Use of Quick Response (QR) coded bracelets and cards for the improvement of cortisol deficiency / Addison's disease management; an audit of quality of care of the management of steroid deficiency in acute illness

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ABSTRACT

An adrenal crisis is a rare but life-threatening condition in which hydrocortisone and fluid resuscitation must be given promptly to prevent hypotensive shock and death. A clinical audit assessed health care professionals' experience of adrenal crisis management and if there was a need for immediate access to clinical guidelines. The proposed system in which a patient-worn Quick Response coded bracelet provides health care professionals with web-based clinical information in acute settings, was explored for the management of adrenal crisis.

Methods

Fifty four health care professionals, 21 doctors, 12 nurses, 15 paramedics and 6 dentists completed a questionnaire about the care, confidence in managing an adrenal crisis and the feasibility of using a QR coded bracelet designed and linked to

a web site dedicated to patient information on steroid replacement therapy we have developed.

Results

37% of health care professionals have never seen and 59% have never managed an adrenal crisis. The median confidence score (1-low to 7-high) in managing an adrenal crisis varied for doctors, nurses, paramedics and dentists between 5, 2, 4.5 and 1.5 respectively. 94% of health care professionals thought the proposed QR code-linked system was useful and 84% would use it in an acute setting. The median usability score (1-low to 7-high) for the QR code-linked system for health care professionals was 6.5 out of 7.

Conclusion

There is a clinical need to improve the acute management of adrenal crisis and QR code-linked information was desired by health care professionals. QR code-linked information may allow patients with rare diseases presenting acutely, to receive improved management through immediate access to treatment protocols.

Key words

Addison's disease, adrenal crisis, Addisonian crisis, cortisol deficiency, hydrocortisone, QR code, treatment protocols, web, patient information, patient education

INTRODUCTION

Addison's disease (primary adrenal failure) is a chronic disorder of the adrenal glands resulting in inadequate production of the vital stress hormone, cortisol. [(1)] It is a rare disease treated by taking daily tablets of an oral synthetic analogue of cortisol

called hydrocortisone or prednisolone and an oral synthetic analogue of aldosterone called fludrocortisone for life. Glucocorticoid replacement is required for both primary and secondary adrenal failure whereas mineralocorticoid (fludrocortisone) replacement is only required in primary adrenal failure. Other equally rare conditions such as bilateral adrenalectomy and hypopituitarism (causes of secondary adrenal failure) are similarly managed with daily frequent doses of hydrocortisone or once-daily doses of prednisolone. Cortisol is essential for maintaining a person's wellbeing by contributing to blood pressure regulation, glucose levels, and the body's response to stress.

What is an adrenal crisis?

As long as patients on steroid replacement (stress steroids) therapy are able to take their regular medication they remain well and live normal lives. Adrenal crisis precipitated by inter-current illness, surgery, missed steroid medication, medication not absorbed by the patient (diarrhoea/vomiting) or stopped by the patient / attending physician is a medical emergency and can be fatal if left untreated. The cardinal features of an adrenal crisis are becoming acutely unwell with symptoms that may include nausea, abdominal pain, drowsiness, dizziness, vomiting and signs of hypotension. The patient can become completely incapacitated and helpless within an hour of onset of these symptoms.[(2)] Thus an adrenal crisis is a medical emergency and the patient will die unless they are given intramuscular / intravenous hydrocortisone and admitted to hospital urgently to receive further resuscitation with a saline infusion and hydrocortisone. [(2)] Any underlying cause of adrenal crisis such as inter-current illness including bacterial infection should be treated if possible. The

regimen of intravenous hydrocortisone and normal saline is rapidly effective and the patient should feel better within hours.

