

New technologies in burn care: A clinical psychologist's perspective of opportunities for advancing psychosocial care

2017 James Laing Memorial Essay

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Abstract

New technology has had a major role in advancing medical aspects of burn care; however, it also has potential to develop psychosocial care. New technological innovations enable healthcare to be accessed, delivered, and/or supported through use of information and communications technology, giving rise to eHealth. eHealth now has the capacity to facilitate patient access to psychosocial support, and could enhance the way psychologists work with patients and other members of the multidisciplinary team. It could change the way services communicate within and between themselves, and how screening and outcome data is collected from patients. eHealth can also provide information and education, and change the way in which patients access peer- and other forms of support. This paper discusses ways in which psychosocial care within burn services could be facilitated or enhanced by eHealth technology from the point of view of a clinical psychologist. Some important considerations for establishing a successful eHealth system are also presented.

Key words: Burn care; Psychosocial care; Telemedicine; eHealth; mHealth; Technology

Introduction

Burn injuries can cause significant harm to all aspects of the patient, from the physical to the psychological.¹ Burn care and wound management has evolved with improving technologies and the increasing sophistication of critical care medicine. This includes the development of positive pressure ventilation, lung protective ventilation strategies, general critical care techniques, improved anaesthetic procedures, and innovative modes of support and pain-management techniques within both paediatric and adult burn care.²⁻⁵

Such advances in the medical treatment of burn injuries means that the mortality rate has decreased and nearly all burns patients are now regarded as having good chances of survival.⁶ However, increased survival rate has resulted in more burn survivors coping with complex issues throughout their recovery.⁷ For this reason, issues concerning rehabilitation and quality of life have increasingly become the focus of burn care specialists and researchers within the field.⁸⁻¹¹ Within the United Kingdom (UK), clinical psychologists have become an integral part of the burn care team.¹² How can these professionals utilise new technology within burn care to increase the efficacy of psychosocial care?

The term 'technology' can be vague. This paper will concentrate on communication-focused technology whereby electronic methods may be used to facilitate the psychosocial care of both patients and their families. This technology may also be used to enhance assessment, training and multidisciplinary team (MDT) working within burn care. In an ever-changing health service, burn care teams within the UK must also be willing to adapt and evolve following National Health Service (NHS) restructuring resulting from the Health and Social Care Act 2012,¹³ as well as to integrate with other UK trauma networks.¹⁴ Changes utilising new technology are also in keeping with sustainability and transformation planning which is ongoing in the NHS. Services must adapt as society and patients' health needs change,

enabling patients to make choices about how they can access the care that best meets their needs. Whilst burn care is the focus of this essay, readers are invited to consider how technology could facilitate care within other services.

The centralisation of burns services within the UK means that specialised care is delivered at burns facilities, units or centres: a tiered approach dependent on burn severity. This model of care ensures clinical sustainability and the provision of specialised medical, nursing, and therapy expertise for patients. Burns patients should have access to surgeons, anaesthetists, nurses, physio- and occupational therapists, psychologists, and specialist clinical support professionals, who provide the full range of physical and psychosocial care.¹² Whilst the centralisation of care within specialist services ensures that patients receive integrated, multidisciplinary care, it can result in patients being treated at a location that is a significant distance from their home.

Due to the variety of mechanisms through which burn injuries are acquired, the patient population is heterogeneous. The reliance of patients on different professionals for support can vary greatly due to their differing premorbid psychosocial needs. Once discharged from hospital, or when treated as an outpatient, patients can have multiple visits to the hospital to meet the variety of specialists involved in their care. Recovery and rehabilitation is often lengthy and can result in persistent distress due to reminders of the event and chronic stress from continuing increased demands.¹⁵ Parents of hospitalised children may also be struggling with the additional stress from increased responsibility and load,¹⁶ and dividing their time to meet the needs of any uninjured siblings. Modern burn care must consider the multidisciplinary nature of the team that provides care to patients and families within the hospital setting. It must also consider the most accessible ways in which this care can be delivered. Accessibility is an important consideration when engaging and supporting patients and families during what are often demanding treatment and rehabilitation regimes.

