Visual Illness Narratives of Depression

Abstract
Illness narratives refer to unique understanding of patients’ personal experiences around illness. Visual medium, such as photographs, provide a rich form of self-expression. Tumblr, a heavily used micro blogging site provides a unique opportunity for researchers to understand visual illness narratives. This paper discusses the Q-sort method to analyze depression-related images from Tumblr. The data has the potential to reveal critical insights about personal and social life of individuals living with depression. The paper concludes with implications for using Q-sort methodology to study visual narratives of depression on social media.

Author Keywords
Q-Sort; Depression; Visual Illness Narratives; Tumblr; Social Media, Qualitative, Subjectivity.

ACM Classification Keywords
J.3 Life and Medical Sciences, Medical information systems.
Introduction
Sharing illness narratives bring positive therapeutic effects. The process of narrating one’s illness empower both story tellers and the listeners (Frank, 1995). Giving patients the opportunity to tell a story about their illness help them actively participate in improving their wellness (Reavey & Johnson, 2008). Hearing other’s stories help patients cope with their own disease by realizing that they are not alone (Frank, 1995).

Visual Illness Narratives
Most research on illness narratives is based on human conversations generated from diaries, interviews, focus groups, case studies, and surveys, focusing on texts and words (Frank, 1995). However, speech and text is not the only way people interact and engage with their surrounding world. Through social media, patients have found more visual ways, such as images and photos, to express their illness. Images are important because of their ability to signify inner mental states, attitudes and emotions, that is often more elaborate and in depth than what the image alone depicts (Reavey & Johnson, 2008).

The ubiquity of camera phones and rise of image-based social sites has led to the dramatic increase in image sharing as part of online social interaction. Social media is increasingly becoming visual and this abundance of images on web underscores the importance of studying visual illness narratives (White & Epston, 1990) expressed as signs, symbols, non-verbal gestures, paintings, motion graphics, graffiti and other visual forms. The advent of visual social media such as Tumblr, Pinterest and Instagram provide people an opportunity to document this experience visually (See Figure 1 and 2 for examples). Based on this premise, this paper examines research methods to explore how people with depression use images to express their illness on social media.

Visual Research Methodologies
Pervasive use of images on social media has prompted visual research methodologies from traditional objectivist forms of analysis to more subjective ways of looking into social life (Harper, 2004; Pink, 2006, 2007, 2012; Ruby, 1995). To address this transformation, several research methodologies have been proposed to study visual narratives including visual ethnography (Banks, 2001b), ethno-ethnography (Arnold, Graesch, Ragazzini, & Ochs, 2012), ethno-methodology (Mondada, 2003), documentary photography (Brown, 2011), rephotography (Klett, 2011), visual content analysis (Bock, Isermann, & Knieper, 2011), photo or video diary (Chaplin, 1994), photo elicitation (Banks, 2001a), participant drawing (Mitchell, 2001) and photovoice (Mitchell, 2001). In addition to the research methods mentioned above, this paper introduces the Q-sort methodology as an alternative to study illness narratives produced from images related to depression.

Depression
Depression is a common but serious illness. It interferes with daily life and causes pain for both patients and caregivers. According to the substance abuse and mental health services administration (SAMHSA, 2014), an estimated 43 million adults in the United States suffer of any mental illness (AMI). The

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1 Illness narrative is defined as “the comprehensive experience of symptoms and problems as felt by the patient, family and society” (Kleinman, 1988).
percentage of adults with AMI is highest for adults aged 26 to 49 (21.5%), followed by those aged 18 to 25 (19.4%). An additional 10 million (4.2%) suffer of serious mental illness (SMI). Women aged 18 or older are more likely than men to have AMI (22 vs. 14%) and SMI (4.9 vs. 3.5%).

Untreated depression can lead to serious health hazards. CDC surveillance report (2008-2009) collected representative data from 92,264 respondents (age 18+) across U.S. In terms of Michigan specific data, the report stated 2.7 million (1.1%) people made suicide plans in the past year, and 1.3 million (0.6%) attempted suicide. Overall, an estimated 9.3 million adults (3.9%) aged 18 or older had serious thoughts of suicide out of whom 1.4 percent are females and 1.7% males (Crosby, Han, Ortega, Parks, & Gfroerer, 2011).

Depression is a serious health concern among student population as well. Michigan State University’s (MSU) State of Spartan Health report (Hembroff, 2014) found anxiety and depression as two of the top six health concerns among college students. The report noted that 84 percent of the MSU students felt overwhelmed at least once in the past year. About 28 percent students reported that stress seriously affected their academic performance whereas 58 percent students reported feeling very sad or very lonely (54%). Around 27% students reported they felt so depressed that it was difficult to function at least once during the school year.

Illness Narratives of Depression on Internet
Internet is becoming an important space for patients to express their illness experience (Conrad & Stults, 2010). Although, sharing illness is a largely private experience, the development of Internet, specifically social media, is turning it into a public activity. Patients now share their illness experience at online blogs and support groups, indicating a transformation from private to public experience of talking about their illness.

