

**“I need to compartmentalize myself”:
Appropriation of Instagram for chronic illness
management**

Authors: *Nwakego Isika, Dr. Antonette Mendoza and Dr. Rachelle Bosua*

Presented by: Nwakego Isika

Overview

- Background
- Placing the case in context...
- Research aim and question
- Practice lens
- Research design
- Findings
- Discussion
- Conclusion
- Limitations and future directions
- Q&A

Background

- Social media technologies (SMTs) have infiltrated all facets of modern life with users numbering roughly around 2.789 billion globally.
- Recent studies have highlighted the growing global burden of chronic disease such as diabetes and similar chronic illness due to biological and preventable lifestyle factors such as increased sedentary living and an ageing population.
- Scholars have suggested that technologies such as social media could serve as a cost-effective tool in self-management of chronic illness as proposed in variations of the chronic care model.
- A recent report by the World Health Organization (WHO 2016) states that currently 60% of deaths globally are due to chronic disease; these figures will rise to 73% of all deaths regardless of socio-economic class by 2020.

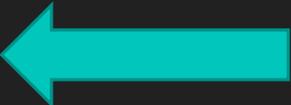
Background

- Studies conducted on social media for health are focused on motivation mechanisms, i.e. Influences on health-related outcomes in these settings
- Previous studies have overlooked the processes of appropriation of social media tools and the influence of the technology under appropriation.
- There has been limited investigation into how social media technologies are utilized by these individuals, to better understand and manage their illness
- We take a holistic view of appropriation that includes the environment provided by technology, the goals of the user and the processes undertaken by the user to achieve their goals within this technologically mediated environment.
- It is necessary to further explore how social media tools are used to gain a more in-depth insight into potential benefits or drawbacks of these tools in the context of chronic illness self-management.

Background

- Developing an illness-management practice is essential for chronically ill adults to obtain better outcomes while living with their conditions.
- Mechanisms like social media could result in reduced overall individual and public-sector spending on managing illness and maintaining an individual's well-being
- Therefore, we respond to the numerous calls for research that scholars across various domains have extended for more empirical work in the chronic illness and social media domain
- We also extend the work of these scholars to this context

Placing the case in context...

- This study forms part of a larger research project that aimed to provide insights into how adults with chronic illnesses engage with and appropriate social media tools as part of their illness management practice
 - Case study 1: Reddit
 - Case study 2: YouTube
 - **Case study 3: Instagram** 
 - Case study 4: Facebook

