Gamification of Medication Adherence in Epilepsy

Abdul Rahim MI, Thomas RH

Mohammad Izzat Abdul Rahim [a]

Rhys Huw Thomas [b,c]

Institutional addresses

  a. School of Medicine, Heath Park, Cardiff University, Cardiff, United Kingdom
  b. MRC Centre for Neuropsychiatric Genetics & Genomics, Hadyn Ellis Building, Cathays, Cardiff University, United Kingdom
  c. Institute of Neuroscience, Henry Wellcome Building, Newcastle University, United Kingdom

Corresponding authors

Dr Rhys H. Thomas

MRC Centre for Neuropsychiatric Genetics & Genomics, Hadyn Ellis Building, Cathays, Cardiff University, United Kingdom

Rhys.Thomas@newcastle.ac.uk

Present address - Institute of Neuroscience, Henry Wellcome Building, Newcastle University, United Kingdom

Gamification of Medication Adherence in Epilepsy

Abstract

Adherence to medication regimens is a crucial factor in seizure-freedom and well-being for people with epilepsy. In contrast, taking medication inconsistently increases the risk of not only seizures and their adverse effects, but drug side-effects and unnecessary modifications to treatment plans. Epilepsy is prevalent across all age groups and we have been slow to utilise both the technologies and psychologies derived from computer gaming. Gaming has broken through to the mainstream and is no longer the preserve of younger males, mirroring the adoption of smart-phones. 'Gamification' motivates users into engaging in an activity with a higher intensity and duration. Introducing gaming elements into a non-gaming context has the potential to transform routine tasks into more enjoyable and motivating experiences. This has been exploited by marketing executives, but also has clear uses in a healthcare setting too. We discuss how previously published frameworks could be employed to help people with epilepsy adhere to medication regimens to create a patient-focussed, modifiable and fun experience.

The Concept

'Gamification' is a neologism coined in 2002 by Nick Pelling, the British born computer programmer and game developer (Marczewski, 2012).[1] It is still a nascent concept, and hence a universally agreed definition is pending. Deterding *et al.* [2] explain the two main definitions of the term 'gamification'. The first is how video games are increasingly

widespread throughout today's society, influencing everyday life and interactions; the target group for video games used to be younger males. The same couldn't be said for today, as video games are targeted and played by males and females across all age groups. The Entertainment Software Association (ESA) in the United States release annual reports on video games sales, demographics.[3] 2016 usage data shows that: 59% of gamers are male; 27% of gamers are under the age of 18, 29% between 18 and 35, 18% between 36 and 49, and 26% of the age 50 and above. Interestingly, it was shown that there is a significantly higher number of female players over the age of 18 (31%) compared to males below the age of 18 (17%). With the growth of technology, platforms for gaming have also expanded from consoles to computers as well as smartphones, making video games more accessible and affordable than before. The second definition – which this paper will focus on – is the use of video games or gaming elements to motivate users into engaging in an activity with a higher intensity and duration. The introduction of gaming elements into a non-gaming context has the potential to transform mundane and routine tasks into a more enjoyable and motivating experience.

The Problem

Incomplete patient adherence to medication regimens has been, and still is, a problem in effectively administering evidence-based treatments. Adherence is actively following a medication schedule, in contrast to compliance or concordance which are passive.[4] Adherence to long-term treatment for chronic diseases in developed countries can be as low as 50%.[5](Sabaté E, 2003). Kardas *et al.*[6] described 771 individual factors that affect patient adherence. The review highlights lack of support, lack of motivation, and forgetfulness as key

