"The Crowd Keeps Me in Shape": Social Psychology and the Present and Future of Health Social Machines

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ABSTRACT

Can the Web help people live healthier lives? This paper seeks to answer this question through an examination of sites, apps and online communities designed to help people improve their fitness, better manage their disease(s) and conditions, and to solve the often elusive connections between the symptoms they experience, diseases and treatments. These *health social machines* employ a combination of both simple and complex social and computational processes to provide such support. We first provide a descriptive classification of the kinds of machines currently available, and the support each class offers. We then describe the limitations exhibited by these systems and potential ways around them, towards the design of more effective machines in the future.

Categories and Subject Descriptors

H.5.3 [**Information Interfaces and Presentation**]: Group and Organisation Interfaces—*Collaborative computing*

Keywords

health, social machines, social computing, gameification

1. INTRODUCTION

Health and well-being are visible indicators of technological progress, as advances in healthcare and medicine are invariably reflected in increases in average lifespan, reduction of disease and suffering, and shortening of time needed to recover from illness and injury. As such, it is natural to ask how and whether the Internet and the Web, two of the most significant inventions in recent human history, have or may have an effect on health and well-being.

In this position paper, we examine a specific class of systems enabled by the Web and pervasive Internet-enabled systems, which we call *health social machines*. We define health social machines to encompass a broad class of systems that provide technologically-mediated interaction of large groups of individuals, typically via a website, app, and sensor-based online community. Individuals usually communicate and interact, directly or indirectly, through some mediated or moderation mechanisms, in order to collectively accomplish or address a health-related problem or need [10]. Such problems, as we illustrate through examples we provide later, may be on the scale of an individual's disease or well-being management, to that of contributing evidence and insight to fundamental questions at the frontier of modern medicine.

We first describe the emerging landscape of health-related social machines, identifying sets of classes and characteristics such machines typically exhibit. We then focus on specific challenges faced by these classes in the longer term, and how emerging insights from behavioural economics and technological platforms may address some of these needs.

2. CURRENT HEALTH SOCIAL MACHINES: A BRIEF CLASSIFICATORY ANALYSIS

We first collected examples of popular health social machines through an iterative process which started with filtering several popular blogs focused on health-technology, the "quantified-self" and "life hacking", for announcements related to apps and websites dedicated to addressing health issues. We then clustered the collected candidates using a Grounded Theory approach. This process yielded three, partially overlapping clusters of machines by the ways these machines sought to address health needs. Table 1 lists these clusters, comprising *behavioural intervention*, *disease management*, and *collective sense-making* of symptoms, and associated machines falling in each category.

2.1 Behavioural Intervention

The first which we refer to as *behavioural intervention machines* are systems that seek to help individuals achieve certain health-related goals by altering their daily routine(s) and activities. The majority of systems we found in this category, which, itself is the largest of the three categories, aim to help individuals increase their general activity levels to increase fitness. Since these systems generally do not target any particular demographics or those conditions, we consider them general, preventative health machines with a focus on increasing fitness.

A large number, but not all, of such fitness machines either require, or are designed to complement, sensor devices that are intended to simplify regular measurement of various vital statistics of the individual. As such, they are designed to be quick and easy to use, and, even, in some cases,

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worn directly on the body, for the measurement of physiological signals or activity levels, at high temporal granularity. These on-body activity measurement devices range from simple accelerometer-based devices (such as the FitBit[1], Nike+ FuelBand[2], that can approximately estimate the number of steps/distance the wearer has traveled in a day, to slightly more complex on-body devices (such as the BodyMedia CORE[3]) that measure multiple physiological signals in tandem with activity level. Other, non-worn devices include iPhone-enabled blood pressure cuffs (e.g. Withings'[4] Blood Pressure Monitor), internet-connectivity enabled weight/body mass index scales (e.g., Withings' WiFi Scale), and iPhone-enabled heart rate, blood oxygen level measuring devices (e.g., Zensorium[5] Tinké).

