IDENTIFYING A SET OF TECHNOLOGICAL FEATURES TO AID DECISION-MAKING FOR PROSPECTIVE LIVE KIDNEY DONORS AND RECIPIENTS

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IDENTIFYING A SET OF TECHNOLOGICAL FEATURES TO AID DECISION-MAKING FOR PROSPECTIVE LIVE KIDNEY DONORS AND RECIPIENTS

Research

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Abstract

Patients with end-stage renal disease are often faced with choosing between dialysis, deceased donor transplantation or live kidney transplantation. Both kidney donors and recipients need more information and knowledge about live kidney donor transplantation (LKDT) in order to make that decision. This project aims at identifying and recommending appropriate information technology features to address the information needs of donors and recipients in live kidney transplantation and assist them in their decision-making. This project pursued four research objectives: 1) identify the decision-making process with a focus on the decision points, choices and barriers experienced by live kidney donors and recipients; 2) review reported uses of technologies to address the information and decision-making challenges and identify beneficial features; 3) review whether existing systems have these features, and 4) provide a recommended set of technological features which may effectively address the information challenges of live kidney donors and recipients and assisting their decision-making in the LKDT process. We found that potential donors and recipients preferred to use online tools in four main areas: information, communication, management and decision-making. Existing transplant-related websites in Australia provided text and video links, search, downloads, email and some social networking features but lacked guidance with the LKDT process.

Keywords: live donor kidney transplantation; donors; recipients; information technology; decision-making.
1 Introduction

Chronic Kidney Disease (CKD) is a considerable and growing public health problem, which leads to serious illness and early mortality. According to the 2014 annual data report of the United States Renal Data System (USRDS) from the Centers for Disease Control and Prevention (CDC), an estimated greater than 10% of adults may have CDK in the United States - some 20 million-plus people. In 2011, 113,136 patients started treatment for ESRD in the United States. The 2012 European Renal Association—European Dialysis and Transplant Association Registry Annual Report In Europe (Pippias et al., 2015) covering 30 countries in Europe reports that on December 31st, 2012, 451,270 patients with ESRD were receiving renal replacement therapy (RRT) treatment. Typically, CKD has no early signs for people to discover, as such most people may be unaware they have symptoms of this disease. If the disease is detected late, people may reach end-stage kidney disease (ESKD), also referred to as kidney failure or Stage 5 CKD.

When the function of the kidney is no longer enough to sustain life, patients with ESKD require RRT for survival. There are various treatment options of RRT for patients, with four main options, including haemodialysis, peritoneal dialysis, deceased donor kidney transplantation (DDKT) or live donor kidney transplantation (LKDT). There are two kinds of transplantation, one is DDKT and the other one is LKDT. Since one kidney provides adequate function to remove waste from the body, another kidney can be donated from live donors who have two kidneys. It is widely accepted that LKDT is considered the optimal treatment among other treatments for patients with ESKD (Horvat, 2009; Ismail et al., 2012) because of better matching, waiting time and outcome.

The burden of ESKD on patients and family is significant. To address the lack of information and potentially assist with the decision making process of LKDT, it is necessary to identify and recommend appropriate information technologies to support families. Technology intervention can help to deliver available information at the right time and facilitate communication in order to address the barriers or concerns of potential donors and patients. The internet provides a chance for potential donors to research live kidney donation related information regarding risks to their health, the transplantation process, as well as procedures and financial considerations (Moody et al., 2007). Patients can use the internet to share their feelings and disseminate related information. Concurrently potential donors or patients can take their time to access information 24/7 with the internet. Additionally technology can help reduce the anxiety of potential donors and recipients in the decision-making process through avoiding face-to-face communication (Chang et al., 2013). Similarly, social media can be used to facilitate communication and generate support from others. Potential donors can converse with other live kidney donors about their actual experience. Patients can discuss their problems and search for potential live kidney donors.