factors that lead to poor adherence. Adherence to anti-epileptic medication specifically can be poor. A recent poll by Epilepsy Research UK showed that half of respondents forget to take their epilepsy medication at least once a month.[7] Davis *et al.*[8] conducted a retrospective study on the prevalence and cost of non-adherence with antiepileptic drugs using the PharMetrics database in the United States. They used the medication possession ratio (MPR) to calculate adherence to anti-epileptic medication. This is the total number of days where the medication is supplied divided by the number of days in the observation period; they considered anything below 0.8 to be non-adherent. Of 10,892 patients, 39% of patients scored below 0.8 MPR. The mean MPR for individual drugs was also looked at, the highest being lamotrigine (0.83) and lowest being gabapentin (0.70). The difference in adherence between drugs can be attributed to multiple factors, and the varied efficacy and tolerability of each drug will directly affect this. The paper also showed that non-adherence was associated with increased use of healthcare services, and thus an increase in cost. Furthermore, although multiple factors, from genetic to environmental, are thought to contribute to sudden unexpected death in epilepsy (SUDEP) to date, antiepileptic treatment is the only preventative measure proven to be effective.[9] Therefore, an increase in patient adherence, no matter how small, could help reduce mortality in epilepsy. This paper will look at the possibility for the use of gamification in a mobile application to improve patient adherence for epileptic patients.

Current strategies to improve patient adherence target better communication between clinician and patient. Atreja *et al.*[10] groups the strategies with the mnemonic 'SIMPLE':

1. Simplifying regimen characteristics;

2. Imparting knowledge;

3. Modifying patient beliefs;

4. Patient communication;

5. Leaving the bias; and

6. Evaluating adherence.

These strategies, while useful, are confined only to points of contact between the healthcare professional and the patient. They do not represent ongoing strategies for the times when patients are left to their own devices. If the benefits of gamification that are currently employed elsewhere could be transferred with similar efficacy to healthcare, it would be an important aid in ensuring patient adherence to treatment.

Past Applications of Gamification

Gamification revolves around the core idea that people have a natural drive to seek achievement, status, and competition.[11] Video games are fun to play because they give a sense of achievement when one successfully completes a level, usually while being entertained by either the story or the game mechanics itself. Gamification seeks to replicate this by using gaming elements in a non-gaming setting. This could be done via virtual rewards for completing tasks rather than punishment for non-adherence. To keep people engaged, the experience could be further expanded by increasing difficulty over time as well as adding a compelling narrative, just as in video games. While gamification has been applied to many industries successfully – mainly in marketing and advertising – healthcare providers have yet to fully take this concept on board. In recent history, some successful examples of gamification within marketing include M&M's 'Eye Spy Pretzel' and StarBucks' 'Rewards'. In

2010, M&M's devised a simple game to promote their new pretzel-flavoured sweets. This involved a Facebook picture full of M&M's with a small hidden pretzel in. The task – much like Where's Wally (or Where's Waldo) – was to locate the pretzel. It was simple and inexpensive, but the result was obvious. There was an increase of 25,000 likes on their Facebook page, demonstrating engagement with their customers and spreading their brand via social media. StarBucks is also known for gamifying their loyalty card programme by introducing levels to their card. Higher levels could be unlocked by more loyal customers, revealing more material rewards such as food and drinks.

Chore Wars (ChoreWars.com) is a different example of gamification, where people can create an adventuring fantasy character online that gains Experience Points based on the completion of everyday tasks in real life, such as household chores and office work. For example, a party of adventurers could be formed by office colleagues. The more work is completed in the office, the higher level the characters become and hence more useful to the fantasy quest they are undertaking. This is a perfect example of using a narrative to encourage engagement with mundane tasks.

A hospital in Portugal trialled the use of gamification to increase the compliance of hand hygiene in nurses.[12] This is done via an indoor location system that tracks the nurses' personal smart tags. Beacons are placed at sinks and alcohol gel dispensers to indicate whether the nurse approaches them first before approaching a bed. This then sends data anonymously to the system to measure compliance. A web application can then be accessed by the nurses at any time to view their results. Compliance was rewarded with badges and virtual goods. There was also a leaderboard which showed their performance compared to the other nurses anonymously. This trial showed that the nurses were highly engaged with

the programme and compliance to hand hygiene was increased. However, this could be due to being engaged in something new, or the feeling of being scrutinised. While evidence is still lacking in the ongoing efficacy of this method, as well as the motivations of the participants, it remains a promising way to improve compliance.

