Beyond dialysis — telehealth initiatives

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Abstract

Background

In August 2009, Australia's HOME Network was established as a national initiative to engage and empower health care professionals working in the home dialysis specialty. The aim was to develop solutions to advocate for and ultimately increase the use of home dialysis across Australia. Emerging telehealth (technology) initiatives were identified as potential facilitators for home dialysis.

Aim

The aim of this paper is to develop a Position Paper on Telehealth for Renal Dialysis that is based on a review of the latest developments in telehealth services in home dialysis and other clinical areas within Australia.

Methods

In early 2014, the HOME Network Technology Working Group conducted a literature review to determine the opportunities for telehealth utilisation in home dialysis. Prior to considering how to advance the use of telehealth in home dialysis within Australia, the HOME Network members undertook a survey to collate information on how many home training units in Australia were using telehealth opportunities and to determine what hurdles there may be to the initiation of telehealth utilisation.

Results

There are limited publications about telehealth used in Australia to advance patient care in home dialysis. However, innovations have been reported informally as emerging from a number of home dialysis programs/units around Australia.

Conclusion

The information reported in this paper will support and drive greater collaboration with respect to the use of telehealth, and a broader awareness about the possibilities available that allow us to provide better support to all Australian home dialysis patients.

Keywords

Renal dialysis, telehealth, chronic kidney disease, home dialysis.

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Introduction

The development of telehealth initiatives designed to assist in the delivery of care and support for people on home dialysis is a logical step in the provision of effective community-based care. There have been significant investments in innovative telehealth projects within Australia since the mid-1990s. In 2001, the National Telehealth Plan (National Health Information Advisory Council, 2001; Department of Broadband Communication and Digital Economy, 2011) was released relating to the need for a coordinated approach to telehealth services delivery. Despite the development of this national framework, telehealth has continued to evolve in an *ad hoc* way, with some substantial developments in the hospital sectors, but limited support for the primary care and specialist sectors.

The aim of this paper is to develop a Position Paper on Telehealth for Renal Dialysis that is based on a review of the latest developments in telehealth services.

Background

Rapid advancements in information and communication technology (ICT) have created great potential for re-shaping the way health care services are delivered. Through harnessing evolving technologies, telehealth has the potential to play a significant role in improving the quality and equity of patient care and reducing inefficiencies in health systems (Agroyannis *et al.*, 1999a; Hoy, 2004; Tunstall Healthcare, 2013). Such initiative includes the HOMER-D project (home rehabilitation treatment-dialysis) in Athens and Italy. HOMER-D was a research project designed to develop, apply and validate telematic monitoring services for supporting home and satellite haemodialysis patients (Agroyannis *et al.*, 1999a; Agroyannis *et al.*, 1999b). It comprises a central control station (CCS) for clinicians and a modified haemodialysis machine. Online remote supervision of the haemodialysis machine and clinical condition of the patient (for example, blood pressure, pulse rate, pulse oximetry, and ECG) are all managed by the CCS and fed back to the clinician (Francoeur & Digambatista, 2001; Skiadas *et al.*, 2002; Schlaeper & Diaz-Buxo, 2004 & 2005). The preliminary finding was positive.

There are different views about the most appropriate definition of 'telehealth'. Some stakeholders include telephone calls and web-based information services, while others deem these to be outside the definition of telehealth. However, according to the New South Wales Agency for Clinical Innovation (2014), telehealth is the secure transmission of images, voices and data between two or more units via telecommunication channels, to provide clinical advice, consultation, monitoring and training, and administrative services. Telehealth is the delivery of health care at a distance, using ICT (Wade, 2014).

Telehealth-enabled models of care are consistently reported as providing a range of benefits to patients (more accurate and timely diagnosis, reduced cost and inconvenience associated with less travel); families and carers (reduced burden, larger networks of care as more carers/family members can attend consultations); health care workers (better networking and collaboration, reduced time spent travelling); and the health system (reduced expenses related to patient transport, reduced inequities in access to health services) (Tunstall Healthcare, 2013; World Health Organization, 2010). Other recent studies describe the benefits of telehealth usage across Australia, further demonstrating the benefit to patients (Jang-Jaccard *et al.*, 2014).

