other methodologies: Alzheimer’s Visual Narratives in Barcelona.

New methodologies applied:

Direct Observation
Semi directed Interviews
Ethnography
QUALITATIVE METHODOLOGIES III

- Digital ethnography
- Participant Observation (online): using SNSs to introduce myself in the field, but also sharing my own images to understand how it works from the inside.
- Artistic experimentation: I also have exposed some of my images of the SNSs as book objects that try to materialize as artworks some of the results of my research.
- Bibliography revision and analysis from other fields
- Visual/semiotic analysis of images
  - To understand the different approaches to illness that have “photographers” that are patients, caregivers, photojournalists or doctors.
  - If there are special semiotics for those that are caregivers or patients and also photojournalists, artists or filmmakers.
  - If it was possible to identify different semiotics in the visualization of illness in concrete themes as the process of anticipatory grief (Alzheimer’s), activism (AIDS) or claim for body agency (breast cancer) with interesting findings.
I have recollected the tags that accompany the images to be able to make a comparison between the qualitative analysis of the images and the keywords that the “photographers” considered essential. That allow me to make some graphics with percentages of use, the more used tags... and it has been interesting that the qualitative and quantitative analysis are parallel and give similar results.

- **Number of followers, likes**... quantitative data that allow me to understand the kind of practices and profiles that are more popular and allow me to give some quantitative data that shows the importance of the phenomena.

With these data it’s also possible to see the “numerical” evolution of the practice and that gives a more “scientific” support to the qualitative findings.
In SNSs and other online platforms (such as blogs or dedicated sites) there is an important increase of images of certain stigmatised illnesses and death.

Changes in what is worth photographing in the digital era along with the transformation of the boundaries of intimacy that favour the integration of pain and grief in daily visual experience.

It is important to notice that these images are frequently domestic or familiar photographs that show autobiographical or self-referential experiences versus other frequent professional images present in other media. Humanizing the image of the patient/illness.

Most of the users tag their images with words related with themes as visibilization, support, association or medical issues. This implies a more humanized and less stigmatizing sense of the representation of illness, and a will for trying to call for awareness and to change the social perception of certain illnesses and some aspects of death and grief.

These issues are key to understand the new practices in this context:

COPRESENCE DESTIGMATIZATION CONECTION VISIBILIZATION
NEW CHALLENGES

- The complex theme of *Anonymity when working with images*, well-known artists or normal users of *SNSs* that publish their images and comments online with their names or… the HTTP has their names included.

- **Ethics and mental illness images**: Is it correct, ethic, that we publish the images, with recognizable faces (with permission, obviously) in such a vulnerable theme? Is correct that the caregiver and/or tutor gives us permission, when may be the patient will not agree if she or he was able to give us the permission?
THANK YOU!
MORE INFORMATION AND WEBSITE

SPANISH

ENGLISH

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