J Med Syst (2019) 43:295
https://doi.org/10.1007/s10916-019-1420-4

PATIENT FACING SYSTEMS

Patients Attitude to Technology

A Way to Improve Hydrocephalus Management and Follow up Using Smartphone Intelligent Application

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Received: 22 May 2019 / Accepted: 10 July 2019

Abstract

Smartphone applications ("apps") have become ubiquitous with the advent of smartphones and tablets in recent years. Increasingly the utility of these apps is being explored in healthcare delivery. Hydrocephalus is a condition that is usually followed by a neurosurgeon for the patient's life. We explore patient acceptability of a mobile app as an adjunct to outpatient follow-up of patients with hydrocephalus. A questionnaire was circulated amongst patients with hydrocephalus (adults and children). Patients were asked questions about their hydrocephalus; expectations for outpatient follow up, whether they have smartphone/tablet/internet access and whether they would be interested in a mobile app for their long term hydrocephalus follow up. 191 patients completed questionnaires, 98 respondents were adults (mean age 46.1) and 93 were children less than 18 years old (mean age 8). Overall 36.1% of patients did not know the cause of their hydrocephalus. 96.7% have a shunt. 76.5% of adults and 80.6% of children had 1-4 shunt surgeries, 14.3% of adults and 11.8% of children had 5-9 shunt surgeries, 3.1% of adults and 5.4% of children had 10-14 shunt surgeries. 71.7% of patients expect to be followed-up routinely in clinic for life. All children had smartphones or tablets, compared to 86.7% of adults. Children were more interested in a hydrocephalus app, 84.9% saying yes, compared to 71.4% of adults. Adults who were not interested in the app did not have a smartphone or tablet. Hydrocephalus management is a lifelong task and innovations in technology for engaging patients in its management are vital. The majority of patients are interested in mobile apps for outpatient management of hydrocephalus. We will follow this up with a feasibility study of a custom designed hydrocephalus app.

Keywords Hydrocephalus · Follow up · Intelligent approach · Smartphone apps

Introduction

Hydrocephalus is variably described as an enlargement of ventricular system of the brain resulting from inadequate passage of cerebrospinal fluid (CSF) from where it is produced within the cerebral ventricles to its point of absorption into the systemic circulation [1], the incidence in high-income countries is approximately 79 per 100,000 births [2]. Treatment of hydrocephalus depends on the aetiology, with ventriculoperitoneal shunt (VPS) being the commonest intervention (up to 3500 performed per year in the UK alone [3]). Endoscopic third Ventriculostomy [4] and choroid plexus coagulation [5] are less frequently used treatments. Hydrocephalus is generally considered as a condition that requires lifelong management. In long-term follow-up series of adults with paediatric-onset hydrocephalus, up to 89% of patients still possess an implanted shunt [5]. It is commonly advised that adults with hydrocephalus who remain shunt dependent should be regularly followed to help manage and avoid potential complications associated with chronic shunting [5].

Headaches are a common complaint amongst patients with a diagnosis of hydrocephalus even when adequately treated, with 10-20% of children reporting severe headache [6]. Serious chronic headaches are seen in approximately 40% of adults with shunted hydrocephalus [7]. Finding new ways to engage patients with their healthcare is

This article is part of the Topical Collection on *Patient Facing Systems*

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Published online: 25 July 2019

essential. Mobile healthcare (”m health”) applications (”apps”) are software programs that run on internet enabled devices like smartphones. Their potential for use in wide range of medical and health related issues is increasingly being explored [8]. The ”Hydroapp”, developed with John Moores University in Liverpool is a web-based management, administration, communication and m-health application that provides follow-up treatment for patients with hydrocephalus or chronic headache. Patients will record all the pain events and the episodes related to those events, as well as a quick way to fill-in diaries, outcome measures and health questionnaires.