This paper includes a review of the latest literature and developments in telehealth to determine the opportunities for technology utilisation in home dialysis services. It also reports a recent online survey which was developed to assess the current practice in telehealth technologies/approaches in the home training units in Australia/New Zealand. In addition, it includes an outline of a number of innovations which have been reported informally as emerging from a number of home dialysis programs/units around Australia.

The home dialysis technology survey

The HOME Network was established in 2009 and includes key stakeholders within the home dialysis community in Australia (Chow *et al.*, 2013). Currently the HOME Network has up to 18 members from across Australia and representing metropolitan through to regional and rural perspectives. Members bring expertise in nephrology nursing and education (pre-dialysis, home dialysis), strategic management, and allied health.

In early 2014, the HOME Network Technology Working Group conducted a literature review to determine the opportunities for technology utilisation in home dialysis. Prior to considering how to advance technology use in home dialysis within Australia, the HOME Network members undertook a survey to collate information on how many home training units in Australia were using telehealth opportunities and to determine what hurdles there may be to the initiation of telehealth utilisation.

Methodology

A six-question online survey was developed to assess the current practice in telehealth technologies/approaches in the home training units in Australia/New Zealand. It also assessed the perspectives, barriers and evaluation of these current practices. ICTs included in the survey were email, phone apps, mobile phone messaging, Skype, online machine monitoring, iPads, video camera images and other. Free text responses allowed participants to elaborate on how technology was being incorporated into daily practice.

The questions were piloted with members of the HOME Network, refined, and then the survey link was sent by email to every renal unit offering home dialysis training services across Australia/New Zealand. Units were asked to respond if they were using some forms of telehealth to support home dialysis. A reminder was sent one month later. The survey was promoted in the HOME Network Newsletter. Frequencies and means were calculated using Microsoft Excel. Open responses were thematically collated.

Results

Distribution of responding home training units: All home training units were metropolitan-based, which reflects the usual location of home training facilities (Table 1). Twenty-one out of 47 home training units across all states and territories responded to the survey, representing a 43% response rate.

Use of technologies: Of the 16 home training units that responded to this question, a total of 35 different uses of telehealth were identified, with a mean average of 2.2 uses per unit (range was one to five uses). (Five home training units that

Table 1: Distribution of responding home training units

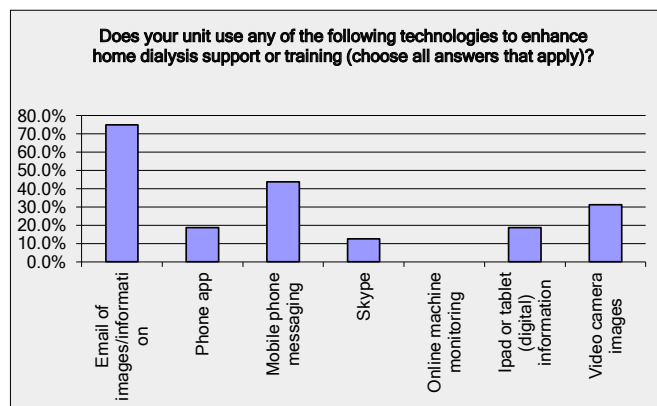| State	Number	Percentage
Vic	6	29
NSW	5	24
QLD	2	10
Tas	2	10
WA	2	10
SA	1	5
NT	1	5
NZ	1	5
ACT	1	5
Total units	21	100

Figure 1: Use of telehealth technologies to enhance home dialysis support or training

registered for the survey did not respond to this question.)

The most common use of telehealth was via email (12 units, 57%) (Figure 1). Free text responses indicated that email was widely accepted for sharing information (in both directions between patients and health care professionals) and was used for general 'catch-ups'. There was limited use in terms of sharing images.

Seven units (33%) used mobile phone messaging, primarily as a reminder for appointments. Five units (24%) were using video camera images to support home dialysis training (video watched back by patients and trainers), capture images and for ongoing monitoring. Two phone apps were described for management of medication and peritoneal dialysis prescriptions (early phase trial). A home haemodialysis monitoring app was also reported in their early phase of development, and will be discussed later in this paper.

Telehealth used to a lesser extent involved iPads used as a hand-held device for training (three units) and one unit reported using videos on YouTube for patients to access to upskill themselves about rarely used procedures related to haemodialysis machine maintenance.

