Using data comics to make data more understandable in the field of medicine

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Introduction

In the era of 'big data', scholars have decried for ways to make data more relatable to the human experience (Lupton, 2017; Gray et al., 2016; Kennedy et al., 2016). Several new methods have attempted to do this, such as interactive visualization, and haptic and visceral manifestations of data, that allow users to get a "feel" for the way data makes sense within their own lives (Lupton, 2017). Although researchers have perfected the aesthetics of data visualizations to capture audience interest, less can be said about how data visualization engages the audience through a deeper connection to its readers. Thus, the goal of this paper will be to explore one way of making data more relatable the audience, using data comics, that has a strong potential of communicating data-driven stories (Bach et al., 2018).

Previous research has shown that use of text and images can significantly enhance understanding of complex information, even in vulnerable populations, such as pediatric patients (Kassai et al., 2016), and those on the spectrum (Ahmed-Husain & Dunsmuir, 2014). Data comics do just that by combining text and images to make data more relatable (Bowman, 2017), approachable (McCloud, 1993) and accessible (Czerwiec et al., 2015). In this case, *relatable* refers to using personal anecdotes as part of the data visualization process; *approachable* refers to a medium (such as a comic) that is familiar to the reader; and *accessible* refers to the presentation of data through a simplified way that may be understandable to the wider audience (with or without data literacy).

A growing number of data comics are being published within the field of medicine (Czerwiec et al., 2015), forming a new category of comic works, called graphic medicine (Williams, 2011). In this paper, I will begin by going over a brief history of graphic

medicine, followed by recent examples graphic medicine used to visualize data. Drawing examples from this emerging field will allow us to understand the benefits and challenges of presenting data in this format. I will end with a proposed study that will explore the use of data comics in patient therapeutic education.

History of graphic comics in medicine

Graphic medicine was a term originally coined by Dr. Ian Williams in 2007. Overtime, it grew into a large field that now encompasses healthcare, illness, as well as patient education, treatment, and experience (Green & Myers, 2010). Founded by Dr. Williams, there is now also an organization dedicated to this, formed by a community of academics, health carers, authors and artists, whose goal is to explore the intersection between comic and healthcare (https://www.graphicmedicine.org/). Later in 2015, the seminal text, *Graphic Medicine Manifesto,* was published by a group of scholars, artists and practitioner, and contained an interdisciplinary collection of essays and comics that illustrate how the graphical format can help to explain medical data. Graphic medicine can humanize data by emphasising health experiences, without the healthcare jargon (Charon, 2006). For instance, graphic pathographies, which are first-person-centred illness narratives, gives ill people a voice beyond their disability, which can resonate with others going through a similar circumstance and provide and act as a form of social support (Frank, 2013). Qualitative data, such as capturing the human experience, is particularly well displayed using the comic format. Graphic elements like thought bubbles and split screens can keep the nuances of interpersonal interactions, while still displaying the necessary data. This will be explored further in the following section by using examples of graphic medicine found in the book Taking Turns.

Examples of graphic medicine

A great example of graphic medicine is from the book Taking Turns created by M. K. Czerwiec in 2017, which keeps an account of the nurses' experiences working in an HIV/AID clinic during the AIDS crisis in 1994 – 1999. Czerwiec uses data from The Foundation for AIDS Research (https://amfar.org/) to hand draw line graphs and create

small drawings to mark important moments during the AIDs epidemic (Figure 1). With these illustrations, Czerwiec visualizes the story of how many lives were claimed by AIDs in the US (y axis) within the period of over two decades (x axis). The choice of red colour highlights the fatality of the event while the hand drawn jagged lines can create an experience of data visualization that is more intimate to the reader.