The provision of information and knowledge to patients is also an important part in maintaining good adherence. A study by McLeod *et al.* [13] assesses whether gamification could increase participants' engagement in learning a new skill, and whether they were driven more by intrinsic or extrinsic motivation. They found that gamification of the process of learning helped the participants to engage with the activity, more so through extrinsic motivation such as badges, scoreboards, and other reward systems. Even in the healthcare professional setting, Lamb *et al.* [14] showed that a more gamified approach encouraged resident surgeons to engage in academic reading. They used Twitter as a platform where questions were posted daily, and participants would gain points based on their speed and accuracy. The moderator of the Twitter account would engage with the participants and fuel academic discussions based on the questions. 6 months into the programme, participants took the ABSITE (American Board of Surgeons In-Training Examination) and had an increase in examination percentile rank compared to their counterparts who were not involved in the gamified programme.

All the above have a common theme: Increase in engagement via an increase in motivation. Social interactions via online social media also helps motivate participants. Allam *et al.*[15] ran a trial of a web-based rheumatoid arthritis self-management programme with social support as well as gamification. The participants were randomly allocated into 1 of 5 groups, each with different levels of accessibility to the website. The groups were the information

group (only access to informational sections of the website), support group (online support and information), gaming group (gamification and information), full access group, and control group (no access). The study showed that gamification and online social support decreased healthcare utilisation and increased patient empowerment. Furthermore, patients who were offered the gamified experience were shown to use the website more than the other groups. These findings can be extrapolated to a gamified application to empower patients to take healthcare into their own hands, leading to an increased adherence to medication.

Gamification of Epilepsy Treatment

The concept of successfully improving medication adherence via an application of gamification for people with epilepsy is tantalising. An advantage of applying gamification in this group is the prevalence of younger people with epilepsy, to whom games are more culturally relevant. In a developed nation most patients would own a smartphone (91% of those aged 16-34 in the UK)[16] making the mobile application highly accessible. People with epilepsy also currently use electronic alerts and alarms which this mobile application could supplement; for example, the SUDEP app EpSMon (Epilepsy Self-Monitor) is currently used by patients to calculate their risk based on a variety of risk factors. This aids the self-monitoring of their condition between doctor visits.[17]

To apply all the theories into a gamified mobile application that could help patients comply to their medication, recent guidelines by Exeter *et al.*[18] on gamification of the self-management of chronic diseases could be used. The guidelines are heavily influenced by a conceptual framework for the gamification of diabetes self-management called 'The Wheel of Sukr'.[16] The Wheel of Sukr (Figure 1) consists of 8 components: fun, esteem, growth,

motivation, sustainability, socializing, self-representation, and self-management. Based on the guidelines, a rough plan for the application could be constructed:

Fun:

To create an engaging experience, a user-friendly interface should first be created. A system of rewards such as badges and achievements could then be applied. A series of challenges that unlock achievements when completed could further aid in encouraging patients to comply to treatment. This goes hand in hand with the 'motivation' component of the Wheel. With the base functions in place, further innovative functionality such as a narrative could be implemented.

Esteem:

The implementation of social media in the application could aid in the esteem component of the Wheel. Leaderboards could be designed so that patients could see where they rank amongst others with similar conditions/treatment regimens. It should be carefully designed so to encourage patients to do well rather than discourage them for doing poorly. This could be done by emphasising their successes and turning their 'failures' into positive learning experiences. If a narrative is applied, challenges or 'levels' that are completed could unlock further storylines.

Growth:

A feedback system (such as a weekly summary) could be implemented to show the patients how well they're doing. Another way to encourage growth would be to have patients be able to set their own goals, no matter how small, and reward them for achieving them. Information

about the patients' conditions could be included in the application to educate the patient about their illness, further empowering them towards self-management.