2.2 Disease management

A second class of health social machines aim to help individuals cope with various kinds of conditions, including illness, disease, and mental health. While a few of such systems are general and designed to accommodate a wide variety of conditions, a majority of systems focus on one class of diseases, such as diabetes, mental health, and autism, or, in some cases, a highly specific condition, such as post-traumatic stress disorder (PTSD), attention deficit hyperactivity disorder (ADHD), or Coeliac's disease. These systems, as described in Section 3, generally provide a combination of general knowledge resources, such as places and things to eat, information on activities to perform to support wellness, to social support and advice, and, in some cases, intervention techniques.

A dimension along which these systems vary considerably is the degree to which these machines encourage/support participant anonymity or identity disclosure. Some sites encourage individuals to use their real "actual" identities, saying that this allows people to gain trust, "see the face behind the name" and connect more naturally. Others, such as BigWhiteWall [6], remain very careful to ensure that participants remain anonymous, and do not unwillingly disclose anything about their identities, so that the forums can remain "a safe place to talk about *anything*". Most sites, however remain somewhere in the middle, allowing individuals to choose nicknames that may or may not resemble their real names, and to disclose or hide their full names from other members of the network.

2.3 Collective sensemaking

The final class of social machines, which is the smallest set, including only a handful of existing examples including, PatientsLikeMe [7] and MyHeartMap [8], aim to crowdsource knowledge about disease, symptoms, treatments, and available resources to individuals who have personally experienced them. To do this, these platforms facilitate the independent report of information, such as the symptoms individuals are experiencing, connections between the symptoms and the particular disease(s)/conditions which they have been diagnosed with, and the effects of particular treatments on their conditions. The result of this aggregation, at large scale, is a model relating symptoms to diseases to treatments and effects. This model can then be used by other individuals in a number of ways; first, those who are experiencing symptoms can diagnose themselves based on the symptom-disease associations, while those already diagnosed with a condition can use the disease-treatment-effects model to choose treatment(s) that might lead to the most favourable outcomes, based on experiences of others like them.

General preventative fitness:
Device-based: Nike+ FuelBand, FitBit, Withings, BodyMedia, Zeo
App-based: RunKeeper, Lose-It, Fitness Pro, GymGoal
Site-based: Fitocracy, Traineo, Dailyburn, ExtraPounds, SparkPeople
Disease management:
ALZConnected, Prevent, BigWhiteWall
Collective sensemaking:
PatientsLikeMe, MyHeartMap

Table 1: *Health social machines* – A listing of the social machines we studies for this analysis, organised by the categories derived.

Summary of support provided by current health social machines		
behavioural intervention (BI)	disease management (DM)	collective sensemaking (CS)
* **M**easurement & **T**racking * **S**alience through **F**eedback * **G**ameification * **S**ocial Elements: **C**ompetition, **P**eer **P**ressure & **S**upport	* **I**ntervention **D**elivery (in ways similar to BI) * **K**nowledge **Ex**change: Peer Q&A, Knowledge Garden * **S**ocial **E**motional **S**upport: Advice, Sympathy, Empathy	* **K**nowledge **El**icitation * **A**ggregation & **S**ummary of **C**ontributions

Figure 1: *Support offered by type of machine* - Summary of all of the types of support identified across machines, described in Section 3, organised by type of machine.

3. CURRENT METHODS OF SUPPORT

In order to understand better how the social machines just described functioned to help individuals with their health related goals, we performed an analysis of each site/app's features and derived a set of observations pertaining to how they supported the goals each sought to achieve. We describe each, in turn, next.

3.1 Supporting behaviour change

In order to support individuals to conform to their behaviour change interventions, we identified the following elements that these machines support.

1. *Measurement and Tracking* – As described earlier, in order to be able to provide feedback on progress, most of the machines provided support for some degree of data collection, ranging from facilitating manual data recording to automatically sensing activity and physiological signals through wearable sensors.

