

# Using mobile phone technology to support young liver transplant patients moving to adult services: A systematic rapid review

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# **Using mobile phone technology to support young liver transplant patients moving to adult services: A systematic rapid review**

## **Introduction**

Approximately two young people (aged 16 to 24 years) a day are diagnosed with some form of liver disease.<sup>1</sup> Recent UK statistics<sup>2</sup> show that 86% of transplanted livers continue to function for at least one year post-transplant. This suggests that the majority of young people receiving liver transplantation will survive into adulthood, thus making the transition from paediatric to adult services.

During transition, which is the preparation and process of moving from child to adult services, young people face new challenges. Young peoples' perceptions of transitioning can often create or heighten anxieties about the quality of healthcare<sup>3</sup>, raising issues concerning engagement with services and self-management.<sup>4</sup> The period of transition to adult services is noted as a period of vulnerability or deteriorating health. An example of this is non-adherence to medication being more common in young people<sup>5</sup> and that is exacerbated after transition to adult services.<sup>6</sup> The result of a negative transition experience can undermine previous good practice during paediatric care<sup>7</sup>.

In the UK, the process of transition has previously been seen as variable and inconsistent.<sup>8</sup> Recent national guidelines from NICE<sup>9</sup> provide guidance for how healthcare services should support young people transitioning from paediatric to adult services. However, this is generic guidance and therefore does not provide specifics for meeting the needs of young people with particular conditions. It is reported in the literature that young people who have received a liver transplant perceive transitional care as important, but have a poor knowledge of the process.<sup>4</sup> The National Health Service (NHS) Health Apps Library currently contains 239 apps and over 13 000 health apps are available through iTunes,<sup>10</sup>

suggesting that this is an area of substantial investment. There is a paucity of mobile technology apps to support young liver transplant recipients during transition.

## **Objective**

To explore the viability of mobile phone technology to support young people who have received a liver transplant transitioning from paediatric to adult healthcare services.

## **Methods**

A systematic rapid review approach to identify and summarize the evidence was used. In line with the definition by Grant & Booth<sup>11</sup> the review was rigorous and systematic yet made allowances for the limited time of the project. Featherstone, et al<sup>12</sup> have noted the variability of principles used when conducting rapid reviews however, this review has transparent and clear methods. Furthermore, the dissemination of the recent Knowledge to Action programme<sup>13</sup> shows that rapid reviews can produce ‘timely, user-friendly, and trustworthy evidence and transparently report these methods for the scientific community’.<sup>13(p1)</sup>

## *Search Strategy*

Two independent searches of four online databases (PubMed, MEDLINE, CINAHL, PsychINFO) were undertaken. The first search aimed to identify literature pertaining to the use of technology to support young people transitioning to adult services. The second search aimed to capture literature exploring transition for liver transplant recipients. Key search terms were used including: young people, technology, mobile, transition and support for Search One; and young people, liver, transplant, transition and crossing services for Search

Two. Only contemporary literature was sought and therefore searches were limited to articles published between 2005 and 2015. See supplementary material for the Search Protocol.

### *Inclusion criteria*

Original articles (including empirical studies, systematic and narrative literature reviews) published in peer-reviewed journals were included. Expert consultation and articles concerning best practice were included if they sought to establish standards of practice.

### *Review Process*

Eligibility of sources for inclusion in the review was assessed by two team members independently. Figures 1 and 2 outline the included articles by search category (Search one or Search two). Information from studies that were selected for inclusion were entered into a data extraction sheet that included: topic, study design, methodology, quality appraisal, outcomes, author's conclusions and limitations. This process was verified by three research team members (JC; AT; RT) before synthesizing the included articles into prominent themes.

[Insert Figure 1]

[Insert Figure 2]

## **Results**

Collectively, searches resulted in 12 articles that met the inclusion criteria, once duplicates were removed. Table 1 and 2 summarise the key characteristics of the included articles.

[INSERT TABLE 1]

[INSERT TABLE 2]

## **Search One: The use of technology to support transition**

Results from search one identified six articles that focused upon the use of technology to aid transition to adult services.<sup>3, 14, 15, 16\*, 17\*, 18\*</sup> Some studies, (denoted with an asterisk) mentioned transition after evaluating a technology program. Although it is not the main focus of the study there are implications that might be useful for future research.