An adrenal crisis may be the initial presenting feature of Addison's disease.[3] In a postal survey of 841 patients with Addison's disease done in the UK, Australia, Canada, and New Zealand in 2003, 8% of patients needed hospital treatment for an adrenal crisis**.** Nausea and vomiting were the most frequent presenting symptoms. [4] An infection together with failure to increase the hydrocortisone dose during times of stress in patients already known to have Addison's disease, are common precipitants of an adrenal crisis. Increased stress may be due to physical injury, childbirth, major and minor surgery such as endoscopy and dental procedures.[3] Six cases of adrenal crisis secondary to dental surgery have been described and the precipitants were dental pain, infection or procedures involving a barbiturate general anaesthetic with one case presenting as newly diagnosed Addison's disease. [5] The standard mortality rate of patients with Addison's disease is twice that of the normal population and an adrenal crisis has a mortality of 0.5 per 100 patient years.[2, 6]

The adequate management of a medical emergency of any type depends on familiarity with protocols and retention of skills by health care professionals. Rare medical conditions are prone to poor management in non-specialist units by definition as their presentation is uncommon and some health care professionals do not feel they have the appropriate knowledge or confidence to manage these cases. Since the advent of smart devices (smartphones and computer tablets), the dissemination of information has exploded facilitating the use of them to access the web. Quick Response (QR) codes, 2D bar codes used for accessing information, have been available in the retail field since 1994 and their popularity has only just increased with the appearance of free smart device programs, called apps that can

scan the code. [7] As the medical use of QR codes is in its infancy, we have developed a novel system featuring a QR code printed on a bracelet and card which can be carried by patients with Addison's disease or other patients on steroid therapy. Our proposed, novel Addison's Disease Information System (ADIS) uses a web app running on a smart device, linked to a QR coded bracelet, that provides patients with Addison's disease, comprehensive clinical management advice for their condition. It is accessible at all times and shareable with the health care professionals or the public patients may encounter in their everyday lives. Our first audit assessed health care professionals' experience and confidence in managing adrenal crises. Our second and final audit was set up to close the loop and was aimed at assessing health care professionals' views on our QR code-linked solution to improve the management of adrenal crises.

METHODS

Audit 1 – Health Care Professional experience in managing adrenal crises

Fifty four health care professionals working in the Accident and Emergency Department of the Queen Elizabeth Hospital in Gateshead, UK and local dental practices were questioned about their experience and confidence in managing an adrenal crisis graded by a score (1-low to 7-high). In addition, health care professionals' use of smartphones, clinical apps and QR codes was explored. The questionnaire for Audit 1 is shown in Supplement 1.

Audit 2 – Health care professionals views on QR code-linked bracelets and the ADIS

A different group of twenty four health care professionals including 12 doctors, 8 nurses and 4 paramedics were questioned about the usability of the QR code-linked ADIS system to improve adrenal crisis management in acute settings using a score of 1-low to 7-high. The questionnaire for Audit 2 is shown in Supplement 2.

QR codes – what are they?

The technology behind the novel medical use of this type of two-dimensional bar code is described in part 1 of the Appendix .

Creating and printing QR codes on bracelets and wallet cards

How QR codes are generated using software and printed on the patient bracelets and wallet cards is described in part 2 of the Appendix.

Accessing the ADIS by scanning the QR code-linked bracelet or card

The process of scanning a QR code-linked bracelet / card together with the main menu of the ADIS web site is shown in Figure 1. The ADIS menu, some of the information content of the ADIS and the technical details of scanning QR codes with smart devices are summarised in part 3 of the Appendix.

Addison's Disease Information System (ADIS) Technical Design

The design of our QR coding System and ADIS is given in part 4 of the Appendix.

Information Content, Provenance and Security of the ADIS

Information on this topic is provided in part 5 of the Appendix.

Insert Figure 1 here

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Figure 1 Scanning a QR code-linked Addison's disease bracelet / card with a smartphone.

Clinical Governance

Our two audits were registered with the Clinical Audit Department of the Queen Elizabeth Hospital, Gateshead, UK. No ethical approval for NHS audit is needed in the UK.

Statistical analysis

The data has been presented as median values (not normally distributed).

Results

Audit 1 – Health care professionals' experience of adrenal crises

A group of fifty four health care professionals made up of 21 doctors, 12 nurses, 15 paramedics and 6 dentists completed a questionnaire on their experience of adrenal

crises. Twenty one health care professionals (39%) have never seen an adrenal crisis and 33 health care professionals (61%) have never been involved in the management of one. A poorly managed adrenal crisis was seen by 7 health care professionals (13%)(Figure 2). The health care professionals' confidence score (1-low to 7-high) in managing an adrenal crisis varied for doctors, nurses, paramedics and dentists between 5, 2, 4.5 and 1.5 respectively and the median confidence score for all health care professionals was 3.