Methods

A questionnaire was circulated in an electronic form via a google forms through the patient group Shine[1] (Spina bifida • Hydrocephalus • Information • Networking • Equality). Parents were asked to complete questionnaires on behalf of children with hydrocephalus. The questionnaire included 33 questions in 2 parts; Part 1 asked participants about their hydrocephalus, aetiology, number of shunt operations, outpatient follow-up experience, and accessing emergency or urgent help. Part 2 explored participant access to internet/smartphone technology, opinions about using technology to manage living with your shunt and how important or relevant certain potential features of a hydrocephalus app would be to them. The reliability analysis of our questionnaire has been measured using Cronbach’s alpha approach [9]. It is imperative to note that no personal information was included in the questionnaire.

Results

191 patients completed questionnaires, 51.3% of respondents were adults (mean age 46.1, range 18-83 years) and 48.7% were children less than 18 years old (mean age 8, range 0-17 years).

Aetiology of hydrocephalus

Overall 36.1% of patients did not know the cause of their hydrocephalus. Of the 98 adults, 29 had normal pressure hydrocephalus (NPH), 29 did not know the aetiology of their hydrocephalus, 18 had tumour related hydrocephalus, 7 had Idiopathic Intracranial Hypertension(IIH), 7 had post haemorrhagic hydrocephalus, 5 had post infection hydrocephalus and 3 had spina bifida associated hydrocephalus. Within the paediatric group, 40 of the 93 respondents did not know the cause of their hydrocephalus. 22 had post haemorrhagic hydrocephalus, 9 had NPH, 8 had post infection hydrocephalus, 8 had spina bifida associated hydrocephalus, and 5 had tumour related hydrocephalus. No child had IIH, compared to 7.1% of adults.

Shunts

Overall 97% have a shunt, 95.9% of adults and 97.8% of children currently have a shunt. 76.5% of adults and 80.6% of children had 1-4 shunt surgeries, 14.3% of adults and 11.8% of children had 5-9 shunt surgeries, 3.1% of adults and 5.4% of children had 10-14 shunt surgeries. Non of children had more than 15 surgeries, compared to 3.1% of adults who had 15-19 surgeries.

Waiting time

About 42% of all patients had to wait between 16 and 30 minutes to be seen by specialists, while 5.7% of all patients had to wait up to 60 minutes. As shown in Fig. 1, about half of the patients spent 10-15 minutes with doctor or nurse in the clinic. 36.7% of adults and 25.8% of children spent more than 15 minutes in clinic.

Patients’ expectations for follow up

Patient preference for how they would like to be followed up can be seen in Fig. 2. The majority of patients, both adult and children, would like to be seen by the neurosurgery team in clinic every 6 months or yearly. 20% of adults prefer to be seen in clinic only when they have problems. Overall, 71% of patients were expected to be followed-up routinely in clinic for life. The commonest long-term concern for these patients is blockage/shunt failure/malfunction (66/98 adults, 72/93 children) followed by infection (13/98 adults, 16/93 children).

Access to internet/smartphone

The majority of patients have a home computer with internet access (95% of adults and 90% of children). All children had smartphones or tablets, compared to 87% of adults. Type of smartphone was evenly split between Android and Apple iPhone. 44.9% of adults and 43% of children owning Android smartphone versus 40.8% of adults and 53.8% of children owning an Apple iPhone.

Interest in a hydrocephalus app

Children were more interested in a hydrocephalus app, 84.9% saying yes, compared to 71.4% of adults. Adults who were not interested in using hydrocephalus app (mean age

