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TASoMe: Validating a Framework to Generate Evidence About Health Outcomes from Social Media Use

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Abstract. Research surrounding social media's impact on patient-reported health outcomes continues to emerge. However, an ongoing challenge for researchers is generating valid and reliable evidence that draws upon rigorous frameworks. This manuscript details the development and refinement of a framework that defines criteria and methods for generating and evaluating evidence about social media use in chronic disease management; the Therapeutic Affordances of Social Media (TASoMe) framework. TASoMe was built through the considered combination of mixed research methods and data collection instruments. It represents a systematic methodology for conducting research that brings together the key concepts of: therapeutic affordances, patient-reported outcomes, and evidence-based practice to generate evidence about health outcomes from social media use. Its key building blocks include: the key research concepts, research methods, and stakeholders standing to benefit from outcomes. TASoMe contributes to the field of participatory health informatics by offering a stringent and reliable model for advancing research and practice. It has begun to be independently validated across a range of health conditions, and has the potential to be applied to a range of participatory health informatics technologies.

Keywords. Social Media, Chronic Disease, Evidence-Based Practice, Therapeutic Affordances, Patient-Reported Outcomes

1. Introduction

Social media in health research continues to emerge and has seen an exponential rise in the number of peer-reviewed studies published in the last few years [1]. In regards to social media's utility in helping to manage chronic disease, several reasons have been reported for why people turn to various social media platforms to enhance their self-management options. These might include (to name a few) to: explore online health information, connect with other people in similar situations, mitigate isolation, share experiences with illness, and improve overall health status [2, 3]. However, the ongoing challenge remains as to how to generate reliable evidence showing social media's impact on health outcomes.

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1.1. Generating Evidence About Social Media Use in Health Informatics Research: The Challenges

Despite a growing body of knowledge about the perceived benefits of social media use to enhance self-management, there remains a challenge for research and practice to approach social media use within an evidence-based practice (EBP) framework. This in part can be attributed to the lack of conceptual frameworks informing how to structure and evaluate different strategies [1, 4]. Whilst this is diminishing as more social media studies emerge, evidence is still not adequate. The ideal solution is more systematic reviews that synthesize primary research but difficulties will keep arising if study designs remain low quality, when study results prove inconclusive, or where findings are inconsistent across studies. Until such time as social media research can draw upon rigorous frameworks, standardize, and validate research findings, decision-making surrounding social media will continue to rely upon experiential knowledge to circumvent lack of evidence [5].

Hence, the aim of this manuscript is to articulate the systematic refinement and validation of a conceptual framework to establish a sound evidence base that defines criteria and methods to generate and evaluate evidence about social media use [4]. The authors created a preliminary conceptualization of this framework that was peer-reviewed and published [4]. Three key concepts underpinned its foundations, including: Therapeutic affordances (TAs), Patient-reported outcomes (PROs), and EBP. While the latter two are well known in health research, TAs require clarification. Mainstream social media are not primarily designed for healthcare use. However, when individuals contemplate social media platforms to assist them with health self-management, they are perceiving what social media 'therapeutically afford' [4].

Since its inception, the authors have conducted much research as part of a large project to develop and refine a robust framework for research and practice. The aim of this manuscript is to comment on the results of the process, as well as present a final iteration of the model, named the 'Therapeutic Affordances of Social Media (TASoMe) framework. The manuscript also discusses several implications, challenges and recommendations for the three key research concepts underpinning the framework as they relate to key stakeholders standing to benefit from this research (i.e. patients, clinicians, health researchers, and health informaticians).