Willingness to share telehealth experience: Home training units that were using telehealth were willing to share their experience, although most felt their experience was standard and had not evaluated their use in any way. Two telehealth-based programmes are currently being formally evaluated and the sites were willing to share data when results are finalised.

Confidentiality and telehealth: Home training units felt there were no confidentiality issues associated with telehealth use (10 units) or were unsure of confidentiality restrictions (nine units), despite currently using telehealth. Only two units reported that they were aware of confidentiality and data transfer issues in their state. One of these units reported that confidentiality impacted on patient care, who were required to travel to attend appointments instead. Assuming all units should potentially be aware of this as an issue or at least have policies, units were asked to elaborate on how telehealth is managed from this viewpoint. Only three units responded to this free text question. There were no responses to suggest any participants were aware of any policy related to telehealth use and patient confidentiality. One unit responded that their information technology department required them to put their hospital logo on the developed videos.

How is technology being used to advance patient care in home dialysis?

Overseas, there is a growing body of literature documenting various e-health technology and initiatives to advance patient care in home dialysis. These initiatives are primarily summarised into two categories, as below.

Real-time telemedicine: The procard or smart card from the peritoneal dialysis cycler (Automated Peritoneal Dialysis, APD) is one example of real-time telemedicine which has been used for data storage to assist in data collection and treatment monitoring (Mitchell, Disney & Roberts, 2000; Ghio *et al.*, 2002; Gallar *et al.,* 2007; Chand & Bednarz, 2008). Modem technology has been added to the procard for transmission of real-time data, and remote monitoring and problem solving over videoconferencing with patients while they are having dialysis at home. This telecommunication strategy has been reported in reducing travel time and promotes home dialysis (Cresswell & Hicks, 1996; Rygh *et al.*, 2012). Unfortunately, there are no clear quantifiable outcomes utilising this devise.

Remote monitoring: Over the past several years there has been growth in the number of dialysis units performing remote monitoring in nocturnal home haemodialysis (particularly during the first three months). The technical options available for remote monitoring have grown, and creative approaches have helped to overcome previous limitations (Hoy *et al.*, 2004; Morgan, Schlaeper & Lockridge, 2004; Cafazzo *et al.*, 2010; Polaschegg, 2010).

What can we learn from technology use in other clinical areas?

In Australia, the Commonwealth Department of Health provides policy direction and funding for telehealth services in Australian jurisdictions. This includes managing and distributing reimbursements for telehealth services under the Medical Benefit Scheme (MBS), funding provided through Activity Based Funding (ABF), and provision of purpose-specific grants (for example, Telehealth Pilots Programme) (Department of Health, Commonwealth, 2014).

In Australia, telehealth is more widely used in regional, rural and remote regions, particularly as a means of overcoming difficulties in accessing health care and the lack of experienced health care professionals experienced in these areas (Medical Technology Association of Australia, 2012). Telehealth consultations can only be billed through Medicare for patients who reside outside a metropolitan area, creating a financial disincentive for using telehealth services with patients who live within a metropolitan area. In Australia, telehealth is used in some clinical specialties to deliver outpatient services as well as for clinical education, training and workforce support (Hunter New England Area Health Service, 2010).

Telehealth initiatives in Australia

There are limited publications about telehealth use in Australia to advance patient care in home dialysis. However, there have been informal reports about innovations emerging from a number of home dialysis programs/units around Australia, some of which are profiled below.

Phone apps

The World Health Organization has defined the term "mHealth" or mobile health as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices" (World Health Organization, 2011). Widespread use and adoption of smartphones, tablets and other hand-held mobile devices in Australian society has meant applications for mobile devices (apps) are increasingly becoming part of everyday life for all age groups. Increasingly, apps are being developed that can help people manage their health and their disease with greater ease (Sutton and Fraser, 2013). Apps can provide patients with simple tools to organise and track their health record, assist patients to access information when and wherever needed, and can aid effective communication with health teams (World Health Organization, 2011). The development of apps designed to assist in the delivery of care and support for people with chronic kidney disease who are on home dialysis is a logical step in the provision of effective community-based care.