[1] https://www.shinecharity.org.uk/

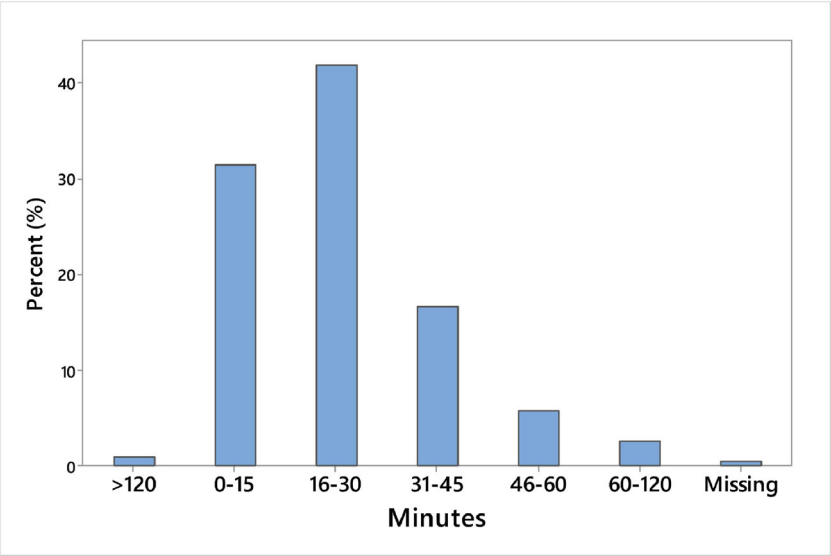

Fig. 1 Waiting time at the clinic

56.5 years) didn't have a smartphone or tablet as shown in Figs. 3 and 4.

Of those who were interesting in using Hydroapp for long-term follow up, most cited reasons shown in Table 1 as very or extremely important on a scale of 1 to 5 (i.e. from least important to most important). Recording details about their shunt was the most commonly cited reason for interest in an app for adults (78% of adult respondents, though 96% of children also), whilst in children it was to alert the treating team in 95%. It is obvious that recording headache score, general health, and alerting medical team, were also seen by patients as important aspects in term of using Hydroapp for self-management and follow-up. However, making video-call in general was the lesser important aspect from patients point of view.

The biggest concerns of shunted patients

This subsection demonstrates the main worries for patients about their shunt. Our analysis reveals that 75% of patients were worried about shunt malfunction or blockage. Moreover, slightly less than 7% of patients were anxious about a headache that the shunt may cause for different reasons. About 5% of patients are concerned due to the infection that may occur because of the shunt. However, patients who did not possess concerns shared an equivalent percentage of patients who were fearful of shunt infection. Undoubtedly shunt malfunction and blockage were the biggest problems that patients are afraid and concerned about. Therefore, patients have a need to regular follow-up method with the intention to avoid shunt blockage and discover any