### *How technology can be used to assist with transition*

From the evidence reviewed, two main ways that technology could be used to assist with transition were identified that included: to provide information and education material; and to encourage self-management and independence.

Technological programs contained education for both the transition process and diseases. Applebaum et al<sup>3</sup> noted that in order to manage disease, young people need to have good information, with importance placed on quality of the information and its source. Young people wanted information from healthcare professionals such as doctors whom they had built up a professional relationship.<sup>3</sup> Information from online sources was not trusted and advice from friends was not valued.<sup>3</sup> However, other studies suggest that the sharing of information amongst peers is an important activity and can offer an extra layer of support. Huang et al<sup>13</sup> reported that patients wanted to interact with others like themselves, particularly through social media and networking technologies. This appeared to be a result of loneliness and isolation and the desire to learn about others' experiences. This was in contradiction to the findings of Applebaum et al<sup>3</sup> who suggested that young people did not feel comfortable about discussing sensitive health issues with strangers. Also the participants "expressed little interest in talking to their friends at school because, 'They ask dumb questions' and 'They do not understand'".<sup>3(p123)</sup>

Huang et al<sup>15</sup> found that young people needed to have good ‘health literacy’ skills, which in turn would improve the transition process. It was proposed that reading and writing skills were essential for understanding about health and being able to engage with information provided about illness. The authors developed the MD2Me texting system that gave young people information and promoted self-management. The system was tested using the Test of Functional Health Literacy in Adults that aimed to measure literacy skills in adults. The authors concluded most of the patients demonstrated adequate health literacy skills, but those who used the MD2Me system “demonstrated greater improvements in disease management but not in health-related self-efficacy or patient-initiated communications”.<sup>15(p1645)</sup> Those with inadequate skills did not benefit significantly from the intervention. The issue of quality of information was not addressed and where the information originated was not stated.

Other research has linked education/information to transition readiness. Fredericks et al<sup>12</sup> measured transition readiness by testing knowledge of: medication name, dosage, prescription timing between dosage, and drug functions. Although they did not make the link to the potential use of technology to assist with this type of education, the authors reported an increased chance of successful transition if young people understood their healthcare needs. Such information could easily be transmitted using technology such as web-based systems and mobile applications.

Self-management of health was seen as vital for making a successful transition. Results suggested that this aspect could be supported through the use of technology. For example, Franklin et al,<sup>18</sup> in their evaluation of the Sweet Talk SMS programme, suggested that technology could keep young people engaged. They also argued that because young people use mobile phones on a daily basis it aligns with their lifestyle.<sup>18</sup>

For liver patients, technology was seen as a useful method for facilitating independence in young persons, whilst still involving the parents. Miloh et al<sup>17</sup> explored the use of an SMS system to improve medication adherence, which is key to self-management. Study participants were sent a reminder to take medication; this was followed with a reminder sent to the caregiver if confirmation from the young person was not received. This form of independence was also suggested in the findings by Applebaum et al<sup>3</sup> who reported that their participants welcomed receiving appointment reminders via SMS or email.

### *The benefits of using technology*

Technology can have a unique impact because it is portable and easily assessable. Huang et al<sup>13</sup> argued that technology had benefits because it was fast, can be tailored to individual participants needs, and could deal with sensitive issues because it was anonymous.

Using technology for transition could enable easy access to information. Taylor et al<sup>7</sup> suggested that one of the key dilemmas during transitioning was that young people wanted to be treated as adults yet hold onto their childhood. Technology has the ability to speak to different age-groups including those who are in the process of moving into adulthood.

### **Search Two: Support for liver patients moving to adult services**

Six articles were found that focused specifically upon how best to support young liver transplant patients making the transition to adult services.<sup>4, 6, 7, 8, 19, 20</sup>

Results were organised in five key themes: 1) Improving the transition process; 2) Tailoring transitions to the individual; 3) Supporting medication adherence; 4) Providing information on both the transition process and health; and 5) Developing support networks.