This project pursued four research objectives: 1) identify the decision-making process with a focus on the decision points, choices and barrier experienced by live kidney donors and recipients; 2) review the reported use of information technologies to address the information and decision-making challenges and identify beneficial features; 3) review whether existing systems have these features, and 4) provide a recommended set of technological features which may effectively address the information challenges of live kidney donors and recipients and assisting their decision-making in the LKDT process. To achieve Objectives 1 and 2, we conducted a review of the relevant literatures, the summarised results of both are presented in sections 2 and 3, respectively. The methodology section, Section 3, describes how the decision support features identified from the literature reviews were used to evaluate current LKDT decision-support tools (Objective 3) and deliver a set of recommendations (Objective 4). The results of tool evaluation appear in Section 5, with recommendations in Section 6 and conclusions in Section 7.
2 Background: LDKT Decision making process

The LDKT process is used as a model to identify and discuss potential barriers of donors and recipients in each phase. It is important to understand the phases both potential donors and recipients pass through to achieve the final phase involving transplantation. Several studies describe the LDKT process. From the potential donor’s perspective, Sanner (2005) proposed seven steps to the donation process: 1. awareness of suffering, 2. imminence of transplantation, 3. information acquisition and deliberation, 4. attribution of responsibility to oneself, 5. examinations, 6. facing nephrectomy and 7. postoperative experiences. In addition, according to the guidelines for ethical practice for health professionals of the National Health and Medical Research Council, there are 8 steps (NHMRC, ) for living donation for adults including: 1. prospective donor considers living donation, 2. prospective donor provided with information on the purpose and process of evaluation, 3. assessments, 4. donor advocate appraisal of donation, 5. surgical team decision on donation, 6. competent donor gives consent to donation, 7. donation proceeds and 8. ongoing care of donor.

From the potential recipient’s perspective, Devitt et al. proposed 5 steps for patients considering transplantation (Devitt et al., 2008). The steps are: 1. being deemed medically suitable, 2. becoming informed and making appropriate decisions, 3. completing the preparation or ‘workup’ for transplant, 4. being placed on the waiting list and 5. receiving a transplant. Purnell et al. (2012) also suggested 4 steps to assess kidney transplants (Purnell, Hall, & Boulware, 2012) including 1. donor identification, 2. transplant evaluation, 3. kidney transplantation and 4. after LDKT. Given the intertwined nature of the donor and recipient decisions, we draw the patient and donor perspectives together in the seven phases and 6 decision points shown in Figure 1. This is a proposed model in which the sequence of phases will be different for different potential donors and recipients depending on their personal situation. In each phase, both potential donors and recipients may face their own decision-making point for considering processing further for transplantation (Fujita et al., 2006; Gordon, 2001; Simmons, Marine, & Simmons, 1987). For example, potential recipients who are eligible for a transplant can decide to keep moving towards receiving transplantation at any phase or may quit the process at any time and decide to remain on dialysis. The same situation applies to potential donors, they can proceed further to donate their kidney to reach the final phase of transplantation or withdraw from going ahead with the donation at any phase and the reasons of withdrawal should be kept confidential. These six phases are listed to guide the evaluation of an assessment.

![Figure 1. Transplantation process for potential donors and recipients with decision points](image-url)
We draw on the literature further to identify potential barriers and challenges for both donors and recipients at each phase of the decision-making process, such as the inability to communicate and insufficient information to decide (Hanson et al., 2015), anxieties and uncertainty (Finkelstein et al. 2003), etc. Figure 2 identifies each of the issues faced by patients and donors at each decision point and the supporting reference. The articles cited include surveys, interviews and meta-analyses of studies to capture voices of patients and donors. For example, donors may enter the “decide treatment options” phase because they feel duty-bound, sympathy, guilt, owe a debt towards the patient or desire to reduce the current daily burden of care of the patient (Ye, 2003). At the same phase, the barriers faced by the potential recipient are quite different and relate to lack of support (Sheu, 2003), information, skills or knowledge (Hanson et al., 2015). Figure 2 draws the literature together summarising the potential barriers to decision-making facing live kidney donors and recipients during the LDKT process, achieves the first research objective of this project.