[1]FitBit - www.fitbit.com
[2]Nike+ - nikeplus.com
[3]BodyMedia - www.bodymedia.com
[4]Withings - www.withings.com
[5]Zensorium - www.zensorium.com
[6]BigWhiteWall - www.bigwhitewall.com
[7]PatientsLikeMe - www.patientslikeme.com
[8]MyHeartMap - www.med.upenn.edu/myheartmap

2. *Salience and Feedback* – To remind individuals to comply with their intervention and reinforce encouragement for incremental progress, individuals' progress was made highly salient using a number of mechanisms. For wearable sensors, visible indicators (lights / displays) on the sensor often indicated progress, while for apps and services, visual prompts, messages and alerts delivered through social networks, e-mail, text messages, and asynchronous "push" notifications were common.

3. *Gamification (Achievements and Prizes)* – To further motivate compliance, many of these systems incorporated a number of "gamification" features [7] meant to make progress seem like play. Such features typically involved rewarding participants with "points", "badges" and "prizes" for achieving milestones.

4. *Social Encouragement* – In addition to the individual gamification elements, social features were provided for most machines that encouraged individuals to either compete to achieve their objectives either individually or in groups, or to support one another by "cheering them on" and supporting them in various ways. Competitive elements included "battles" and "challenges", supportive capabilities included "cheer-leading", wagering, and donating "points" in support of another individual's cause.

3.2 Facilitating disease management

Disease management machines provide three kinds of support to individuals: first, like the behavioural intervention machines, to deliver actual interventions specific to individuals' conditions. One of the best examples of such intervention delivery is BigWhiteWall, which delivers mental health services through an online social network through a full-time staff of professional counsellors who monitor the site 24 hours a day.

The second role these machines serve is a place to exchange knowledge and insight, serving as both *answer gardens* [1] and *serendipitous knowledge archives* [3]. As answer gardens, these sites let individuals find and post answers to specific questions they have. As knowledge archives, individuals with similar circumstances can post and more easily stumble upon tips that are relevant to their particular situation(s)– which might help them improve their situation (even if they did not know to specifically ask or look for this information to begin with).

Third, these systems provide a mechanism of social emotional support, both in terms of empathy from people who have experienced similar situations in the past, or sympathy, from those who can relate and provide words of encouragement or advice.

3.3 Enabling crowd-based sensemaking

Health machines that seek to crowd-source health-related information, including information about diseases, treatments, and available resources at large scale require the ability to acquire information effectively and as accurately as possible from participants. Thus, effective elicitation of information becomes a primary challenge. Towards this capability, PatientsLikeMe supported a structured elicitation approach for the gathering of symptoms, relevant diagnosed diseases, treatments, and reports of experiences. Gathering structured data directly (in terms of ratings, diseases and treatments from a fixed lexicon) allowed these data can be compared and aggregated automatically across individuals.

Beyond elicitation, such sites require the ability to produce useful views of collected data so that participants are not overwhelmed by the volumes of raw data produced by others. Towards this end, PatientsLikeMe used the structured data captured to synthesise raw simple aggregate visualisations and result summaries that could be easily interpreted.

4. CHALLENGES AND LIMITATIONS

In this section we synthesise a set of problems and challenges that have been voiced concerning the effectiveness of health social machines, including concerns voiced by the medical community.

4.1 Potential Dangers of Self-Diagnosis

Many of the examined machines encourage individuals to make their own decisions concerning their health, with such slogans as "take back your health now!". To do this, they give seemingly appropriate and relevant information to individuals that let them choose options, such as intervention programmes, or, in the case of PatientsLikeMe, treatments from which to choose. One of the appeals of this idea is that if individuals are the ones that choose their intervention, they would feel more ownership over it and would be more likely to comply fully.

However, clinicians and medical professionals have voiced concern about this initiative, because individuals lacking medical expertise or experience are likely to make bad decisions on incomplete knowledge that may put their health in peril. For example, an individual who is feeling unwell might suspect that they need more physical exercise and sign up to an "increased activity" intervention programme, when in fact they might have a heart condition that might become more severe under increased cardiovascular strain. If they had seen a medical professional instead of self-diagnosing themselves, the heart condition may have been identified earlier and more easily addressed.