Motivation:

The idea of the mobile application would be to first encourage patients to adhere to medication regimens via extrinsic motivators (badges, achievements, etc). However, in the long run, the aim would be to help patients increase intrinsic motivation to self-manage their condition. When a patient is empowered to manage their condition and is motivated to hit their own targets, it enhances adherence to medication. Social media is also a tool to increase motivation, as it connects patients to the community, making them feel as though they are supported and not alone. Some patients already go on Twitter to proudly announce how long they have been seizure free to their peers (Figure 2). It is also important to keep in mind that different people will have different factors that motivate them.

Sustainability:

Once patients start using the application, it will then be important for them to continuously engage with it. As previously stated, an added narrative could make it so that the patient is going through a journey, possibly ensuring continuous engagement. Since one of the factors of non-adherence stated by Kardas *et al.* [6] is forgetfulness, push notifications could be utilised to remind patients to engage with the mobile application. This application could also be linked to various other social and monitoring apps to increase its utility, further ensuring constant engagement with the application.

Self-representation:

To create a link between the patient and the application, customisable avatars could be implemented, as well as in-game usernames. The application would then serve as more of a guide utilised by the patient to improve their adherence. Activities and goals could be set by patients, with recommendations by healthcare professionals, to create a sense of autonomy for the patient. This is a core component in ensuring the development of intrinsic motivation. The application could be used as a personalised log for the patient, where their complete seizure and drug history could be recorded. It could also be used by healthcare professionals to record and instruct patients on medication changes, such as up-titrations of medication.

Socialising:

The application could be used as a social platform to connect patients living with the same condition. A forum and support system could be implemented so patients could share, connect, and support each other. There can also be an option to connect the application to social media such as Facebook and Twitter so patients can share their achievements with their friends, as well as connect with other patients through other platforms.

Self-management:

A feature such as a to-do and reminder list could be included in the application to help patients, not only in complying with their medication, but with other aspects of their management, such as to improve attendance at follow-up clinics. Links to other self-management sites as well as tutorial videos could also be included to aid patients.

Summary

Gamification appears to be a valuable technique to motivate people to adhere to medication regimens. Although there will be no universal solution, particularly for those with comorbid learning disability, we advise harnessing the talent of software designers to help yield novel support for complex problems. Of course, these challenges are not limited to medication adherence; the purpose of the mobile application is to be an interactive intermediary between healthcare professionals and patients. Potential applications include improving adherence with scheduled appointments or recruiting patients to clinical trials. If the game is interesting enough, it could also be circulated to, and directed at, the public to change attitudes about epilepsy. While society is focusing on the negatives of video gaming, we should utilise the positives of all current technology, and apply them to patient-centred care. A mobile application, for example, could be a first step towards a more gamified, fun, and engaging experience in epilepsy treatment.

References

1. Marczewski A. *Gamification: A Simple Introduction*. [e-book] Amazon Digital Services, Inc. 2016.

2. Deterding S, Khaled R, Nacke LE, Dixon D. Gamification: Toward a Definition In CHI 2011 Gamification Workshop Proceedings, Vancouver, BC, Canada. http://gamification-research.org/wp-content/uploads/2011/04/02-Deterding-Khaled-Nacke-Dixon.pdf; 2011. [accessed 20.06.2017]

3. Entertainment Software Association. *2016 Sales, Demographics and Usage Data. Essential Facts about the Computer and Gaming Industry*. [pdf] Available at: http://essentialfacts.theesa.com/Essential-Facts-2016.pdf; 2016. [accessed 9.07.2017]

4. Aronson JK. Compliance, concordance, adherence. *Br J Clin Pharmacol* 2007;63(4):383–384.

5. Sabaté E. Adherence to Long-Term Therapies - Evidence for Action. *World Health Organization* 2003, p87-94.

6. Kardas P, Lewek P, Matyjaszczyk M. Determinants of patient adherence: a review of systematic reviews. *Frontiers in Pharmacology* 2013;4:91.