3 Literature Review

To identify what information technology had been used to aid LDKT, we conducted a literature review following the methodology used in (Casey et al., 2014) and other researchers in the kidney transplant field (e.g. (Hanson et al., 2015). The method involved four steps: 1) identifying databases and keywords; 2) screening; 3) synthesis and 4) analysis. Following that methodology, we conducted a keyword search on MEDLINE, EMBASE, PsychINFO and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases reviewing articles from January 2000 through to August 2014. The first two authors were involved in the screening process to ensure included articles concerned live kidney transplantation and the use of information technology to provide support and/or aid decision-making for potential donors and recipients. Descriptive synthesis was used to extract key information from the article such as target population, the technology used, data collection method/s, analysis techniques and findings of the study. Finally the features of the technology were identified to provide a list of criteria for measuring current online sites.

In addition to 330 duplicates, many of the articles returned concerned deceased kidney transplantation, did not involve the use of ICT, or concerned surgeons or other non-donor/recipient groups. From an initial set of 1260 articles, only 10 actually concerned live kidney donation and the use of ICT to assist donors and recipients (Akoh & Caton, 2008; Bramstedt & Dave, 2013; Chang et al., 2013; Costello and Murillo (2014); (De la Torre-Díez & De La Torre-díez, 2012; Hanif, Read, & Clancy, 2012; Moody et al., 2007; Moore et al., 2013; L. A. Taylor et al., 2012; Williams, 2006).

These ten remaining articles consisted of six articles related to websites (60%), two articles related to web-based social media (20%), one article related to both a website and discussion forum (10%) and one article related to a web-based application (10%). Five articles originated from the USA (50%), two articles from the UK (20%), one article from Canada (10%), one article from Spain (10%) and one article from Australia (10%). Across the ten eligible articles, 15 different technology features were identified, presented later and listed in black with the technology review results in Table 2. We have classified these features into 4 types of tools: Information tools were used to present information or knowledge in structured ways through various means such as text links, videos, downloads or navigation search; Communication tools were used to communicate or interact with others through various means such as emails, chat rooms, forums, blogs or social networks; Management tools were used to create accounts to become a member on the website through registration; and Decision-making tools were used to provide additional structure and direction such as an evaluation function to provide immediate feedback. The set of technological features identified from the literature achieve the project’s second objective.
Figure 2. Summary of potential barriers of live kidney donors and recipients

4 Methodology

Our project aims to identify technology-based solutions for live kidney patients and donors and to aid them in the decision making process that leads up to transplantation. From an understanding of the literature on the decision making process, (section 2) and review of studies reporting the use of ICT to assist donors and recipients to identify useful technological features (section 3), we sought to identify whether current systems provide the support needed. While, there are methodologies for evaluating websites, such as WebSCORE (Qiao et al., 2011), that provide a reference model for website evaluation in general, our goal was to benchmark the top accessible sites against technology evaluated in the literature that was specific to LDKT, and given the life-critical nature of this decision, we provide an analysis of the sites according to accuracy and coverage, readability, relevance and appropriateness.

Using the features identified from our literature review, we began our evaluation phase of existing relevant websites. As prospective donors and recipients are likely to use a search engine in their decision-making process, a search was conducted via Google. A search was conducted in September 2014 on current transplant-related websites via searching Google using the term “live donor kidney transplantation”. Note that links to documents were ignored but links to sites were viewed as websites and the sites returned were specific to our geographic region. We sought to simulate the search that a potential donor or recipient might perform. From the search list, the first 50 websites were examined and the “useful links” section of each website was also searched. Only those transplant-related websites mainly from non-profit organizations or charities, state or national organizations, government sites or Health on the Net certified sites were extracted for assessment. These sites are likely to be recommended by the patient’s health care professional, as identified by our medical team. The websites are listed in Table 1 together with their name, URL and a description taken from each website. A score was created to assess the quality of each website on how well they provide technological support to potential donors and recipients. Each feature was awarded 1 mark if the website contained the feature and it was relevant to LDKT, 0.5 of a mark if the website contained the feature but its use was not related to LDKT and 0 marks if the website did not contain the feature at all. While we acknowledge that some features may be more important than others, the level of importance is likely to depend on the phase in the decision cycle and maybe specific to individuals. Thus, despite the crudeness of the scoring, to allow initial comparison, the marks of all features were summed up to calculate the total score of each website. Scores could be recalculated based on weights if specific motivation or preferences identified appropriate weights. The results of the review of current LDKT websites were analysed together with the needs and barriers identified in our LDKT decision process model and the literature, to formulate a set of recommendations. The first and second author worked together to perform the analyses.