4.2 Adherence to Intervention Programmes

A second associated concern pertaining to democratising the creation and administration of intervention programmes is simply, first, that having non-medical professionals devise intervention programmes means these programmes have not been rigorously evaluated, and thus may be less effective (or entirely ineffective) beyond a placebo effect [12].

Furthermore, professional clinicians, therapists and psychiatrists have methods to make sure individuals are comply and adhere with their intervention and receiving maximum benefit. When the professional is removed from the loop, interventions may become less effective as patients are not guided to adhere to the prescribed programmes. Thus other mechanisms (such as the gamification components described above) will need to fill this role.

On the other hand, the potential for the new wearable sensor activity monitors means that an individual's activities can be recorded at little or no cost, and analysed to produce a more complete picture of an individual's activities; this could be useful in increasing compliance and understanding of how an individual is behaving and can improve their performance.

4.3 Sustaining Motivation

A second challenge concerns the effectiveness of the methods applied by health social machines towards sustaining long-term involvement, in particular for encouraging compliance and adherence to the more difficult interventions that challenge the very centres of people's motivational systems, such as those concerning weight loss and mental health.

In particular, a number of recent studies on gamification have revealed that simple approaches for introducing extrinsic reward, such as points and "badges" may wear off after a short initial period of novelty [6]. Even the most successful example of gamification, Foursquare, experienced a widespread engagement problem across its user population 6–12 months after adoption [4]. Meanwhile, other studies of gamification showed that gamification elements actually decreased participation by reducing individuals' intrinsic motivation to participate, which, in some cases returned when the gamification elements were once again removed [15].

4.4 Self-Report, Bias and Explaining-Away

In the realm of crowd-sourcing disease knowledge, several of the health machines rely on self-report as the primary method of knowledge elicitation. Controlled studies have demonstrated the many problems of self-reporting across domains, with the most significant biases being revealed in health, such as concerning a person's estimates of their own fitness, including body mass and weight [8] and happiness, including depression [11]. Such biases, which vary among individuals and factors estimated, could significantly impact the validity of the data collected if it is information concerning diseases and symptoms.

Of additional difficulty concerning self-reporting arises in situations where there is need for patients to perform causal inference between symptoms, causes and treatments, such as is the case with PatientsLikeMe, which asks patients to describe symptoms experienced with a disease and the outcome of particular treatments. The well-studied psychological effect of confirmation bias [13], which causes individuals to gather evidence in support of pre-existing beliefs, could cause individuals to report what they *think they should see* instead of what they actually experienced. Furthermore, illusory correlation [5] could cause individuals to draw connections between experiences, situations or conditions merely due to their salience or co-occurrence, rather than due to an actual causal relationship. A particular type of illusory correlation is *explaining away*, in which individuals attribute causes to the most salient explanation, rather than the most probable one [9].

An additional bias that emerges when self-reports are produced in groups is *collective conservatism*, a very strong bias that people in a group tend to say (or agree with) what others say instead of contributing what they actually observe, feel or know. This phenomenon, well studied in social psychology (e.g. [2]), has been shown to cause individuals to conform to, and even believe, incorrect group conclusions even when they disagree with these conclusions themselves. In public discussion forums such as PatientLikeMe, collective conformation could dramatically shape the conclusions that patients arrive at, and that future patients might experience.

4.5 Device and App-centricity

An additional problem pertains to the fact that a majority of the current behavioural intervention machines described earlier are highly device and app-centric; that is, the sensor(s) and app(s) designed to record data are closely integrated with the methods for storing the data, and the intervention delivery mechanisms. This means that, in these machines, the device and app makers retain the data collected about and by users, and specified the kinds of interventions that are possible, often in a one-size-fits-all approach. This vendor-centricity precludes the kinds of highly personalised, multifaceted medicine which many be more effective.

5. TOWARDS BETTER HEALTH MACHINES

In this section, we discuss ways to address the limitations described in Section 4, towards making health social machines more versatile, robust and effective in the long term.