This transformation is more evident in younger population who are also more avid users of Internet. For example, 17 percent teens use the Internet to gather information about health topics, such as depression and drugs, which may be hard to discuss with others (PEW, 2010). An additional, 21 percent adults said they look online for information about depression, anxiety, stress or mental health issues. More women than men are information seekers about depression, anxiety and other mental health issues (35% female v. 22% male). These statistics capture the reasons to understand how young patients with depression express their illness on Internet.

Q-Sort Method for Visual Illness Narratives
The study employs Q-Sort method to select and discuss the images with subjects. The Q-sort method was developed by Stephenson in 1953 to measure any situation in which subjectivity is at issue, such as attitudes, beliefs and behaviors (Stephenson, 1965, 1968). Q-sort method has specifically gained popularity in measuring attitude (Cross, 2005) towards chronic pain in disciplines like medicine and nursing (Risdon, Eccleston, Crombez, & McCracken, 2003), and information technology adoption (Valenta & Wigger, 1997). The Q-sort method has been used to study photographs as well (Fairweather & Swaffield, 2002) in addition to measuring other subjective issues like public opinion (Webler, Tuler, & Krueger, 2001), communication (Carlson & Trichtinger, 2001), policy analysis (Durning, 1999), environmental issues (Barry...
Proops, 1999) and education (Lecouteur & Delfabbro, 2001).

Procedure
The Q-Sort method requires subjects to rank-order sets of images on a scale ranging from options such as agree/disagree, like/dislike, best/worst and even mood states. Overall, the number of items per pile varies, but usually forms a near-normal distribution, with fewer items in the extremes and more in the center.

<table>
<thead>
<tr>
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<td>0</td>
<td>1</td>
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Table 1: Q-Sort distribution

The Q-sort procedure consists of following steps:

- Collecting the images. This step is called concourse in which a comprehensive set of most popular images about Depression will be collected from Tumblr.
- Reducing the concourse into a set of meaningful images called Q-Sample. A trained mental health counselor performs this step.

First two steps will result in gathering a representative sample of around 100 most popular images about depression.

- The resultant images will be randomly numbered and color-printed on a piece of card.
- Subjects will sort through the images and place in a structured Q-sort distribution (See Table 1). This step is called Q-sorting.

Finally, subjects will participate in a semi-structured interview to talk about the Q-sort distribution of images they have themselves created.

Data collection
The first step is to collect virtually any visual (photos, paintings, cartoons, selfies, memes, GIF animations) on Tumblr searched by the keyword “depression.” Only images will be collected because the study is to explore how subjects express their illness experiences in visual narratives without text. Posts that only included text or videos, but not images, will be excluded. For example if the post contained an image showing only text then the image will not be included in the dataset. However, the study will record the corresponding written text such as caption and description for each image, to provide the context for that particular image. All posts will be de-identified during the collection. Poster information and other meta-data, including ‘share’ and ‘like’ counts, will not be collected.

Rationale to use Tumblr for data collection
Tumblr social media will be used to collect images because of its increased popularity among Internet users and due to its image sharing features. From 2007 to 2014, the website hosted more than 169 million
blogs and 75 billion posts (Tumblr, 2014). Social Media Trends ranked Tumblr as the fastest growing social media site with a growth rate of 120% in 2014 (GlobalWebIndex, 2014). Until 2014, Tumblr also has the youngest audience, with more than 70 percent of users between ages 16-34 (Tumblr, 2014) which is the main audience of this study.

**Recruitment**
Subjects will be recruited from depression support groups. The study will recruit both male and female subjects ages 18 to 45. After the sorting exercise, described above, subjects will be asked what each image ‘means’ to them and what is their interpretation of the image. The interview will be open-ended, focusing on the subjects’ reaction and responses to the images. The interview will be terminated if talking about their experience cause anxiety among the subjects. The Interview will last for around an hour and will be recorded and then transcribed. Subjects’ confidentiality will be protected according to human research and rights protection guidelines.

**Data Analysis**
Data will be analyzed using Atlas.ti qualitative software, which is a well-known computer package to analyze qualitative research data. Data analysis can be divided in following steps:

- First stage of analysis involves open coding of each interview transcript to identify core categories (Strauss & Corbin, 1998).
- Next stage involves axial coding in which links between the codes will be established across the sample.
- Final stage involves, selective coding to develop research propositions (Creswell, 2007).

The data analysis will start in early stage of data collection and new findings will be constantly compared with earlier data. The data collection will terminate once a saturation point is reached i.e., new findings are found redundant. A project log will be kept to maintain record of all research activities.

**Conclusion**
Images and photos may exist materially in the world, but depends on humans to gain meaning. To capture this meaning, this paper introduces Q-sort method with introducing a photograph in the research interview process. Because patients with depression may find it hard to discuss their illness, images may serve as a bridge to provide access into latent thoughts and feelings. Additionally, the interview process may motivate participants to provide a new perspective on what may not be directly related to that photograph and providing a backstory of the illness experience. This interview approach may also produce different pieces of information to understand and improve illness treatment that may be unique to what is normally expressed in a clinical setting. These narratives may also help improve communication between patients and caregivers, offering opportunities and possibilities to improve patient care in home, neighborhood and clinical settings.
References


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