5 Website Review Results

The results of applying our general scoring, in Table 2, show that Kidney Health Australia (website #3) obtained the highest score. Note that some new features were found in our review of the websites and these have been added in red. As information tools, we can see that most websites provided text links (100%), navigation/search (80%) and download functions (80%). Only 3 websites provided video (30%) to help site visitors further understand the information provided. Through our evaluation we identified some additional features, indicated in red. Graphics/images were used by (70%) to help describe information. Two sites used animation (20%) for expressing information. Graphics/images and animation can help make the information memorable and easy to understand. Additionally, three websites posted stories (30%) of patients or donors experiences of transplantation in websites; this allowed sharing of real experiences or cases of donors and recipients. One website provided ReadSpeaker function (10%) to give a voice to the website; this text-to-speech function helps pa-
Digital Health Initiatives

tients/donors who preferred to listen or had trouble reading the content online. Only 4 of the websites displayed the logo of ‘Health on the Net’ (40%). To aid communication, most of the websites provided email (90%) to allow site visitors to provide feedback or ask questions about the information on the websites or inform the site owner about broken links, out-of-date information etc. Text submission boxes (40%) were used for contacting site owners. Some sites stated they could not answer any medical-related questions, since individuals face different situations they should consult a doctor for professional advice. Social networks (90%), such as Facebook or Twitter, commonly provided patient or donor communication. Within their social network sites, most sites provided an images/graphics sharing function (80%) for end users. However, the coverage of content was very broad including deceased organ donation, kidney diseases, general health information etc. which was not really focused on LKDT. Only a few sites provided online forums/message boards (30%), live chat rooms (20%) or personal blogs (20%). None of the websites included wikis to allow site visitors to edit online content together and there was no evidence of telemonitoring or text messaging. Three additional communication features included (links to) video sharing - e.g. YouTube (40%), newsletters or announcements (80%) and one website provided RSS (Really Simple Syndication) (10%) or podcast (10%) to feed content or audio file to site visitors. Communication tended to focus on general health information rather than LKDT.

Management tools were offered by most websites (70%) via membership registration with costs or free newsletter subscription registration to get the latest information, or participate in networking activities. Decision-making was less supported, with only 3 websites (30%) providing evaluation tools to help site visitors perform risk assessment of kidney disease, or educate patients about making decisions on treatment options.

6 Analysis

Based on the survey conducted by Hanif et al. (2012), 70% of patients preferred to use the internet as a source of health information and 85% of patients wanted their transplantation centre to create a website providing transplant-related information for them. Since the process of assessing whether to proceed with LKDT is complex with medical, psychological and ethical considerations, we suggest a comprehensive website is needed to help both potential donors and recipients to address their information and decision-making challenges.

The set of technological features in Table 2 can be used as a guide to develop such a site together with consideration of the salient issues presented below in addition to standard features of good websites such as search bars and site maps to aid navigation and reliable performance.