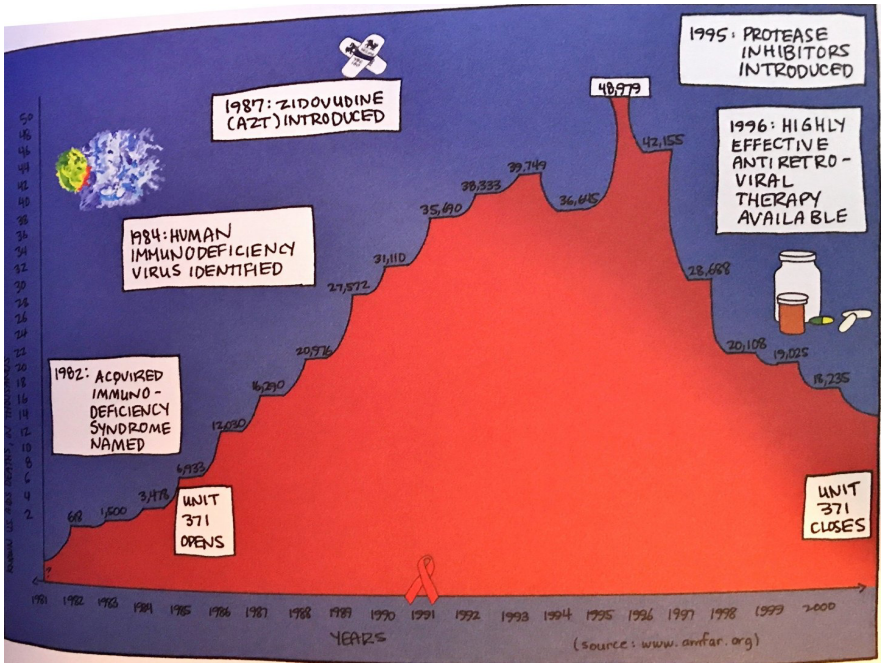

Figure 1: Nurses' experience in Unit 321 during the AIDs epidemic. Created by MK Czerwiec in the book Taking Turns (2017).

Taken from: https://www.sutori.com/en/item/2017-taking-turns-by-mk-czerwiec-a-hospital-unit-dedicated-to-the-care-of-pa

The author precedes the graph with textual information describing the emotional narrativity of the experience. For instance, the HIV virus illustrated at the top left corner of the graph (Figure 1) is originally introduced at the beginning of the story with its own panel (Figure 2). This is done in order to personify the virus as a villain and create narrativity within real life events. Victims of HIV were often synonymously associated with being homosexual, so giving the virus a villain character in this comic format of data visualization physically antagonizes the disease and not the person suffering from the disease. In this way, Czerwiec effectively humanizes the data that affects

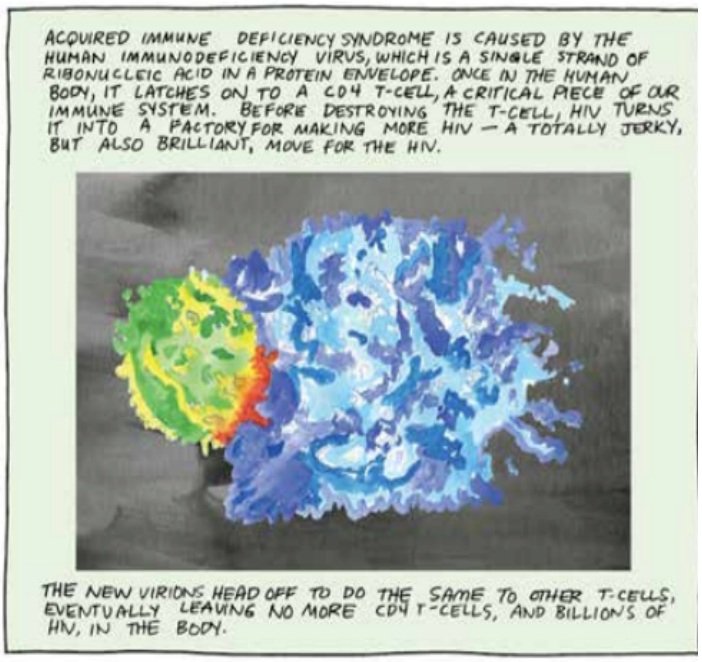

Figure 2: Watercolour picture of HIV virus affecting the immune system. Created by MK Czerwiec in the book Taking Turns (2017).

Taken from: https://comicnurse.com/taking-turns-in-process/

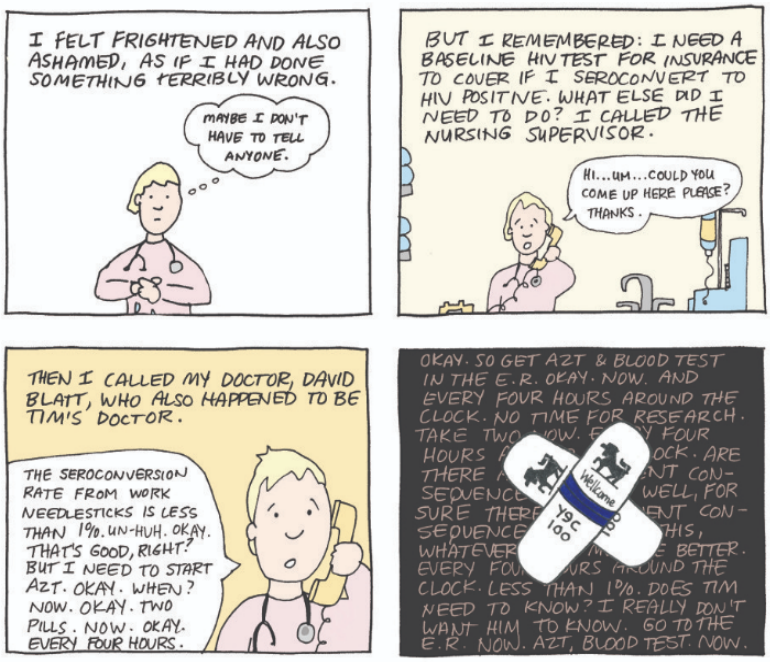

Figure 3: AZT pills narrative, created by MK Czerwiec in the book Taking Turns (2017).

