

VISUALISING THE SELF-CARE OF COELIAC DISEASE

Introduction

Coeliac Disease is managed daily by patients via the gluten free diet. My PhD research has found that Coeliacs actively share and communicate this experience across social media networks.

However, Ziebland and Wyke (2012) noted that there were very few places, where people could learn to tell their story and visualise experience with disease. While there now exist many smartphone apps that allow users to share photos, videos and memes via social media, there are currently very few apps that have tools that enable patients to easily visualise their experience with Coeliac Disease in particular.

There is a gap to be filled, where a chronic illness tagging app could be used to act as a creative bridge between 1) the everyday use of smartphones to take pictures, and 2) the visual storytelling/sharing of the lived experience of Coeliac Disease and long-term chronic illness via social media.

Methods

Extensive social media analysis of patient discussion of Coeliac Disease has uncovered many patient created hashtags that are used to describe living with Coeliac Disease. These include: #coeliacproblems and #glutenfreelife and #autoimmuneprotocol. However, almost ¼ of my 2014 - 2015 Instagram dataset (n=102,000 posts) contained messages that had both the terms #coeliac and #spoonie. Further investigation shows that this is a term used when patients discuss what they call 'hidden' chronic diseases, such as Coeliac Disease, IBS, CFS or MS and how they go about daily practices of self-care and self-management

Thus the term #spoonie refers to an individual who suffers from a chronic illness, and explains how they hypothetically measure out their ability to carry out daily tasks by counting "spoons" of energy - allowing for situations when the amount of "spoons" or feelings of wellness come up short.

Results

Based on this social media network analysis, the Spoonie Living app was built to work as a digital creative bridge between patient self-care and visual and creative therapy. Spoonie Living gives Coeliacs and chronic illness sufferers a visual tool to help them with the process of learning how to manage and express their symptoms and experiences. It uses sticker overlays that are themed with proactive expressions to help patients tag photos cataloguing food consumption. It also uses emotive stickers that help them visually express symptoms of being glutened, from fatigue, to pain, and brain-fog.

Discussion

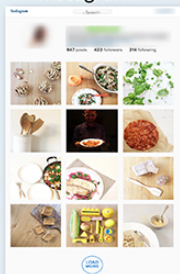
Individuals can use this app as an expressive bridge between their smartphone photography and the visual social media apps they already use to communicate their experience of self-care, whether this be Instagram, Twitter or Facebook. Spoonie Living can also act as a **research toolkit for Coeliac Disease**, with an internal commenting and sharing system that can be used to encourage patients to create diaries, where they visually tag and track prescribed diets, and share/discuss painful or difficult symptoms related to Coeliac Disease and multi-morbidity chronic illness.

Conclusion

Coeliac patients have shown a knack for utilising and gamifying general social media technology to help them manage the mundanity of the self-care of Coeliac Disease, and are actively sharing lived experiences and symptoms via social media. They fill in gaps in knowledge about where to find resources on the move, and offer relational support to each other via chronic disease hashtags like #spoonie #coeliacproblems

There is great potential to utilise this data via eHealth toolkits and apps for improving digital health-based resources, and education of individuals both pre and post diagnosis of Coeliac Disease.

- Self-Care from the mundane to the imaginative: Using social media to gamify self-care of Coeliac Disease
- Coeliacs share poems about being glutened, plus artistic portraits of Gluten Free food via photo diaries on Twitter and Instagram



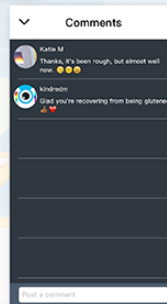
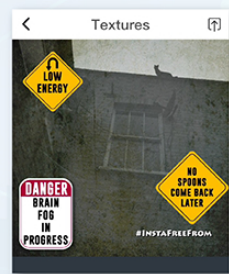
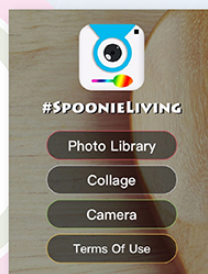
peace
ginger tea and
peppermint tea
multivitamin with iron
Rx and OTC medicine (toxic)
(probably)
internal organ anger or
mere fatigue?
either way...
I'll do whatever I can to
make peace.

(c) @Rinaberry_Jam, Coeliac.com

- #Coeliac + #Spoonie + #cleaneating
Hashtag graph of Instagram network of a 35 year old patient, who used Instagram to document his Coeliac Disease, ME and CFS



The Spoon Theory, a way to explain what it feels like to live with chronic illness



References

Ziebland, S. and Wyke, S. (2012) 'Health and illness in a connected world: how might sharing experiences on the internet affect people's health?', The Milbank quarterly, 90(2), pp. 219-49. doi: 10.1111/j.1468-0009.2012.00662.x.

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