6.1 Accuracy and coverage

Both potential donors and recipients require correct information about treatment options that are free from bias. In order to increase the accuracy of information, the website should have the ‘Health on the Net’ seal of approval (Moody et al., 2007) or be made by official authorities such as the government, national organization or transplantation centre/hospital (Hanif et al., 2012). It is also important to provide scientific support of the posted information. It is necessary to show the author’s name or source of each piece of posted information in the website. Relevant links to the author or source should be shown if it exists. Communication technology, especially social media, uses peer networks to exchange information and generate communication among communities. User generated content may be inaccurate; in order to maintain the accuracy of content within peer networks, it is necessary to assign moderators, such as transplant team members or social workers, for monitoring the content/postings to ensure the accuracy of the information. Regular checking can also prevent other ethical issues such as donor coercion or organ commercialization in the website.
<table>
<thead>
<tr>
<th>Website</th>
<th>URL and description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Transplant Australia</td>
<td>Website: <a href="http://www.transplant.org.au/Living-Donors.html">http://www.transplant.org.au/Living-Donors.html</a> Transplant Australia is the national community voice promoting organ and tissue donation and caring for those touched by transplantation such as transplant recipients, donor families, living donors, carers, etc. They focus on broader area including deceased donor organ and tissue donation such as lung, heart, kidney, pancreas, eye tissue, heart valves, musculoskeletal tissue, skin, etc., and live donor organ and tissue.</td>
</tr>
<tr>
<td>2. DonateLife</td>
<td>Website: <a href="http://www.donatelife.gov.au/donor-family-support/living-donors">http://www.donatelife.gov.au/donor-family-support/living-donors</a> DonateLife is Australian’s national reform program which is led by the Organ and Tissue Authority. Their role is to establish a nationally coordinated approach to organ and tissue donation for transplantation, in partnership with states, territories, clinicians, consumers and community. DonateLife Network comprises a number of agencies and hospitals across Australia that work specifically on organ and tissue donation, donor coordination, donor support, education coordination, communication activities and data and audit.</td>
</tr>
<tr>
<td>3. Kidney Health Australia</td>
<td>Website: <a href="http://www.kidney.org.au/OrganDonation/LivingKidneyDonation/tabid/691/Default.aspx">http://www.kidney.org.au/OrganDonation/LivingKidneyDonation/tabid/691/Default.aspx</a> Kidney Health Australia is a non-profit organization whose focus is to improve kidney health outcomes. It leads to substantial improvements to the quality of life for people with kidney and urinary tract diseases, their families and carers, as well as developing initiatives to reduce the incidence of kidney disease in the Australian community. Their focus is to promote good kidney health through education, advocacy, research and support.</td>
</tr>
<tr>
<td>4. Organ Don. in WA</td>
<td>Website: <a href="http://www.odatwa.org.au/living-donors/live-kidney-donation">http://www.odatwa.org.au/living-donors/live-kidney-donation</a> Organ Donation &amp; Transplant Foundation of West Australian is a registered West Australian charity and operates as a non-profit and independent organization. Their mission is to foster and develop organ and tissue donation and transplantation, for the benefits of patients and society, and increase community awareness about organ and tissue donation in the WA community.</td>
</tr>
<tr>
<td>5. myDr</td>
<td>Website: <a href="http://www.mydr.com.au/first-aid-self-care/organ-donation">http://www.mydr.com.au/first-aid-self-care/organ-donation</a> myDr is Australian healthcare website to provide comprehensive and relevant health information resource in Australia, such as articles of disease and conditions, tests and treatment, health and fitness issues, and medications. It covers general health problem and live organ donation is only one part of it.</td>
</tr>
<tr>
<td>7. Renal Resource Centre</td>
<td>Website: <a href="http://www.renalresource.com/booklets/kt.php">http://www.renalresource.com/booklets/kt.php</a> Renal Resource Centre provides information and education material to renal patients throughout Australia for assisting them in managing the effects of renal disease on their lifestyle. They are a community health service of Northern Sydney Central Coast Health.</td>
</tr>
<tr>
<td>8. Virtual Medical</td>
<td>Website: <a href="http://www.myvmc.com/treatments/kidney-transplant">http://www.myvmc.com/treatments/kidney-transplant</a> Virtual Medical Centre is Australia’s leading medical information website which delivers the latest medical information written by medical professionals. They aim to provide current conventional medicine information. It covers general health problem and live organ donation is only one part of it.</td>
</tr>
<tr>
<td>10. Home Dialysis</td>
<td>Website: <a href="http://homediagnosis.org.au">http://homediagnosis.org.au</a> Home Dialysis provides a comprehensive source of information about home dialysis. It provides help to Australian to choose the suitable option of dialysis with supportive information. Options for choosing include peritoneal dialysis, haemodialysis or transplantation.</td>
</tr>
</tbody>
</table>