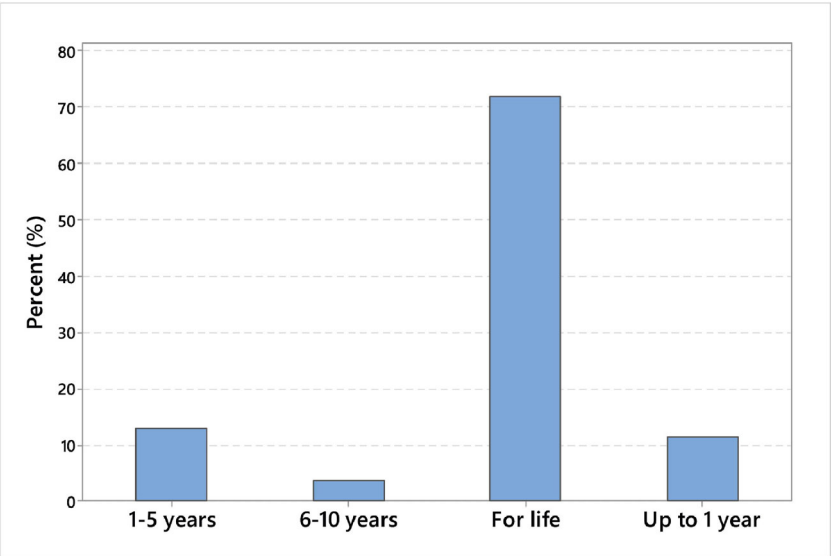

Fig. 2 Patients' expectations for follow up

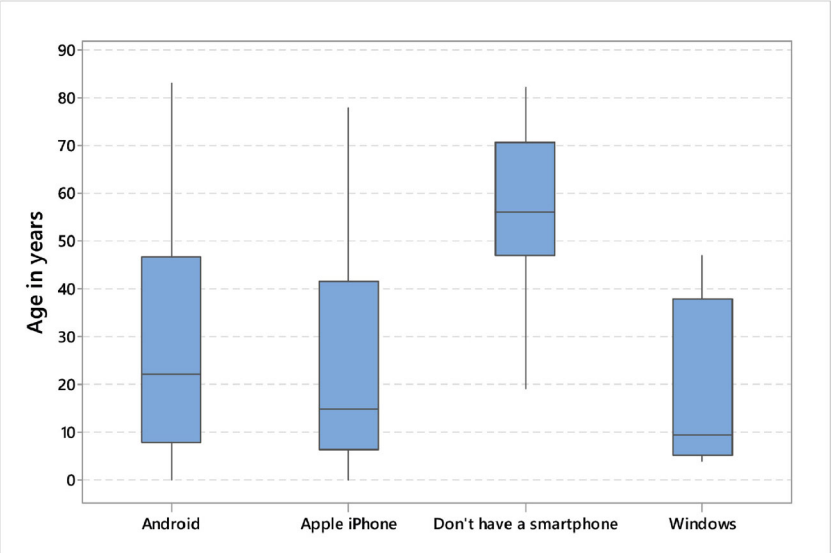

Fig. 3 Type of smartphone

infections early so to avoid headache and consequences that could occur to shunted patients. Figure 5, shows a cloud of patients comments with respect to their concerns.

Discussion

According to the Office for National Statistics the percentage of adult internet users has increased from 80% in 2011, when comparable records began, to 89% 2017. Virtually all adults aged 16 to 34 years were recent internet users according to the Office for National Statistics[2]. In 2017, 76% of UK consumers owned a smartphone, up 5% year on year. Laptops were the second most commonly-owned internet enabled device in households (64%), followed by tablets (58%) [10]. Mobile apps are increasingly being used for more than just social networking and entertainment with 80% of users aged 18-24 using at least one finance app and almost two-thirds of users aged 18-24 using a fitness app [10].

There has been an explosion of mobile healthcare applications in tandem with the expansion of internet access and smartphone ownership. 325,000 health apps (health, fitness and medical apps) were available on all major app stores as of 2017. $5.4 billion have been invested in digital health in 2016 alone [11]. Text message interventions via mobile phone are widely reported in conditions like in diabetes [12–16] and in smoking cessation programmes [17–22]. Smartphone apps have been used to allow physicians to monitor patients with chronic heart failure [23] and in diabetes education [24]. Like with diabetes, the application of "m health" is a promising adjunct to clinical care as it addresses the demand for ongoing support in the management of chronic conditions.

There is an obvious enthusiasm for developing m health apps but there are challenges to adopting this technology. A study in 2015 showed two-thirds of apps within the NHS health apps library [25], a pilot programme which list NHS approved healthcare related mobile apps, sent identifying information over the internet and did not use encryption. Developing an app that will transmit patient identifiable information requires adherence to the major governing legislation (in the UK this is the Data Protection Act 1998 [26]) and as such needs to be developed with due diligence.

The Hydroapp is being developed with John Moores University in Liverpool, in accordance with the requirements of hydrocephalus specialists at Alder Hey Children's NHS foundation trust and Walton centre, Liverpool. The central database and server application will be hosted on AIMES[3] data centre, which meets the NHS criteria for information security and governance and currently hosting data for The Institute of Child Health and Liverpool Heart and Chest Hospital. The central database of Hydroapp will store anonymised data in numerical format rather than plain text. Therefore, only the server app can display this representation into understandable format. Moreover, numeric representation requires much less storage space and query time.