7. Epilepsy Research UK. *Poll shows that almost 50% of people forget to take their medication at least once a month.* [online] Available at: https://www.epilepsyresearch.org.uk/poll-shows-that-almost-50-of-people-forget-to-take-their-medication-at-least-once-a-month/; 2017. [accessed 9.07.2017]

8. Davis KL, Candrilli SD, Edin HM. Prevalence and cost of nonadherence with antiepileptic drugs in an adult managed care population. *Epilepsia* 2007;49(3):446-54.

9. Hampel KG, Rocamora Zuñiga R, Quesada CM. Unravelling the mysteries of sudden unexpected death in epilepsy. *Neurologia* 2017. [e-Pub ahead of print] doi: 10.1016/j.nrl.2017.02.004

10. Atreja A, Bellam N, Levy SR. Strategies to Enhance Patient Adherence: Making it Simple. *Medscape General Medicine* 2005;7(1):4.

11. Park HJ, Bae JH. Study and Research of Gamification Design. *International Journal of Software Engineering and Its Applications* 2014;8(8);19-28.

12. Lapão LV, Marques R, Gregório J, Pinheiro F, Póvoa P, Mira da Silva M. Using Gamification Combined with Indoor Location to Improve Nurses' Hand Hygiene Compliance in an ICU Ward. *Studies in Health Technology and Informatics* 2016;220:3-7.

13. McLeod A, Hewitt B, Gibbs D, Kristof C. Evaluating Motivation for the Use of an Electronic Health Record Simulation Game. *Perspectives in Health Information Management* 2017;14(Spring):1d.

14. Lamb LC, DiFiori MM, Jayaraman V, Shames BD, Feeney JM. Gamified Twitter Microblogging to Support Resident Preparation for the American Board of Surgery In-Service Training Examination. *Journal of Surgical Education* 2017. [e-pub ahead of print] doi: 10.1016/j.jsurg.2017.05.01

15. Allam A, Kostova Z, Nakamoto K, Schulz PJ. The Effect of Social Support Features and Gamification on a Web-Based Intervention for Rheumatoid Arthritis Patients: Randomized Controlled Trial. *Journal of Medical Internet Research* 2015;17(1);e14.

16. Statista. *UK: smartphone ownership by age from 2012-2016.* [online] Available at: https://www.statista.com/statistics/271851/smartphone-owners-in-the-united-kingdom-uk-by-age/; 2017. [accessed 9.07.2017]

17. Mclean B, Shankar R, Hanna J, Jory C, Newman C. Sudden unexpected death in epilepsy: measures to reduce risk. *Practical Neurology* 2017;17:13-20.

18. Exeter C, Yang S, Wilig J. Guidelines for the Gamification of Self-Management of Chronic Illnesses: Multimethod Study. *JMIR Serious Games* 2017;5(2):e12.