Taken from: https://comicnurse.com/taking-turns-in-process/

Figure 4: HAART medication for AIDs. Created by MK Czerwiec in the book Taking Turns (2017).

Taken from: https://comicnurse.com/taking-turns-in-process/

marginalized communities. The second picture in the graph (Figure 1, middle) depicts the scene when azidothymidine (AZT) pills were prescribed to Czerwiec to fight off any transmission after she accidentally stabbed herself with a needle used to treat a patient (Figure 3). The inclusion of this picture provides context around the anxiety and fear as a healthcare worker, which relays the major tragedy within the data-story narrative. The third picture on the right side of the graph (Figure 1) depicts a bottle of pills, the Highly Active Retroviral Therapy (HAART), which was a promising treatment option for HIV during that time (Figure 4), signifying signs of resolution and hope near the end of the data-story. Even the placement of the images convey a story in the graph. The virus placed at the starting of the line graph (introducing a conflict), the AZT pills placed near the highest number of deaths (representing fear and anxiety), and the HAART pills above decreasing number of deaths (instilling feeling of hope and renewal) as the visualization progresses. These examples demonstrate how data comics can be an excellent tool for data visualization by providing context to data though an emotive narrative.

Although Taking Turns shows the narrative through the lens of the health care workers (i.e., nurses), another possibility could be to use this format to communicate the stories from the patient side. As such, data comics can be an excellent medium for therapeutic education for patients. Therapeutic patient education takes a patient-centred approach with an emphasis on patient needs and resources (WHO, 1998). It aims to keep patients involved in improving their knowledge and skills regarding their illness and treatment procedures (Maldonato et al., 2001). The emotional impact of data comics can help to make data more accessible to patients by providing a familiar and easy format to understanding their diseases, while simultaneously providing a support system to current patients with the story of those who have undergone a similar journey.

Using data comics for therapeutic patient education

Therapeutic education isn't a new concept and have previously been used to treat an accumulation of diseases including cardiovascular diseases (Eriksson et al., 1998), pulmonary diseases (Bourbeau et al., 2003), and even sleep apnoea syndromes

(Golay et al., 2006). Using therapeutic education has shown to bring an increased quality of life, decreased complications, and a of greater therapeutic compliance from patients (Assal et al., 1993). In this framework, patients become an active participant in their own treatment with motivation to change and improve their current situation. The biggest challenge in therapeutic patient education is getting patients to change their behaviour. This is done by increasing patient knowledge about their condition, so they are aware of their problem, and therefore more likely to take the doctor's recommendations seriously (Assal et al., 1993). To increase patient knowledge, previous studies have used motivational interviews (Miller & Rollnick, 2002) and cognitive behavioural approaches (Fossati et al., 2004), which has shown mixed long-term results (Lagger et al., 2010; Albano et al., 2010). Data comics can be a promising candidate in increasing patient understanding of their disease which may improve overall treatment outcome.

To this end, I propose a study to evaluate the efficacy of using data comics in therapeutic patient education. To test this, there will be two groups of participants: an education group and a control group with approximately four to five patients in each group. The education group will undergo a therapeutic education program and will also be provided with a data comic related to their illness that they will read after each session. The control group will only undergo the therapeutic education program. The therapeutic education program will be delivered by a multidisciplinary team (i.e., physicians, physiotherapists, psychologists, etc.) over 3 consecutive days, 6 hours each day, for 3 weeks. These sessions will contain lectures, question-answer format, as well as group workshops and simulations. The goal of the therapeutic education program is to increase knowledge and skills of patients regarding their illness. All patients will be interviewed prior to the education program to determine a baseline of their quality of life (i.e., physical symptoms, mental, social) around their illness. A self-questionnaire will be provided after each session to keep track of changes throughout the program. At the end, patients will undergo an end-of-program interview, and a follow up interview (6 months from the end of the program) to determine long-term effects of therapy on knowledge retention. Therefore, there will be both quantitative and qualitative evaluation

of progress. Together, the results of this study would provide empirical evidence for embedding data comics into patient therapeutic plan.

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