Hydroapp includes a range of patients self-reported outcome measure and monitoring forms such as hydrocephalus outcome questioner (Hydro-OQ), EQ5D-Y and EQ5D-3L, headache impact test (HIT6), headache diary and visiting reports. Using Hydroapp as a follow-up technique and data collection method will ensure that economic and patient-reported outcomes are recorded efficiently. It will be assumed that the standard use of such smartphone-based

[2] https://www.ons.gov.uk/

[3] http://www.aimes.uk/

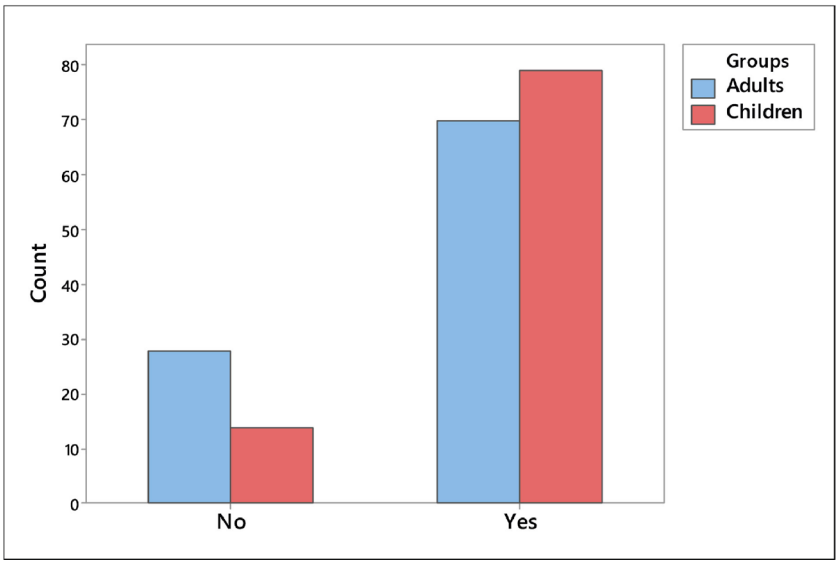

Fig. 4 Patients' interest in using technology for follow up

PRO (Patient Reported Outcome) and intelligent software will be able to reduce unnecessary visits to neuroscience centres, whilst enabling and improving communication between patient and neurosurgical care and follow by creating appropriate clinical thresholds for alerting medical staff of changes in symptoms or of changes of behaviours and of symptoms automatically.

Hydroapp improves monitoring of historical responses to therapies and recording of side effects. This platform provides an on-the-go analysis of a patient's data, which improves doctor's productivity and decision-making. The accumulation of data and doctors' experience will be stored in a knowledge base, which enables Hydroapp to train itself allowing knowledge to be expressed and bounded to identifying risk and alert healthcare provider. The use of intelligent methods within Hydroapp can improve healthcare delivery by allowing a proactive resolution such as identifying risk level of certain cases, and then automatically prioritise alerts and waiting list. Without such intelligent solution, too many hours can be spent analysing pain events to reveal meaningful patterns, whereas identifying risk in early stage helps specialists to take action before serious complication occurs. Hydroapp with support of artificial intelligence can absorb thousands of patients' records and make sense of them instantaneously. Hydroapp automates all the heavy lifting of analysis and discovery that take teams of medical experts hours or days, artificial intelligence does on the fly to proactively identify problems and pinpoint the underlying root cause. Such application enabled by data science and advanced intelligent methods would convey revolutionary impacts in the healthcare domain.

Table 1 Important aspects of using Hydroapp for follow-up

Important aspects	Adult	Children
Record headache score	70%	77%
Record general health and well-being	68%	84%
Alert treating team	86%	95%
Record/update details of your shunt	78%	96%
Video-call appointment	56%	52%
Emergency consultation via video-call	65%	68%

The market penetration of internet access and smartphone usage means that the vast majority of our patients have the potential to engage with smartphone apps in their daily lives. Our survey shows that there is an appetite amongst our patients to engage with healthcare in new ways and with new technologies. We are facing an increasing need to balance patient expectations with the resources available in a modern NHS. We have shown that patients expect to be followed by their neurosurgery team for life when they have a shunt. Patients are understandably concerned about the potential for shunt malfunction/infection and wish to maintain contact with the treating team. These concerns are mirrored by neurosurgeons who fear missing a potential shunt malfunction which is potentially a life-changing/life-threatening event.