Blacktown/Nepean Hospital (NSW): home haemodialysis phone app

Funding

In New South Wales (NSW), a home haemodialysis app is being developed and evaluated by Western Renal Service Sydney West as part of a government-funded pilot project for Remote Patient Monitoring via Web-based and Smartphone Apps (Baldacchino & Kim, 2014). The project aims to utilise an innovative model of service delivery using new technologies to provide ongoing support, communication and monitoring for home haemodialysis patients, regardless of their geographical location. It is being developed through collaboration between the Western Renal Service, NSW, and the Nepean Telehealth and Technology Centre (NTTC)/Institute of Biomedical Engineering, The University of Sydney.

Capability

The app can be downloaded onto an Android or iOS device. Potential issues such as confidentiality and security have driven how data is handled. The patient enters data into a personalised, password-protected app (replacing the patients' conventional data entry into an exercise book). Data entered digitally into the app allows for remote monitoring of treatment parameters in real time by the home training unit and the nephrologist, allowing preliminary assessments of dialysis parameters without needing a face-to-face consultation or home/clinic visit.

Features

App features developed to date include: supports patient recording of HD parameters (pre and post blood pressure, pre and post weight, blood flow rates, arterial and venous pressures, ultrafiltration goals, hours of treatment); provides automatic notifications for pre-set treatment parameters (high blood pressure, intradialytic weight gain higher than three kilos, long gaps between dialysis days); provides summary of trends/graphs on clinically significant parameters; utilises a highly secured cloud server, with encryption and password protection; is accessible from multiple sites by health care professionals with unique login credentials; supports printable versions; allows recording of medications for easier analysis of patients' issues; and has an additional comments section to alert staff about non-urgent matters.

To date, 76 out of 124 prevalent patients are actively using the app, which has been incorporated into the unit's home training syllabus. Patients are assisted with app download while in the unit. Approximately 14 patients are remotely reviewed per week. Phone calls/emails are made to discuss treatment data available online, rather than visiting patients at home. Changes to dialysis prescriptions, number of home/unit visits avoided by nursing staff or patients, travel distance and time saved are being recorded prospectively as part of the ongoing evaluation of the app and staff are engaged in evaluation of technical issues encountered.

Evaluation

Preliminary evaluation has shown patients have an increased feeling of security, through feedback such as: "nurses can see what's happening", "I don't feel so isolated anymore", and "notifications are helpful in reminding me about my fluid restrictions". To date, substantial cost savings in terms of travel time and distance have been identified, plus additional hours of nursing and patient time saved due to home or unit visits

avoided. Full analysis of the app evaluation results and impact are under way and due to be reported in 2016.

Geelong Hospital (VIC): home haemodialysis phone app

Funding

Funded by Baron Health, The University Hospital Geelong home haemodialysis app aims to offer a new channel for communication with their home dialysis patients.

Capability

The renal unit currently communicates with and manages client contact using telephone, email, SMS and Facebook. The app aims to create a user-friendly system that offers an alternative to hard-copy versions of dialysis record sheets, stocktakes, medication reviews, discussion and reminders for routine blood results, and so on. By linking the app with the unit's current renal management programme and electronic health record (RenalNet), the documentation of contacts, stocktakes, dialysis runs and machine problems will be automatic and easily accessible for all staff. It is anticipated that the reduction of data entry by nursing staff will allow for more patient care time. It will free up staff to enable more efficient training of new patients, provide respite and offer greater support and education opportunities. The app aims to compile all dialysis care into one application, thereby improving care and connectedness with patients, especially those in rural and remote areas.

Features

Compared to the Blacktown home haemodialysis app, it is hoped that the Geelong app will link not only to the current renal program, but to the patient's electronic health record. In doing so, it will provide patients with access to current medication charts, prescription changes and blood results. Patients will be able to refer to and confirm current treatment orders via the app. Furthermore, the Geelong app will provide patients with the facility to send messages to staff directly from within the app.

Initial stages of development have been completed, interface designs have been tested with patients and received positive feedback, and the next stage of programming is under way. In order to advance and develop the app for broader, trouble-free use, the Geelong team aims to partner with the developer of the unit's existing electronic health record system to create an app that is not only user-friendly but useful and of clinical value to both patients and clinicians.