Table 1: Selected Websites
Table 2. Identified technological criteria/features from the selected website

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<th>Technological criteria/website number</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td>Yes (1)</td>
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<td>No (0)</td>
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<td>Yes (1)</td>
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<td>Yes (1)</td>
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<td>Yes (1) under 3.</td>
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<td>No (0)</td>
<td>Yes (1) under 3.</td>
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<td>Partly (0.5)</td>
<td>Partly (0.5)</td>
<td>Partly (0.5)</td>
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LEGEND: Yes: contains feature / No: does not contain feature / Partly: contains this feature but not specific to LKDT / Unknown: not sure whether contains or not / Black features were identified via the review of related studies red color: additional features found in one or more sites that were not included in the features identified in the literature review.
According to the survey by Coorey, Paykin, Singleton-Driscoll, and Gaston (2009), around 36% of respondents know about LKDT after they started dialysis. All treatment options, including haemodialysis, peritoneal dialysis, Dead Kidney Donor Transplantation (DKDT), LKDT or latest treatment, should be provided by an official authority to patients and their family before they start dialysis. Besides general information of treatment options, long-term and short-term risks and benefits of dialysis, DKDT and LKDT with scientific approval, financial considerations, psychological and relationship influence, donor evaluation, length of hospital stay and the transplantation process should be provided to both parties for understanding the underlying implications of each treatment option (Moody et al., 2007; Zimmerman, Albert, Llewellyn-Thomas, & Hawker, 2006). Risks, pros and cons, alternative perspectives and opinions (e.g. doctor, nurse, family or patient) should be provided, to offer more complete information to site visitors. Another approach is government-driven early education to the public about various CKD options to increase awareness of this growing public health problem.

6.2 Readability

Text at no greater than fifth-grade level based on Flesch–Kincaid grade level scores (Moody et al., 2007), should be used. Text with graphic/image or numbers is encouraged to present the information. Different languages of materials should be provided to address linguistic need. Cartoon animation with sound/audio description or video like YouTube talking about possible case study from previous donors and recipients, insurance issues, how to talk to potential donors are suggested to be included. ReadSpeaker function is suggested to give a voice to the website. This text-to-speech function helps those patients/donors who preferred to listen or they have trouble reading the content online.

6.3 Relevance & appropriateness

Concerns of relevance considered here include compatibility, accessibility, user identification/classification, currency of information, use of a timeline, interactivity, security and navigation. Websites need to be compatible with all popular web browsers across the Mac and PC platforms as well as accessible via mobile devices to support easy access at any place, time or device. Reports can be provided to both patients and doctors to address consultation time limitations (Dageforde & Cavanaugh, 2013). Communication with doctors via email or submission boxes could also be considered. General information queries can be asked to a moderator via online confidential text or voice chat. Images should have alternative text explanations. Additional information or brochures should be downloadable. Evidence showed that transplantation information often does not provide the last amendment date (Moody et al., 2007). Newsletter/Announcement, RSS, Podcast or SMS message can be used to provide up-to-date information or reminders to patients/potential donors.

The decision-making process involved with LKDT is complex which may need a minimum of five years from the start to the actual transplantation (Laura A. Taylor & McMullen, 2008). A number of assessments are required to make sure the safety of both potential donors and recipients (Afaneh & Hartono, 2012; Kamal & Serur, 2012). The behaviour with regard to seeking information may be different at different phases; for example, potential donors may need to explore what assessments they require. After finishing the assessments, they may need to explore how long they need to wait for the actual transplantation and operation procedures, then they may want to know how long they need to stay in hospital and the proper preparation after donation. Therefore, a timeline for exploring to LKDT may be provided as a roadmap for reference to both potential donors and recipients. A graphic timeline like ‘dipity’ see Figure 1, is recommended to allow adequate time to plan and gain information.