The reality is that the vast majority of routine outpatient appointments for hydrocephalus do not uncover new symptoms that require neurosurgical attention. The patient +/- their family take time out of school/work and travel, often significant distances, to attend clinic. Outpatient clinics are very regularly at capacity or overbooked and the

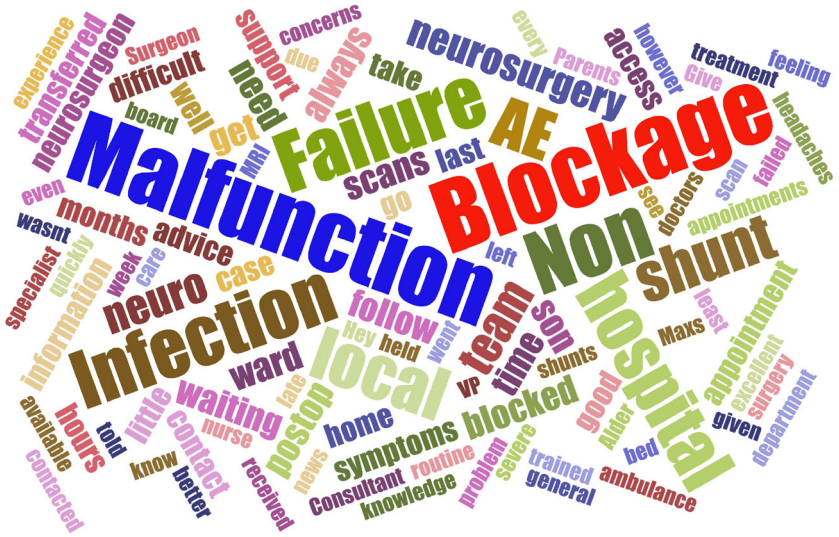

Fig. 5 The biggest concerns of shunted patients

time and resources spent on these routine interactions could well be better utilised. When a problem with a shunt does arise, patients commonly present to their GPs or their local hospital, which can lead to delays in accessing neurosurgical advice and care. We propose that following these patients with a hydrocephalus app could facilitate a more efficient patient-healthcare interaction with proactively responds to changing symptoms. Thus a technology such as this should be a perfect vehicle to maintain surveillance of a potentially catastrophic event like shunt malfunction without overburdening a health service with regular face to face contacts in the outpatients.

Conclusion

Hydrocephalus essentially constitutes a lifelong disease with brief episodes where patients need actual neurosurgical input. Innovations in technology for engaging patients in its management are vital. In this study, we have found that the majority of patients are interested in mobile apps for outpatient management of hydrocephalus. In response to our survey, we have developed Hydroapp in accordance with expectations as per Table 1. We will follow this up with a feasibility study of the custom designed Hydroapp.

Compliance with Ethical Standards

Conflict of interests The authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed Consent None.

References

1. Rekate, H. L., The definition and classification of hydrocephalus: a personal recommendation to stimulate debate. *Cerebrospinal Fluid Res.* 5:2-, 2008.
2. Dewan, M. C., Rattani, A., Mekary, R., Glancz, L. J., Yunusa, I., Baticulon, R. E. et al., Global hydrocephalus epidemiology and incidence: systematic review and meta-analysis. *Journal of Neurosurgery*. 1–15, 2018.
3. Richards, H. K., Seeley, H. M., and Pickard, J. D., Efficacy of antibiotic-impregnated shunt catheters in reducing shunt infection: Data from the United Kingdom Shunt Registry. Clinical article. *J. Neurosurgery: Pediatrics* 4(4):389–93, 2009.
4. Buxton, N., Macarthur, D., Mallucci, C., Punt, J., and Vloeberghs, M., Neuroendoscopic third ventriculostomy in patients less than 1 year old. *Pediatric Neurosurgery* 29(2):73–6, 1998.
5. Pople, I. K., and Ettles, D., The role of endoscopic choroid plexus coagulation in the management of hydrocephalus. *Neurosurgery* 36(4):698–702, 1995.
6. Kulkarni, A. V., Quality of life in childhood hydrocephalus: A review. *Child's Nerv. Syst.* 26(6):737–43, 2010.
7. Rekate, H. L., and Kranz, D., Headaches in patients with shunts. *Seminar Pediatr. Neurol.* 16(1):27–30, 2009.
8. Klasnja, P., and Pratt, W., Healthcare in the pocket: Mapping the space of mobile-phone health interventions. *J. Biomed. Inf.* 45(1):184–98, 2012.
9. Tavakol, M., and Dennick, R., Making sense of Cronbach's alpha. *Int. J. Med. Educ.* 2:53–55, 2011.
10. Ofcom. The Communications Market Report, 2017.
11. Company rgTMAS. mHealth Economics 2017 – Current Status and Future Trends in Mobile Health, 2017.
12. Wangberg, S. C., Arsand, E., and Andersson, N., Diabetes education via mobile text messaging, Vol. 12, 2006.
13. Pena, V., Watson, A. J., Kvedar, J. C., and Grant, R. W., Mobile phone technology for children with type 1 and type 2 diabetes: A parent survey. *J. Diabetes Sci. Technol.* 3(6):1481–9, 2009.
14. Hanauer, D. A., Wentzell, K., Laffel, N., and Laffel, L. M., Computerized Automated Reminder Diabetes System (CARDS): E-mail and SMS cell phone text messaging reminders to support diabetes management. *Diabetes Technol. Therapeutics* 11(2):99–106, 2009.