Evaluation

Evaluation of the Geelong app will include assessment of take-up and patient engagement (supported by all home dialysis patients being offered a tablet device to facilitate use of the app, plus education about how to use the app effectively) and recording of which features patients use the most. Demographic data will be recorded and patients will be invited to provide formal and informal feedback on the app.

Other telehealth projects

Telehealth is rapidly expanding within the fields of health and ICT, allowing health care workers to act in response to accurate and up-to-date health care information, and leading to improvements in the quality and efficiency of health care delivery. The use of telehealth approaches will also assist in improving provision of health care services to patients in rural and remote locations, who are currently disadvantaged in terms of access to health care when compared to patients within metropolitan areas (World Health Organization, 2011).

South Australian telehealth initiative

In South Australia (SA), telehealth consultation using video conferencing is being used to provide clinical decision support, and improve communication with patients and between health care providers to drive improvements in health care provision. Telehealth approaches can also support improved health education and clinical communication amongst health care providers. They can encompass all stages of health care, from prevention to diagnosis and treatment, as well as ongoing patient monitoring/management.

With respect to dialysis patients, telehealth consultation offers the opportunity to improve health outcomes at all levels, from preventive health, to acute care and self-management of chronic conditions. The ability to transmit voice, data, images and information between patients and their health care team during a dialysis procedure assists the team to deliver supportive health services to patients in remote areas, thereby reducing the need for either patients or health care professionals to travel.

In 2013, the Rehabilitation in The Home Project was implemented, including a communication programme that utilised videoconferencing technology similar to Skype (Under SA Health regulations, using Skype is not permitted due to the Confidentiality Act). The aim of the programme was to use innovative communication approaches delivered via iPads to improve patient management during rehabilitation programmes (Flinders University, 2013).

A proposal to implement a similar programme for home dialysis patients was submitted by the home training unit at Central Northern Adelaide Renal and Transplant Services to SA Health with the support of SA Digital Telehealth Network (eHealth Systems). At the time of the proposal, there were 130 patients across SA performing dialysis independently at home. Approximately half of these patients lived remotely in areas with no local support. By using innovative communication technologies, the unit sought to provide more frequent face-to-face assessments and maintain contact with patients via telehealth approaches. The proposal requested approval to allocate to the unit two generic desktop videoconferencing accounts that could be used by the unit and patients to take part in health care assessments. Research undertaken to support the proposal included a cost-benefit analysis, defining of legality issues, and identifying and addressing other potential concerns. This found that telehealth approaches could be expected to reduce cost and inconvenience by reducing travel, support more accurate and timely diagnosis, improve patient outcomes and, importantly, provide improved support to patients performing dialysis at home.

It was decided that the home training unit at Central Northern Adelaide Renal and Transplant Services would undertake a trial project. Five patients who already had iPads and internet connection were recruited to the project, which used Cisco-Jabber for videoconferencing (approved by SA Health). An iPad was purchased for the unit and Cisco-Jabber was installed.

To date, patients in the trial are contacted weekly, or more frequently if required or if any issues arise. Only one point-to-point call runs at any one time over the IP network. Technical support for patients in their home is the responsibly of the home training unit. Data is being collected for future analysis and evaluation, which is due to be reported in 2016.

Discussion

The utilisation of telehealth in home dialysis is rapidly expanding within Australia, with examples including use of smartphone/tablet apps, web/videoconferencing applications to facilitate teleconferencing with patients and carers, and smart cards for data storage in automated peritoneal dialysis machines (Cresswell & Hicks, 1996; Chand & Bednarz, 2008).

There is no doubt that these telehealth initiatives can enhance our current ability to provide care to patients in the home and track important health information (World Health Organization, 2011), the benefits of which are just starting to be evaluated such as what have been reported from the HOMER-D project (home rehabilitation treatment-dialysis) in Athens and Italy.

HOMER-D was a research project designed to develop, apply and validate telematic monitoring services for supporting home and satellite haemodialysis patients (Agroyannis *et al.*, 1999a; Agroyannis *et al.*, 1999b). It comprises a central control station (CCS) for clinicians and a modified haemodialysis machine. Online remote supervision of the haemodialysis machine and clinical condition of the patient (for example, blood pressure, pulse rate, pulse oximietry, and ECG) are all managed by the CCS and fed back to the clinician (Francoeur & Digambatista, 2001; Skiadas *et al.*, 2002; Schlaeper & Diaz-Buxo, 2004 & 2005). The preliminary finding was positive.