Insert Figure 2 here

Figure 2 The views of health care professionals on whether they have seen an adrenal crisis, been involved in the management of one and whether they have seen a poorly managed one.

Fifty four health care professionals expressed their views on using smartphones and clinical apps at work. 80% of them used smartphones at work. The main users in individual groups were paramedics (93%), dentists (83%), doctors (76%) and nurses (75%) Overall, 78% of health care professionals used clinical apps. The largest users of clinical apps were paramedics (87%), doctors (86%), dentists (83%) and nurses 75% (Figure 3).

Insert Figure 3 here

Figure 3 The views of health care professionals on using smartphones and clinical apps at work, whether they found the QR code-linked ADIS useful and whether they would use QR coding in clinical practice.

Audit 2 – Health care professional usability of the QR code-linked ADIS

Twenty four health care professionals expressed their views on whether they found the QR code-linked ADIS useful and whether QR coding was usable in clinical practice. The majority of health care professionals (96%) thought the proposed QR code-linked system would be useful in an acute setting. The median usability score of the ADIS score (1-low to 7-high) was 7 for all health care professionals, 7 for paramedics and nurses and 6.5 for doctors. The positive and negative free text comments from health care professionals on the QR code-linked bracelets and ADIS are summarised in Figure 4.

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Figure 4 Health care professionals' positive and negative free text comments on the Addison's Disease Information System (ADIS).

The six different types of QR code-linked bracelets we have designed are illustrated in Figure 5.

Insert Figure 5 here

Figure 5 The six different types of QR code-linked bracelets we have designed.

DISCUSSION

We became interested in improving the management of Addison's disease and developing the Addison's Disease Information System (ADIS) after hearing about the totally preventable deaths of two of our patients with Addison's Disease due to adrenal crises in other hospitals. One died after having a colonoscopy without pre-operative admission and pre-medication with intravenous normal saline and hydrocortisone. The other received inadequate steroid pre-medication before major surgery and developed resistant post-operative hypotension due to an adrenal crisis that was wrongly attributed to bleeding.

Thus we have carried out two audits involving health care professionals about the care of patients in adrenal crisis and their confidence in managing it. Furthermore we closed the audit loop by assessing the feasibility of using QR code-linked bracelets to access the ADIS support website we have developed.

In our audit many health care professionals reported lack of experience in adrenal crisis management. It is of interest that paramedics reported the highest confidence score for managing adrenal crisis and ease of use of the ADIS. This reflects the nature of their clinical activity and the first response they offer to patients with

Addison's disease. As the majority of health care professionals have not managed an adrenal crisis before, they may need more support from information systems such as the ADIS proposed by us. In order to address their clinical need, we have purposed QR coding, linked to a bespoke web page, suited to smart devices, for immediate access to information needed by patients with Addison's disease and their carers and described it as ADIS. Smart device users need an internet connection to access ADIS and they may have to download a free QR code reader app if one is not built into their smart device.

In a UK hospital-based multi-centre (5 hospitals), cross-sectional survey of 2107 doctors and 4069 nurses, 98.9% of doctors and 95.1% of nurses owned a smartphone and 92.6% of doctors and 53.2% of nurses found them useful in their clinical duties.[8] A UK online survey of 257 medical students and 131 junior doctors demonstrated a smartphone ownership level of 79% and 74.8% respectively and both groups endorsed the development of more medical apps to support their education and clinical practice. [9] In a web survey of 3306 US post-MD medical trainees, 85% owned smartphones and the most frequently used medical apps were drug guides, medical calculators, coding and billing programs and pregnancy apps. [10] A regional study of smartphone usage in 361 UK medical students revealed concerns about their potential misuse in the professional environment and an overreliance on them. [11] Concerns have also been raised about the safety of medical apps and their current lack of quality assessment by government regulatory agencies that would be applied to new drugs and medical devices. [12] Thus a link to professional bodies, as used by us, such as the UK Addison's Disease Self-Help Group (ADSHG) and NHS Hospital Guidelines provide the only safety guarantee for this medical advice. Our ADIS provides non-endocrine health care professionals with