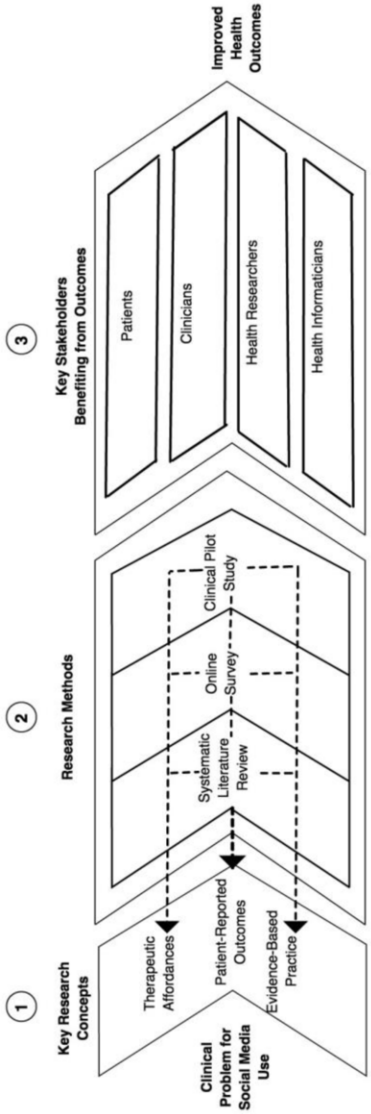
2. Method

The heterogeneity of framework components and its biopsychosocial grounding required that a systematic approach to research be applied, with each component informing the next. Multiple study methods and data collection instruments were combined, leveraging the power and complementarity of mixed methods [4, 6]. These incorporated a systematic literature review to scope the research [7], a global online social media survey instrument to validate findings from the review [8], and a clinical pilot study to develop and test a protocol for conducting social media research in the clinical setting [9]. Mixed-methods research also enhanced the scope to generalize applications of the framework across different study areas within similar health domains, as will be seen [10].

3. Results

The TASoMe framework (Figure 1) is a systematic way to generate evidence about health outcomes from social media use. It provides an in-depth representation of how the three key concepts of: TAs, PROs, and EBP come together through the sequence of systematic informatics research [4]. TASoMe flows through three main blocks: 1) Key Research Concepts, 2) Research Methods, 3) Key Stakeholders Benefiting from Outcomes. Each block of the framework is sequential and represents key phases in the evidence-generation process.

Figure 1. The Therapeutic Affordances of Social Media (TASoMe) Framework



3.1 Key research concepts

TASoMe dictates that the process begins with a clinical problem for which social media may form a suitable part of management. The three key research concepts form its foundations: TAs, PROs and EBP. The framework lends its application to various health conditions and sub-contexts.

3.2 Research methods

Block 2 outlines the primary research methods to be followed in sequence, which will inform the design of the subsequent study. Block 2 is the most comprehensive and complex element of the TASoMe framework. Dotted lines signal one big feedback loop. They represent a connection between all data produced through each study, as well as representing findings that help to validate results from earlier phases (hence, the feedback nature). On a further level, the arrows feeding back from block 2 to the key research concepts are indicative of research studies constantly building evidence to support the key research concepts.

3.3 Key stakeholders benefiting from outcomes

Finally, block 3 represents the stakeholders standing to benefit from research and practice using TASoMe: patients, clinicians, health researchers, health informaticians. This goes with the ultimate goal to improve health outcomes from social media use.

4. Discussion

This research has contributed a framework to advance research and practice in participatory health and social media informatics. Groundwork is laid for the following future research considerations:

4.1 TASoMe framework validation

Independent validation of TASoMe has seen it being applied and tested across a range of health conditions, including: brain cancer, endometriosis and mental health [11-13]. Particularly, the authors of [12] have published a robust application using TASoMe.

However, TASoMe does have limitations. To date it has only be validated for social media use in a few conditions, which cautions against widespread interpretation on an epidemiological level [14]. In order to further validate the framework, future research could not only focus on applying it across a range of health conditions, but also using various other participatory health technologies.

4.2 Health technology development

In the area of eHealth design, TASoMe's systematic underpinnings of TAs, PROs, and EBP lend itself to supporting the development process (inception, design, implementation and evaluation) of various technological products and services in healthcare (i.e. online platforms, monitoring devices and mobile apps) [15].

4.3 *Furthering participatory health*

The TASoMe framework was born out of the participatory health paradigm, recognizing social media's support of participation, empowerment and shared-decision making [16]. Future participatory research could leverage TASoMe. For example, cataloguing technology used by engaged patients using TASoMe may provide insight into their behaviors, perceptions and reported outcomes from use to better understand what engages and motivates people to use technology as part of health management.

5. Conclusion

The authors have presented the systematic development of a framework to generate evidence about health outcomes from social media use that will benefit the health informatics field. As participatory health informatics matures (i.e. through social media, mobile health, self-quantification, and wearables) the need to apply stringent, reliable and validated models to research and practice becomes even more paramount. The TASoMe framework is an important contribution helping to advance this agenda.

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