19. AlMarshedi A, Wills GB, Ranchhod A. The Wheel of Sukr: A Framework for Gamifying Diabetes Self-Management in Saudi Arabia. *Procedia Computer Science* 2015;63:475-480.
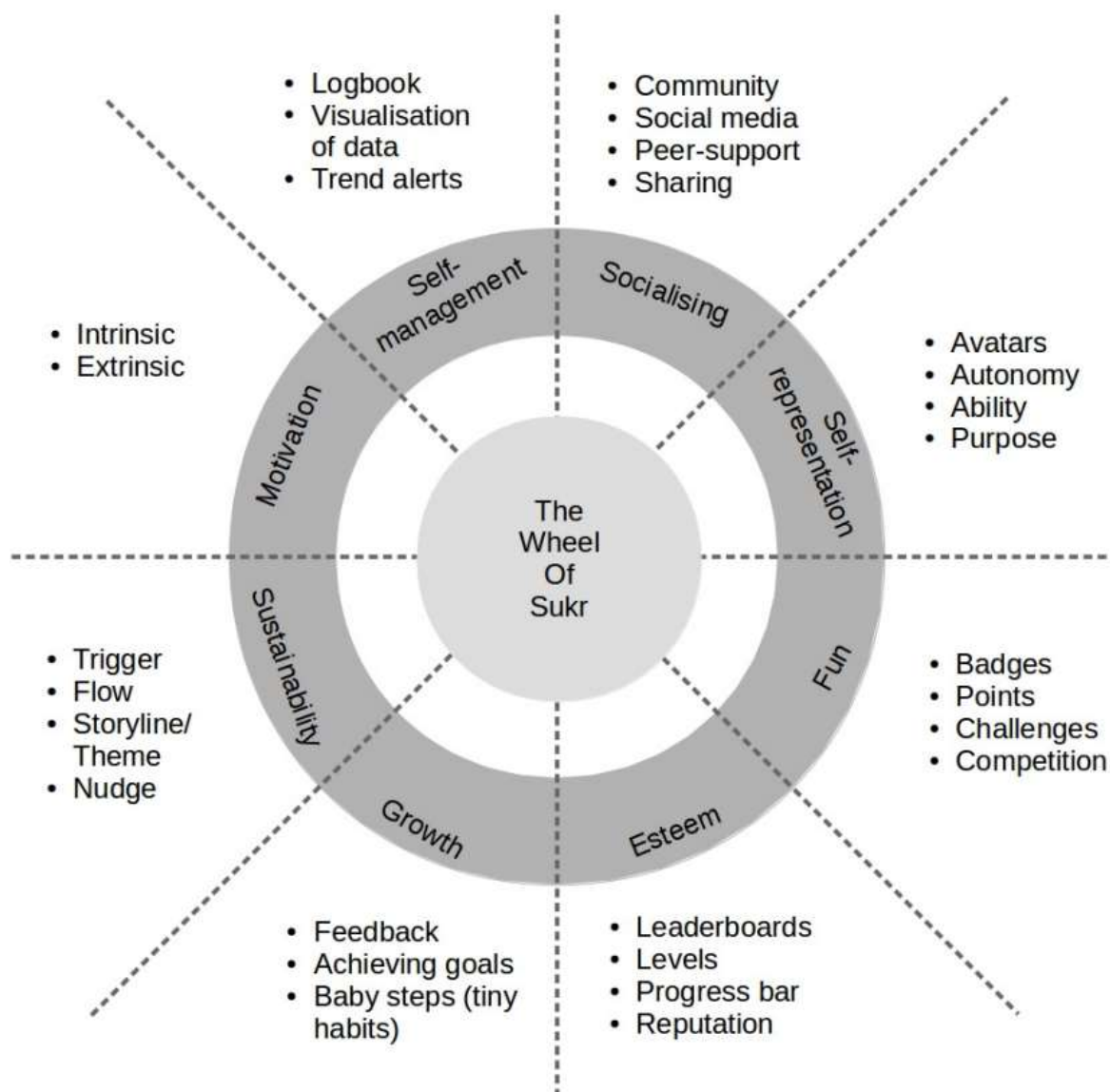
Figure 1

Figure 1: Wheel of Sukr Figure reproduced from AlMarshedi, A., Wills, G. B., Ranchhod, A., 2015. The Wheel of Sukr: A Framework for Gamifying Diabetes Self-Management in Saudi Arabia. Procedia Computer Science. Volume 63, Pages 475-480. http://www.sciencedirect.com/science/article/pii/S1877050915025053 It was published (and can be reproduced) under the terms of Creative Commons Attribution 4.0 licence.

Figure 2

Figure 2: Comments from Twitter, a search for "Seizure Free" People are currently engaging with social media to gain community support and enhance their motivation