5.1 Empowering medical professionals

While goals of greater patient-empowerment are likely to allow individuals to make better health-related decisions in the long term, the idea that health social machines should *replace* the expert assessments of trained medical professionals seems ill-advised for the foreseeable future. Instead, we propose to think of health social machines as mechanisms for giving individuals both a greater literacy about their health concerns and considerations, and a mechanism by which individuals can effectively eliminate barriers to the best medical experts and expertise available, whenever and by whomever it is needed.

If medical consultations with professionals were shared in a PatientsLikeMe social machine context, a number of benefits could be gained. First, patients could weigh and assess several options about difficult medical decisions, using advice from others who have had to make similar decisions in the past. Furthermore, if such opinions were shared in such forums, there will be pressure on clinicians to provide their best, carefully assessed medical opinion for individuals, since such opinions might be scrutinised by their peers and the general public. Such transparency would make visible the track records of such professionals, and essentially give professionals "public reputations" that could further be used by individuals to make decisions about whom they should trust and why.

In such a scenario, medical specialists would see increasing demand for their attention from individuals throughout the world for their opinion, and would likely benefit from being able to increase the efficiency and effectiveness with which they can assess the condition(s) of the patients they see. Here, additional health social machine technology could come into play; specifically, the monitoring sensors used in the behavioural intervention machines discussed in Section 3.1 could be instead appropriated as general-purpose health monitors which could give specialists unprecedented, accurate access to an individual's daily activities and health. This information could give clinicians valuable context for understanding each patient's lifestyle between visits, in order to devise more appropriate interventions.

5.2 Motivation and Commitment

As mentioned in Section 4.3, the gamification approaches currently used to motivate individuals to comply with behaviour-change interventions are likely to prove insufficient for longer-term, difficult programmes. Since compliance is up to the individual but required for success, this remains an area with formidable challenges.

Behavioural economics may provide insight towards approaches that might work. For example, Thaler and Sunstein, authors of *Nudge* [14], cite several examples of using individuals' *loss aversion* techniques to dramatically motivate individuals who have important goals they need to keep. Specifically, they provide two examples where individuals committed to paying their friends or academic advisors large sums of money if they failed to meet particular goals each month (such as turning in a chapter of a dissertation or losing a specified number of pounds).

Due to the importance of motivation, it may make sense to use a combination of approaches. For example, traditional fitness clubs and "gym memberships" provide a combination of pressures to keep members attending and participating; first, they cost substantial membership fees, which, at least for budget-conscious participants provide an incentive to participate; second, they provide a number of strong social pressures and expectations – both from instructors and peers.

5.3 Making better use of sensed data

Finally, there are several ways that the low-cost activity and biosensors could be more effectively used. For instance, de-coupling sensed activity data from device manufacturers' single-purpose apps, which currently provide no long-term archive or access guarantees, could allow this data to be used to produce consolidated, longitudinal archives of health and life activities. Such an archive would allow both individuals and their health care specialists to better communicate and share information, as well as to allow interventions to be more effectively tailored and tracked. Moreover, liberating this data for use by general application developers will help inspire innovation in new sensor-enabled fitness apps, without driving such vendors to flood the market with variations of near-identical devices.

6. CONCLUSION

The level of interest and engagement with the first generation of health social machines suggests that people are eager to try and evaluate new, social technologies that can potentially help them improve their health and well-being. In this paper, we have taken a selection of social machines that we believe are representative of the current set of popular health-related apps and web sites and contributed an analysis of the ways that they support individuals through feedback, social support, monitoring and intervention. Towards serving more effective roles, we have proposed ways that such machines might, in the future, provide more a integrated approach to intervention, management, mitigation and sensemaking, incorporating medical professionals (nurses, GPs, specialists) as expert guides along the way. We see that, rather than competing to provide the same basic support, fitness and activity sensors could be designed to provide complementary information that collectively build a more complete picture of an individual's life. Such portraits could, in turn, help medical professionals more effectively diagnose and deliver interventions to patients at scale.

7. ACKNOWLEDGMENTS

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