15. Goodarzi, M., Ebrahimzadeh, I., Rabi, A., Saedipoor, B., and Jafarabadi, M. A., Impact of distance education via mobile phone text messaging on knowledge, attitude, practice and self efficacy of patients with type 2 diabetes mellitus in Iran. *J. Diabetes Metabol. Disord.* 11(1):1–8, 2012.
16. Saffari, M., Ghanizadeh, G., and Koenig, H. G., Health education via mobile text messaging for glycemic control in adults with type 2 diabetes: A systematic review and meta-analysis. *Prim. Care Diabetes* 8(4):275–85, 2014.
17. Obermayer, J. L., Riley, W. T., Asif, O., and Jean-Mary, J., College smoking-cessation using cell phone text messaging. *J. Amer. Coll. Health* 53(2):71–8, 2004.
18. Schindler-Ruwisch, J. M., Leavitt, L. E., Macherelli, L. E., Turner, M. M., and Abroms, L. C., Motivating smoking cessation text messages: Perspectives from pregnant smokers. *Maternal Child Health J.* 22(6):822–9, 2018.
19. Rodgers, A., Corbett, T., Bramley, D., Riddell, T., Wills, M., Lin, R. B. et al., Do u smoke after txt? Results of a randomised trial of smoking cessation using mobile phone text messaging. *Tobacco Control* 14(4):255–61, 2005.
20. Free, C., Hoile, E., Robertson, S., and Knight, R., Three controlled trials of interventions to increase recruitment to a randomized controlled trial of mobile phone based smoking cessation support. *Clin. Trials* 7(3):265–73, 2010.
21. Vodopivec-Jamsek, V., de Jongh, T., Gurol-Urganci, I., Atun, R., and Car, J., Mobile phone messaging for preventive health care. *Cochrane Database of Systematic Reviews*. 2012(12), 2017.
22. Haug, S., Meyer, C., Schorr, G., Bauer, S., and John, U., Continuous individual support of smoking cessation using text messaging: A pilot experimental study. *Nicotine Tobacco Res.* 11(8):915–23, 2009.
23. Scherr, D., Zweiker, R., Kollmann, A., Kastner, P., Schreier, G., and Fruhwald, F. M., Mobile phone-based surveillance of cardiac patients at home. *J. Telemed. Telecare* 12(5):255–61, 2006.
24. Frøisland, D. H., Årsand, E., and Skårderud, F., Improving diabetes care for young people with type 1 diabetes through visual learning on mobile phones: Mixed-methods study. *Journal of Medical Internet Research* 14(4), 2012.
25. NHS. National Health Service (NHS) Health Apps Library 2013 [Available from: https://apps.beta.nhs.uk/.
26. Data Protection Act 1998- An Act to make new provision for the regulation of the processing of information relating to individuals, including the obtaining, holding, use or disclosure of such information, 1998.

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