The accessibility of healthcare has been increased by eHealth initiatives. eHealth refers to healthcare that is delivered, enabled or supported using information and communications technology. It is a growing field of health services provided through the internet and other new technologies.¹⁷ Telemedicine aims to improve patient health through channels such as videoconferencing, allowing two-way, real time, interactive communication between patients and professionals in different locations. Theurer et al.¹⁸ have recently produced the American Telemedicine Association Guidelines for Teleburn to assist practitioners in providing effective and safe medical care using telemedicine within burn care. Together, telemedicine and eHealth tools can allow the transfer of images and scans, and enable remote interactive clinical assessment, diagnosis and support. This technology can be used to support the provision of care within burns services. It may help to provide services to those who might be difficult to engage in care and/or live a significant distance from the hospital site.

This essay considers how new technology might facilitate communication within and between burn care teams. From a psychologist's perspective, it explores how we might work differently with patients by adopting new technology to facilitate patient support and psychoeducation for the patient and the staff team. This technology may also be used to streamline outcome measurement. Following this, some of the key factors to be considered before such technological systems are established for use will be presented.

Communication within and between teams

The ultimate aim of the burns MDT is to return the patient to their optimal level of physical, psychological and social functioning.¹⁹ For this to occur, professionals must be able to communicate well, not only with patients but also between themselves. Information sharing during MDT meetings can be facilitated by the use of an electronic patient notes and case files system. This should be standardised and accessible by all staff delivering burn care to

the patient. It is also valuable for this system to be adopted by all networks. Such a system would ensure that there are photographic and written clinical records, documenting a patient's care over time, which can be accessed by staff wherever direct care is provided,²⁰ thereby supporting patient transfer and referrals.

Communicating and working with patients

In order to identify and refer vulnerable patients, and their families or caregivers, for appropriate support, screening is needed from the burns service at the inpatient stage.^{16, 21} The UK National Network for Burn Care Standards¹² currently state that an appropriately trained health professional, who can provide psychological care services for patients, their families and/or carers, and staff, should be accessible to the team. Therefore, it is usual for services to employ a clinical psychologist and for patients to visit the psychologist at the hospital where they receive their treatment. Multiple appointments can lead to lengthy hospital visits or multiple trips; consequently, patients may find it preferable to access psychological help more locally. Referrals can be made for psychological support closer to the patient's home, but this may be to a practitioner without specialist knowledge of issues such as the impact of burn injuries, trauma, and coping with an altered appearance.

The provision of telemedicine would enable patients and psychologists to securely make video and audio calls, and engage in 'face-to-face' appointments remotely. Such an approach may not be suitable for everyone. However, this technology can facilitate patient access to psychological therapy, particularly when there are issues that hinder travel to the hospital, such as distance, cost, disability, and other work and family life demands. Examples of such services are the e-therapy service developed by Manchester Paediatric Burns Service (an online therapy service that offers a forum for young people to have an online, real-time, talk with psychologists to discuss worries and build resilience and confidence) and

www.yfaceit.co.uk (a website offering support for young people with conditions or injuries affecting their appearance). Russell et al.²² discuss how specialty telemedicine programs can successfully transition from grant-funded to self-sustaining enterprises, increasing access to expertise in large and sparsely populated regions, without imposing undue financial burdens.

Patient information and education

In addition to improving the accessibility of services, engagement in healthcare can also be facilitated by patient empowerment.²³ Patients can be empowered when they are provided with a range of high quality care options from which to choose, access to information and resources, and included in decision-making. Such an approach supports and respects their autonomy.²⁴ Empowerment is fostered through a patient-centred approach; an approach in which patients are regarded as a valuable source of information about their condition and their rehabilitation goals are self-set, rather than being set by professionals. It is important that staff provide information to patients and their families for the purpose of empowerment and engagement. This enables them to acquire new skills to participate in their health care.¹⁰ Although, due to differences in coping styles, one must acknowledge that some patients will not want to know as many details as others.²⁵