information on how to treat and modify the steroid dose of a patient with Addison's disease before elective surgical and non-surgical procedures. It assists both patients and health care professionals in the optimum management of Addison's disease.
In a world-wide postal questionnaire of 1245 patients with Addison's disease, 84% recognised the need to alter their steroid dose. [13] Health care professionals advise patients with Addison's disease to wear a MedicAlert bracelet, [14] and carry a steroid card (which has limited room for complex information) stating that they are taking daily steroids and how much. These aids, however, do not provide guidance on other important aspects of Addison's disease management. Similarly the suggested education program which involves the patient's relative and a work buddy who can support them when they become acutely unwell does not include others who may need to be involved. [3] Thus the QR code-linked ADIS adds flexibility and comprehensive access to this information. The ADIS could be PIN-coded in the future to allow storage of personal Addison's disease management plans only available to patients registered on the system and could include the different clinical scenarios patients with Addison's disease may face and a section on Frequently Asked Questions.

Existing Internet Educational Resources for patients with Addison's disease

In the UK the Addison's Disease Self Help Group (ADSHG) has an excellent web site containing information useful to patients with Addison's disease [15]The content is approved by the ADSHG Clinical Advisory Panel of senior endocrine physicians engaged in Addison's disease research and includes detailed Guidelines for steroid replacement in surgery and dentistry. [16] The Dutch Endocrine Society (DES) has created a patient support group which has been successful in improving the self-

management of Addison's disease, encouraging proper use of steroid dose adjustments at times of illness or stress. DES allows patients to share their experiences of the condition with each other. It consists of face-to-face meetings of 12 to 14 patients with Addison's disease lasting 3 hours, during which they are given a lecture on the disease, its treatment and "sick day rule" instructions. [17, 18] DES has gone one step further in developing a web-based, patient, peer-to-peer network called AdrenalNet, [19] allowing patients with Addison's disease to exchange information on their illness experiences with other patients and maintain contact with the health care professionals managing their disease. However this facility does not provide immediate access to adrenal crisis emergency management information to the bystander or paramedic. DES has also produced a web app in Dutch and English on how to manage an adrenal crisis together with downloadable and printable steroid cards in 11 European languages. [20, 21]

The ADIS developed by us contains links to all ADSHG-approved guidelines and protocols in addition to storing a personalised letter *To Whom it may concern* provided by Dr JU Weaver. Even a low educational level of patients need not be a barrier to the appreciation of health information on the web if they can quickly obtain the information they need. [22] The ADIS system can be brought to the attention of health professionals in the Emergency Department by unwell patients with Addison's disease or their friends and relatives so they are empowered to receive the correct treatment in a timely manner.

Existing medical uses of QR codes

The most common use of QR codes in clinical medicine has been for tagging ENT patients [23] and the labelling patients' limbs to prevent wrong site surgery. [24]

South Korea is trying to improve the cardiopulmonary resuscitation (CPR) skills of its public by displaying CPR posters showing QR codes linked to a video on how to perform the procedure effectively. [25] Some post-graduate trainee anaesthetic doctors in the UK are using logs incorporating QR codes in clinical database management systems [26] whilst pharmacists have produced QR code-labelled medicines to help the elderly patient by reading aloud the name of the drug and when it should be taken using a text-to-speech system. [27] The QR code has a potential to find applications in the management of particularly complex / rare conditions such as porphyria and sickle cell crisis or common conditions such as diabetic hypoglycaemia where information needs to be patient-specific.

CONCLUSION

QR coded bracelets and cards may facilitate the use of correct and up-to-date clinical information for patient management in health care systems worldwide. Immediate access to clinical guidelines using the ADIS is likely to improve the experience of patients with Addison's disease during acute illness and help prevent future adrenal crises. This needs to be validated in a large group of patients.

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Competing Interests None declared.

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