Research aim and question

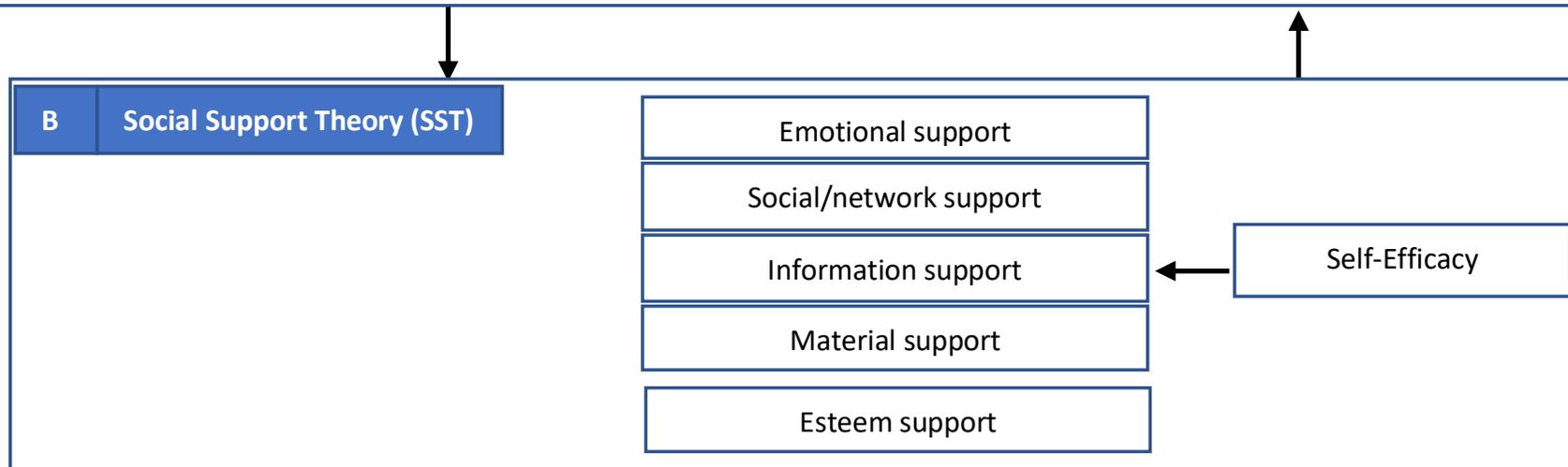
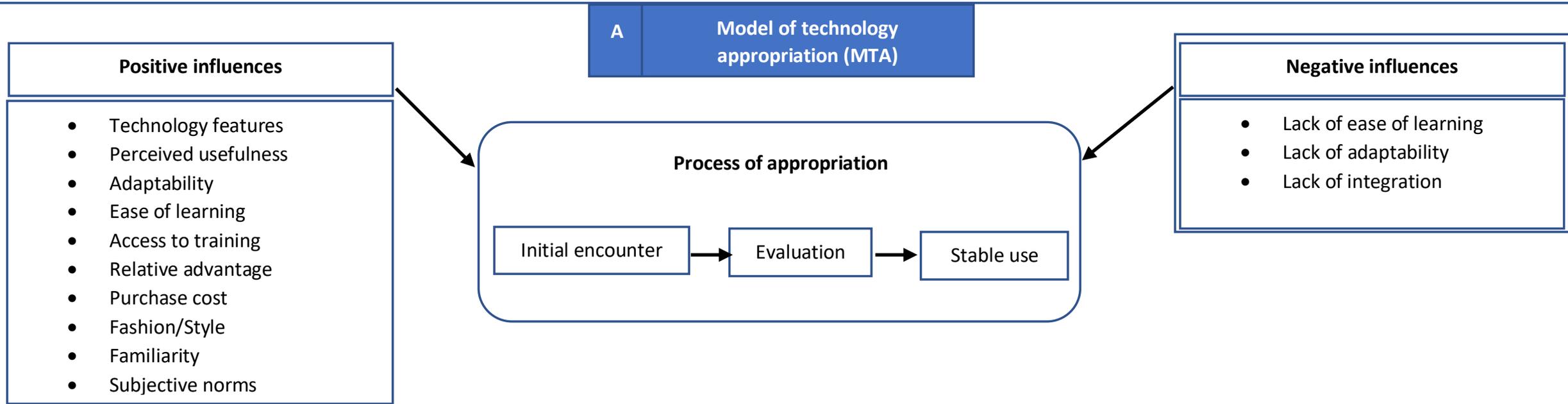
This specific work focuses on Instagram SMT and poses the following research question:

- *How and to what extent does appropriation of a photo sharing social media tool support chronically ill adults to better understand and manage their illness?*
- With the sub-questions:
 - *Why do chronically ill adults appropriate Instagram as part of their illness management practice?*
 - *What are the processes involved in appropriation of Instagram SMT by chronically ill adults?*

Research design

- To address the research questions, we designed the study as an interpretive case study and applied theoretical sampling to guide our case selection.
- We chose Instagram SMT, because it is one of the most used SMTs globally. We selected adults who have been diagnosed with fibromyalgia (self-reportedly diagnosed).
- To derive a complete understanding of social media appropriation and leverage the types of data available through social media, this study used a mixed methods strategy.
- Semi-structured interviews, observations and topic modelling using Latent Dirichlet allocation(LDA)
- Finally, we interpreted our findings as theoretical dimensions which also integrated the data analytics results

Practice lens



Data collection and analysis

- Informant recruitment/data collection and analysis for the Qual strand consisted of:
 - Prior to conducting the study, ethical clearances were sought and obtained.
 - A search for publicly accessible posts tagged #fibromyalgia or #fibro. 824,760 posts tagged with #fibromyalgia; 21,432 posts tagged #fibro.
 - 30 adults solicited, 15 did not respond, 5 declined and 10 consented to participate.
 - Conducting semi-structured interviews lasting between 60-90 minutes via Skype or Gmail chat function.
 - We anonymized the collected data and assigned pseudonyms to our informants in accordance with the order the interviews were conducted in, for instance: Instagram01 and so on.
 - Applied open, axial and thematic coding to the interview transcripts

Data collection and analysis

- **Data collection and analysis for the Quan strand consisted of:**
 - Third-party data service Picodash which was affiliated to Instagram for that purpose to extract open posts tagged with #fibromyalgia for the quantitative portion of the case study.
 - Data cleaning, removing all content that seemed to be spam/not in English
 - 700 text posts were sampled for further data analysis in this study.
 - Data analytic tools such as Natural language toolkit (NLTK) and topic modelling using latent dirichlet allocation (LDA) to extract topic clusters from the text corpus.
 - Finally, these data were also interpreted and integrated with the qualitative data using our practice lens as a scaffold.