Social networks, such as Facebook or Twitter, play a more critical role for supporting health related decision-making. Patients/donors review or rate their experiences on transplantation which becomes useful information, so this feature is added to increase interactive sharing and communication. Discussion forums/message boards are allowed for experienced donors and recipients to share their experience and help with each other. Another advantage is that the content of discussion forums/message boards can be found through a search function. So potential donors and recipients can easily find what they want by using a keyword search.
Advanced features can be provided such as video conferencing, tele-monitoring or virtual characters to deliver primary care for donors/patients/caregivers. Evaluation tests for checking the potential risk of developing chronic kidney disease can be provided online for use. Early assessment can increase awareness about the user’s own health. Decision aids for clarifying the underlying values of each treatment option can be provided to patients. After finding and communicating different information from others and obtaining opinions from different donors or recipients, potential donors and recipients may be confused what is important to them. Through risks and benefits analysis associated with different options, patients can enhance the understanding of various treatment options and choose the right one that result in the greatest benefit. Mobile phone based monitoring application can be provided for kidney transplant recipients which can monitor the situation of patients, such as healthy tips, regular exercise program, blood pressure detection etc., so patients can choose the right options on time.

Since more patients share their health information in social networking sites, there are security concerns on the privacy and confidentiality of patient’s sensitive health information. Digital rights management could be used to protect posted health data. It may place controls on the information whether they can be transferred, printed or copied, which can help to improve confidentiality to some extend and limit unintended use (Myers, Frieden, Bherwani, & Henning, 2008). Also registration could be used to validate users to protect sensitive health information.

7 Conclusion and Future Work

Based on the findings from the literature review, potential live kidney donors and recipients preferred to use various online tools to assess LKDT in four main areas, i.e. information, communication, management and decision-making. Using the features of the tools identified in the literature as a baseline we evaluated and compared existing transplant-related websites. We found that relevant websites provided textual links, search and download capability and while email provision on websites was commonplace providing medical advice was not. Social computing was typically enabled through video-sharing, announcements and podcasts although information provided was general rather than LKDT specific. Again some management tools were also offered in the form of membership registration or newsletter subscription to obtain the latest information or participate in networking activities. Through comparative analysis, we added features or criteria found on these websites to provide a more compre-
hensive set of technological criteria and features. Further, we offered numerous recommendations for
site owners and developers to help them understand the needs of potential donors and recipients.

The assessment of existing transplant-related websites in Australia, showed that some provided inade-
quate support to patients or potential donors in the LKDT process. Ideally they will expand their tech-
nological support to provide a clear roadmap for the whole LKDT process, address barriers and assist
the decision-making of potential donors and recipients.

A limitation of this study is that the search of transplant-related websites was performed on Google
only, and the result yielded several hundred thousand hits. As it was not possible to evaluate all web-
sites from the result, only the first 50 websites were assessed for suitability to be included in the eval-
uation. However, users will normally assess no more than 50 websites based on their keyword search
(Sacchetti, 1999). Nevertheless, some good websites may have not been included in the evaluation and
we only focused on sites returned on Google Australia, as we were working with medical specialists in
Australia.

To determine the effectiveness of the features and recommendations to support LKDT decision mak-
ing - further investigation involving interviews, focus groups or questionnaires should be conducted.
Furthermore as future work, a website based on our suggested technological criteria can be developed
to test its sufficiency and necessity for potential donors and recipients; it is one of the effective ways to
identify the effectiveness of the technological support and determine any issues that may happen. Data
collected from this website can be further analysed to update the criteria and make recommendations.

8 References

INTECH Open Access Publisher.

Journal, 2, 54-57.


survey of hospital websites. Clinical Transplantation, 27(3), E244-248.


Casey, J. R., Hanson, C. S., Winkelmayer, W. C., Craig, J. C., Palmer, S., Strippoli, G. F., & Tong, A.

potential kidney donors using social networking web sites. Clinical Transplantation, 27(3),
E320-326.

Clarke A, Mitchell A, Abraham C. Understanding donation experiences of unspecified (altruistic)

Coorey, G. M., Paykin, C., Singleton-Driscoll, L. C., & Gaston, R. S. (2009). Barriers to preemptive

Costello, K. L., & Murillo, A. P. (2014). "I want your kidney!" Information seeking, sharing, and
disclosure when soliciting a kidney donor online. Patient Education and Counseling, 94(3),
423-426.


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