Early use of telehealth is already raising the issue of privacy, confidentiality and data security when implementing any telehealth application (World Health Organization, 2011; Sutton & Fraser, 2013). An example of this is regulations in SA that prohibit the use of Skype due to confidentiality concerns (Flinders University, 2013). Responses to the survey conducted by the HOME Network identified gaps in health professional awareness and legislation regarding privacy and security issues relating to transmitting patient data. While health care consumers may be happy to release information to their health care team, care must be taken to ensure this information is not used or accessed in ways that the consumer has not agreed to. Gaining informed consent from patients to use any form of telehealth technology is mandatory; patients must be made aware of their right to refuse the use of telehealth if they do not feel comfortable.

Increased access to patients' information also poses a dilemma for health care professionals as to what their responsibilities are to act on information received (Department of Health, Commonwealth, 2014). For example, are they required to intervene when it is obvious that patients are not performing their home dialysis as per the recommended guidelines? Previously this situation went largely unnoticed, but with greater awareness may come greater obligation to act if a patient is putting themselves at increased risk (Gallar *et al.*, 2007; Jang-Jaccard *et al.*, 2014). Some health care professionals have also questioned whether taking such action is in fact taking away the very thing home dialysis offers — the independence and autonomy for a patient to manage their own condition. To date, the Blacktown (NSW) experience of using their home haemodialysis app is showing that patients feel more secure and do not feel they are being watched inappropriately.

From a nursing perspective, telehealth offers benefits in terms of quicker access to patient information and less time spent out of the unit to visit patients at home, while still maintaining that crucial 'face-to-face' contact (Prado *et al.*, 2002 & 2003;

Baldacchino & Kim, 2014). Some possible disadvantages associated with greater use of ICT include increased workload for nurses due to data entry requirements, and greater responsibility to address real-time issues that arise. Implementation will usually incur an increase in budgetary requirements in infrastructure and to facilitate access and appropriate training. Barriers to implementation of telehealth initiatives cited at a global level include: competing health system priorities; lack of knowledge, evidence, experience/skills and/or policy to support implementation of telehealth initiatives; legal concerns; and lack of awareness regarding cost-effectiveness of such initiatives (World Health Organization, 2011).

Patient barriers to use of e-health technology have been identified. Technology can be daunting, particularly for older age groups, and there are often associated costs (Morgan, 2004; Jang-Jaccard *et al.*, 2014). Resistance to its use will occur where technology is considered intrusive and an invasion of privacy. However, in general, patients appear to be advantaged by increased use of ICT approaches; they should benefit from reduced hospitalisation and correspondingly less opportunity for 'institutionalisation' as well as reduced disruption to their lifestyle. Time and cost for travelling to the hospital should be reduced (Baldacchino & Kim, 2014). Patients are likely to feel more supported and less isolated, which is of particular importance for those home dialysis patients who live in remote locations.

Conclusion

Advancement in information technology has created great potential for reshaping the way health care services are delivered. As telehealth continues to evolve, it has the potential to play a significant role in improving the quality and equality of patient care, in particular for those patients living remotely. Via telecommunication channels it is increasingly possible to provide clinical advice, and improve awareness, knowledge, consultation, monitoring, and training and, in particular, support to patients performing home dialysis.

While researching this paper, the HOME Network identified a number of projects under way to develop applications or use ICT approaches to provide greater support to home dialysis patients (examples of which were profiled above). However, in many cases such projects were happening in isolation at the local level. According to the HOME Network technology survey, home training units that were using telehealth were willing to share their experience. As such, the HOME Network has recognised the need to provide a national forum (for

example, via its website http://thehomenetwork.weebly.com/) to share information about telehealth developments — from within Australia and elsewhere — that are designed to improve support for people with chronic kidney disease who manage their dialysis at home. By doing so, the members of the HOME Network hope to support and drive greater collaboration with respect to the use of telehealth, and a broader awareness about the possibilities available that allow us to provide better support to all Australian home dialysis patients.

Acknowledgements

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