Many IT services and web-based interventions are available for people living with chronic diseases, with the aim of increasing patient empowerment, self-care behaviour, and self-efficacy.²⁶ The website www.hello-again.co.uk was designed for young people transitioning from children's burns services to adult burns services. It "aims to provide a helpful source of information for young people, their parents/carers and health professionals, to ensure that anyone making this move into adult burn care or away from care within the children's hospital setting will find the experience as smooth as possible." The website was created by

the Clinical Psychologist's Service Development Group of the Northern Burn Care Network (NBCN), in collaboration with young people attending the Royal Manchester Children's Hospital Paediatric Burns Service and Burns Camp, and young adults attending the Manchester Burns Service and National Young Adult Camp, funded by the charity Dan's Fund for Burns.

The hello-again website was designed around the needs of young patients within the NBCN, rather than those of the individual organisations. The information presented was created via discussion with staff, patients, and others in the communities they serve. It provides material on living with a burn injury, stories from others who have made the transition from a paediatric to an adult burns service, advice, and details of all of the services within the NBCN. As with all websites, it is important that someone takes ownership of the site and maintains up-to-date information for those who access it. In order to provide equitable patient care nationally, it would also be helpful if all services could contribute to this valuable resource. This would avoid repetition of information if other services were to create a similar resource, and could reduce the risk of user confusion when searching independently for such information.

The provision of patient education may also contribute to the empowerment of our patients, furthering their knowledge about their treatment and skills in self-care. For example, beneficial effects of patient education related to patient empowerment within cancer care include increased knowledge, skill development via better decision-making, increased satisfaction, and better quality of life.^{27, 28} The delivery of educational information could take place via a variety of mechanisms, ranging from interactive decision tools, to services that interactively deliver cognitive behavioural therapy.²⁵

Online health information has hugely increased the volume of health information available to patients. Although it is common for people to search for health information online,²⁹ professionals should be mindful that patients' capacity to digest, interpret, and act on such information in an efficient manner may not have advanced as quickly as the volume of information. Feeling overwhelmed by information could cause some people to disconnect from their healthcare.²³ Therefore, it is important that professionals tailor resources to meet patients' individual needs. Research has shown that recipients of information are more likely to respond emotionally, cognitively, and behaviourally to messages tailored to match the ways they typically process health information.³⁰ Another benefit of online information is that this can be done; information presented on websites can be more easily tailored to individual needs than giving everyone the same paper-based resource.

Patient support

The National Burn Care Standards¹² currently state that, for both child and adult services, “a support group should be available whereby patients, their families and/or carers have access to peer support from others who have experienced burn injuries.” The standard that, “all patients, their families and/or carers (should) have information and the opportunity to access an age appropriate burn support group” demonstrates an awareness that burns self-help and support groups are valuable, and that their existence should be encouraged. However, in practice, few burns services within the UK provide self-help and/or support groups.³¹

Batchelor and Williams³¹ found that, in the UK, burns support groups start with some enthusiasm but dwindle due to a lack of patient interest. A website such as www.healthtalk.org may be one solution to providing accessible peer support for patients and family members affected by burn injuries. Although this site does not host burns-specific

information, it is an example of how free, reliable information about health and illness issues can be provided by sharing ordinary people's real-life experiences. Visitors to this website can watch people sharing their stories about cancer, autism, motor-neurone disease, pregnancy, drugs, depression and much more. Perhaps patients with burn injuries would value the opportunity to contribute to a similar resource, as well as using it to access other people's experiences and learn about how they coped.

A similar endeavour might seem costly; however, if a health economics evaluation was conducted on such a resource, it could prove a cost-effective strategy for providing person-centred care compared to alternative approaches. For example, charities, trusts and government departments fund healthtalk.org; each health condition covered is funded by a different organisation. Peers for Progress³² also describe the substantial emerging evidence indicating that peer support programs in a variety of areas of healthcare and prevention are cost-effective. Although, it is important to examine how peer support for people affected by burns could contribute to quality improvement in care and positive return on investment, as different settings and audiences can lead to different business cases of costs, strengths and added value.