Selected examples of identified topics from LDA

| Identified themes | Sample Sentence from Instagram text corpus | Percentage |
|---|---|------------|
| Sharing information about illness symptoms: refers to topic clusters that are about giving or receiving information about illness | “Because I don’t only have fibromyalgia” | 44 |
| Seeking emotional support: represents topic clusters concerned with the exchange of empathy, caring or encouragement | “This is my all-time favourite quote that I always like to go back to and share with others. It takes a lot more energy to be hateful so be kind always don’t judge others focus on yourself” | 32 |
| Forming an illness identity: refers to topic clusters that are concerned with crafting an identity using terms common in the fibromyalgia community such as: warrior, spoonie or fibromite | “Ok spoonies, it’s invisible disabilities week let’s see what sick people look like - show me your selfie” | 14 |

Findings

- **Individual incentives for adoption and continued use of Instagram during chronic illness management**
 - Information support exchanges to better manage living with fibromyalgia
 - Becoming an informed and empowered patient
 - Activism to spread awareness about fibromyalgia
 - Emotional support exchanges and validation
 - Therapeutic exchanges to combat isolation
 - Building borderless friendships
 - Creating shared terminologies to craft shared identity
 - Monetary/Financial benefits: reaching a wider, targeted audience

Findings

- **Effects of the Instagram environment on appropriation for illness management**
 - Accessibility and ease of use of Instagram
 - Technology features providing anonymity and privacy
 - Community formation through hash-tagging
- **Process of appropriating Instagram for illness management**
 - Creating a separate account to compartmentalize fibromyalgia from “normal life”
 - Borderless appropriation of multiple social media tools
 - Adaptive usage patterns to convey support on Instagram

Discussion

- Adoption of Instagram was voluntary, to share and view content from friends and family
- Findings in the present study suggest that Instagram was appropriated in a bid to compartmentalize illness management from other SMT activities
- Yet it appeared that Instagram alone was not sufficient for illness management needs, rather, all key informants also had SMT accounts on other sites which were applying to carry out different aspects of their illness management needs.
- In this study, we unpack the challenges of *invisible illness*; unlike some chronic diseases like diabetes which have clear cut diagnostic criteria, study informants stated that diagnosis for them was a process of elimination, fibromyalgia was considered an invisible illness.
- Moreover, through information support exchanges they could engage in activism about fibromyalgia which these key informants felt was misunderstood and overlooked by their healthcare providers.

Discussion

- These exchanges served to help key informants empower themselves and advocate for better care with their GPs or rheumatologists.
- Emotional support exchanges were a significant incentive to continually use Instagram SMT because most key informants shared that they were unable to get understanding from their family or healthcare providers about the day to day challenges they faced with this debilitating illness.
- These exchanges were a therapeutic outlet because key informants could share and receive positive uplifting content to cope with the mental toll of fibromyalgia
- Instagram SMT environment was a source of structure which exerted influence on appropriation in terms of providing an environment where communities could be formed around content such as posts or hashtags.
- Instagram SMT allowed the creation of ad-hoc communities where users could traverse and find others through viewing shared content or profile information.

Conclusion

- Appropriation of photo-based social media by chronically ill cohorts remains an area that deserves continued research interest by information systems scholars as they have the potential to aid self-management practices of chronically ill cohorts.
- **The theoretical contributions of this study:**
- Extends technology use and appropriation literature by providing empirical evidence which demonstrates:
 - The individual incentives for appropriation of a social media tool for self-management of fibromyalgia illness.
 - The processes involved in appropriation of Instagram and explains the holistic connection between individual motivations, the processes of appropriation and the effects of Instagram technological environment on this practice.
 - The effects of the SMT technology environment on appropriation outcomes

Conclusion

- **The practical contributions of this study:**
 - Provides empirical evidence to inform stakeholders on the processes, influences and outcomes of social media appropriation for chronic illness management

Limitations and future directions

Our study is limited in the following ways:

- The number of participants recruited for the interviews and qualitative portion of the study.
- **Future work could be focused on:**
- A study from the perspective of healthcare service providers in order to contribute a holistic understanding of how best social media tools may be applied to enhance the illness management journeys for chronically ill users.
- The notion of borderless appropriation for illness management deserves more attention
- The impact of SMT appropriation on the provision of care to chronically ill adults deserves further exploration to understand the effects of these technologies on chronic illness management

Acknowledgements

We would like to thank the Computing Research and Education (CORE) team for awarding us with a grant (Student travel award) to cover the conference registration fees. Thank you.

Q&A