Research suggests that peer support is able to offer something over and above that of the family, providing knowledge and reassurance about the condition, coping strategies, inspiration, encouragement and a sense of hope, whilst also decreasing isolation.³³⁻³⁵ In addition to this, studies of burns support groups have shown that people prefer to speak to others who have been through similar experiences and therefore have a better understanding of their situation.^{36, 37} Positive experiences of compassion, expressed and shared in a supportive peer group setting, can be an important source of change when difficulties are experienced.³⁸ However, concern about judgement from others due to shame and/or guilt can

act as a barrier, preventing people from accessing support for themselves.^{39, 40} Perhaps technology can help to overcome barriers such as these, providing anonymous and/or asynchronous support to those who feel too vulnerable to seek face-to-face support.

As well as offering some degree of anonymity, online support groups or bulletin boards can support patient autonomy. Patients and family members can exchange experiences with peers and ask about their most troublesome problems to gain practical advice from those who have shared similar issues. These services are often unstructured and the quality of feedback can be limited by the fact that peers may receive different treatments and lack proper medical knowledge, yet they can be perceived as supportive.²⁵

The website www.talkhealthpartnership.com utilises this model and is a platform for people to “have their say” on current health issues and a place to find information on varying chronic ailments and health concerns. It hosts online clinics, ‘ask the expert’ question and answer sessions, and covers updates on advances in research and treatments for each health condition included on the website.

Groen et al.²⁵ report results of controlled studies on forums and bulletin boards ranging from positive effects on depression, cancer-related trauma, and perceived stress,⁴¹ to no effects and negative effects on psychosocial distress and quality of life.⁴² Therefore, it is also important for professionals to be mindful of the fact that hearing about other people’s experiences, and gaining advice from non-professionals, may reinforce patients’ unhealthy behaviours.⁴³ Consequently, when advocating such a resource, professionals and patients need to be aware of the risks and the fact that these sites may lack moderation by suitably qualified healthcare professionals.

Outcome measurement

Like chronic conditions, burn injuries and their permanent consequences require long-term monitoring and treatment both in inpatient settings and within an outpatient framework. It is therefore important that burn care and rehabilitation is both clinically and economically effective in order to ensure a sustainable healthcare system.⁴⁴ The Chronic Care Model⁴⁵⁻⁴⁷ promotes self-management skills, tracking, and information sharing about health status and treatment programs, maintaining a focus on the individual and family, social, and community networks⁴⁸ – this model may facilitate a sustainable system within many areas of healthcare, including burn care.

Outcome information, such as that relating to health status, adherence to treatment regimes, and psychosocial wellbeing, promises to bridge the gap between what is done and what is actually accomplished.⁸ Through research embedded in clinical practice, such information allows insight into where improvements can be made in practice. High Quality Care for All, the NHS Next Stage Review,⁴⁹ highlighted the importance of using patient reported outcome measure (PROM) data to evaluate healthcare services, and to inform commissioning and regulatory decision-making. In response to this, NHS England introduced the mandatory use of PROMs for all NHS trusts. PROMs are currently being developed for use within burn care after a recent systematic review identified the lack of burn-specific PROMs available to evaluate burn patients' needs.⁵⁰

Patients treated by specialist burns services within the UK receive psychosocial screening;^{12,}⁵¹ often this involves discussion within the MDT, paper-based questionnaires, or checklists.²¹ With healthcare systems constantly struggling to find ways to provide higher quality care in a cost-effective manner, perhaps there is a role for computer-mediated data collection. Mobile health (mHealth) is the practice of eHealth supported by mobile devices, such as tablet

computers and smartphones. These devices are used to capture, analyse, store, and transmit health-related information from various sources, including personal inputs, sensors, and other biomedical acquisition systems.⁵² mHealth could provide an efficient method of collecting health-related outcome data from patients within hospitals and their own homes (providing infection control and data protection policies are adhered to), facilitating timely psychosocial screening and collection of PROM data. In line with this, iPads have already been employed in a small American trial gaining positive feedback from staff and patients.⁵³

The use of online PROMs could be another practical solution for collecting patient outcome data whilst not impinging on clinicians' consultation time. For example, www.proms2.org is an online PROMs programme developed in the NHS to collect outcome data for any patient group. Clinicians can determine which PROMs they want their patients to complete and upload them into the online programme. Patients are then given access to the secure online system via automatic links within emails, sent before and after they receive their care. Once data is collected, there is an option for both the clinician and the patient (where appropriate) to receive automatic explanations of the data. These reports can reduce the burden on time often experienced by clinicians when having to manually enter data or analyse responses to questionnaires.⁵⁴ In addition to this online PROMs programme, burns-specific PROMs will soon be available for use from www.careburnscales.org.uk.

eHealth systems have the ability to interpret and explain patient data, present it graphically, include norm values and cut-offs (where available), before automatically exporting it to the patient's personal health record systems via a secure connection. It is likely that this would be highly valued by staff within busy burns services. Benefits for patients could be appointments that are more focused and efficient. There would also be the potential for their symptom scores and, for example, quality of life rating, to be linked to personalised suggestions/tips

about how to approach these issues with the relevant professionals, or direction to web-based interventions to enhance coping and alleviate symptoms.

Through regular standardised assessment of symptoms, such as anxiety, depression, the impact of the burn event, and appearance concerns, clear feedback could be provided to patients and professionals about progress in psychosocial rehabilitation. This could increase awareness of health status and psychosocial concerns, and how these may change over time. Such information could facilitate communication between all parties and potentially contribute to more effective appointments.^{53, 55} When considering ways to engage and empower patients, it would also be useful to assess the feasibility of supplementing standardised assessments with additions similar to the Patient Concerns Inventory.⁵⁶ This could assist patients in identifying the most significant problems/challenges they are facing, as well as their personal goals, enabling professionals to follow-up on factors that are personally and individually important, rather than purely standardised outcomes. Another use of eHealth could be to send prompts via email to patients that facilitate them in preparing for hospital visits and formulating specific questions for healthcare professionals. These could be generic prompts or based on the patient's individual PROM data, as discussed above.

There is growing interest in using new mobile technologies for the enhancement of chronic disease self-management. Self-management activities could include symptom monitoring and medication adherence, and patient education regarding issues such as diet and physical activity in order to encourage healthier lifestyles.⁵⁷ Patients can be frustrated by having to attend hospital for routine appointments. Therefore, if data could be sent directly to professionals, at pre-determined intervals or when a patient has concerns, perhaps the frequency of hospital visits could be reduced. mHealth could provide channels through which images could be shared, for example a photograph of a healing wound that is causing a patient concern, or in order for an occupational therapist and patient to track scar maturation

over time. Whilst technology will not replace the professional at the other end, it could provide immediate access to medical advice; it could also make appointments, when needed, more efficient. The technology for this is already available (see www.tytocare.com for an example), however, there would need to be evaluation of the feasibility and use of such technology to ensure that any development in UK burn care was evidence-based.

Psychoeducation for staff

As well as using the internet to educate and communicate with patients, perhaps the internet can also facilitate education of staff. Psychologists within burn care are often involved in delivering psychosocial education to the MDT. With staff on different shift patterns, and in the busy hospital environment, it can be difficult to deliver training to a wide enough audience to make a significant difference to practice. Technology can allow professionals to access training resources at a time and location that suits them best. Such educational packages are often interactive and hosted either on the internet (see www.mooc.org), on PC software, or CD-ROM.²⁵ However, the emergence and dispersion of an ‘app’ culture means that the normal mode for accessing information is now via mobile phones.⁵⁸

It could be that a group such as the British Burns Association Psychosocial Special Interest Group, who already has members delivering such training nationally, could work with charities to develop a regularly updated MDT-directed training app or website to allow the wider dissemination of training modules. Modules could cover important topics such as self-harm, screening, pain management, patient experience, and managing patient-behaviour that challenges teams. Automated emails could be sent to subscribers and services to indicate when updates have been made to the information and to encourage further training.

Establishing a successful eHealth system

Research has already demonstrated that psychological intervention is clinically effective. However, in the current climate of the health service, it will be increasingly important to demonstrate that services with the provision of clinical psychology are superior and more cost-effective than those without. As shown above, the development of e/mHealth initiatives could enable psychologists to provide assessment, intervention, training, and consultation to a wider and more remote audience, providing long-term cost-effectiveness. However, there are many ethical issues that would need careful thought before such initiatives could be rolled out; Davis⁵⁹ provides a discussion of such issues.

Regardless of how health services might decide to utilise technological advances, the active clinical engagement of patients is important if they are going to use eHealth technology. In order to engage users, it is important that the technology is patient-centred, attractive and intuitive for patients with varying levels of traditional and eHealth literacy and sociodemographic characteristics.²⁵ eHealth needs to offer a menu of options to patients so that care is personalised and adaptable. The technology needs to support the patient, providing them with something they would not otherwise be able to access. It is also important to ensure that technology is not taking something from the patient, whether that be autonomy or privacy.

Clinical psychology and medicine both have to face chronic care management challenges such as limited patient engagement, limited patient health literacy, and patient readiness to change. Professionals might also be reluctant to change the way they practise, preferring to see patients in a traditional manner.⁶⁰ If progress is to be achieved, it is important that both traditional and eHealth care environments develop evidence-based protocols, a stepped-care approach, and organizational models that increase patient participation and attendance, and

achieve long-term patient psychosocial rehabilitation and cost-savings. Stepped-care, with the inclusion of eHealth initiatives, allows patients to access low-level self-management resources that can provide significant gains and the tracking of progress. This would leave more intensive and expensive medical and psychological interventions for those who did not benefit from first-line eHealth interventions, or where more specialised interventions are required from the outset.⁶¹ This could reduce the number and/or length of traditional hospital visits patients need to make, reducing costs to both the patients and the healthcare system.

When introducing eHealth to services and utilising mHealth systems, there are a number of practical and logistical challenges that need to be considered. Malvey and Slovensky⁶² noted specific factors that are key to the development of a successful care system utilising new technology. Specifically: 1) establishing and assuring privacy and security of data transmission; 2) eliminating regulatory uncertainty so that mHealth can progress; 3) producing rigorous evidence demonstrating that e- or mHealth has an impact on health, access to care, cost, quality, and patient satisfaction; 4) developing apps that focus on the end user to promote their adoption; and 5) establishing actionable goals for innovators, developers and policymakers to achieve sustainability and diffusion of technology to transform healthcare delivery.

Conclusions

Potential uses of new communication-focused technology and web-based interventions as a means of enhancing access to, and delivery of, psychosocial care have been outlined. e/mHealth can supplement good holistic burn care by extending clinical services to more remote locations, reducing unnecessary hospital visits, increasing efficiency, and promoting patient engagement in their own care. Whilst these are significant benefits, it is important that any new approaches to care are not at the detriment of the patient-professional relationship,

as technology can never replace the healthcare professional in a specialist service. Until the benefits of e/mHealth are evidenced, the ability of this technology to have a positive impact on healthcare can only be assumed by investors, providers and patients.

Stakeholders require practice-based evidence to confirm that e- and/or mHealth can achieve the intended goals in a cost-effective manner. For this technology to advance within healthcare, patients and professionals need to be engaged in its development as technology that does not meet the users' needs will not be utilised. It is also important that research determines the key information and support that could be valuable to patients and their families, and how this could be provided by existing health services, on- or offline, within the stepped-care framework. When carrying out this work, researchers should be mindful of the variety of coping styles exhibited by individuals and their different preferences for receiving such information.

Future research should compare traditional models of psychosocial care provision within burn care with stepped eHealth-facilitated approaches. First steps within British burn care could be to roll out telemedicine systems (to assist in discussions between services and for ongoing patient care) and to standardise the clinical record/information systems used across the networks. It is often the case that the development of novel healthcare interventions ceases when external funding expires. Therefore, it is vital that the British Burn Association, and the networks within it, consider new ways funding sustainable services, in collaboration with the NHS and Clinical Commissioning Groups, given the current economic crisis of the healthcare system within the UK.

Funding: This work did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflicts of interest: None.

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