### *Improving the transition process*

As previously noted, recent NICE<sup>9</sup> guidelines made suggestions to improve the transition process and promote best practice. Such guidelines are welcomed. However, research before the publication of the guidelines portrayed transition for liver transplant recipients as inconsistent:

Transition of services was described as scattered and not standardized, resulting in poor communication between adult and paediatric services and poor timing of transition (transition of services was best performed during periods of wellness rather than during periods of illness).<sup>14(p996)</sup>

This quotation highlights the responses from practitioners themselves who felt transition was not an organised process. It was suggested that a formal national framework was required, which would result in patients receiving optimal care.<sup>8</sup> This process would be regulated through best practice and improve standards of care throughout the transition process. Taylor et al<sup>7</sup> noted that a formalised program would improve continuity of care in line with Royal College of Nursing 2007<sup>21</sup> guidelines that suggested poor transition experiences negate positive paediatric memories.

The call for a standard nationwide transition program was echoed through the research specifically focussing upon liver patients, particularly by Fredericks et al<sup>4</sup> who argued that a formalised process would result in the young adult receiving a suitable level of support and necessary resources. Such a program would need administration, particularly with communication between adult and paediatric professionals. This area was explored by Annunziato et al.<sup>6</sup> who evaluated a transition programme of liver patients. The study recommendations included: encouraging communication between the paediatric-adult areas; using a designated transition co-ordinator; and having a transfer checklist to ensure details such as primary care provider, insurance and compliance history would be recorded.



Annunziato et al.<sup>6</sup> suggested that a long-term approach to transition needs to be taken, starting with young people meeting with the new adult program leader within a month of their final appointment with their current care provider. This staggered approach would reduce the disruption caused for the young adult and to make the permanent move less of a radical shift.

*Tailoring transitions to the individual.*

Individually tailored transitions were the preferred to transitions guided solely by age, as explored by Fredericks et al.<sup>20</sup> Thus, despite increased independence over health related tasks, age alone should not determine readiness to transfer from paediatric to adult-focused health care given the risk of medical complications. Rather, the timing of transfer from paediatric to adult-focused care should be individualized and based on the acquisition and mastery of self-management skills.<sup>20(pp950-951)</sup>

The researchers constructed a Transfer Readiness Survey that measured aspects such as self-management skills, knowledge of disease and their schedule and psychosocial adjustment. Findings showed that in general transition readiness positively corresponded to age, although this was not found to be true with medication adherence. For the authors this was a critical finding because medication adherence was a key part of transition.

The suggestion that transition takes place based upon a combination of factors rather than solely on age was outlined in Webb et al's<sup>8</sup> consensus Statement 2. The authors found consensus around the statement that transition should occur in relation to individual growth and development, although this would usually be between the ages of 14 and 24 years.

It could be argued that the underlying factor to every successful transition is the ability to move from parent-led care to self-management. Annunziato et al<sup>19</sup> suggested that promotion of self-management must occur whilst the young adult is still under paediatric care

to minimise disruption. The issue of self-management was complicated by the role of the parents. Fredericks et al<sup>20</sup> suggested that parental monitoring must remain after transition and that roles must be clearly defined.

#### *Supporting medication adherence.*

The issue of medication adherence during transition was investigated by Annunziato et al.<sup>19</sup> The authors compared medication adherence across three different cohorts: those receiving paediatric care, those receiving adult care, and those who were in the process of transitioning. During the study, four who had recently transitioned died; two from suspected non-adherence. The cohort with the worst levels of adherence was the transitioning group. The authors concluded that non-adherence in transitioning young people was a result of the pressures of transition but also due to the fact that they were young people. Although the authors noted that the reasons for non-adherence were seen as being outside of the scope of the study they hypothesised that ‘non-adherence is treated more aggressively in the paediatric clinic, which has a more hands-on approach to treatment’.<sup>19(p612)</sup>

#### *Providing information on both the transition process and health*

Fredericks et al<sup>20</sup> assessed knowledge of the transition process and found that the majority of the participants in their study had not fully engaged with the idea of transition. They concluded that 42% of patients and 48% of parents had never thought of the process at all.<sup>20</sup> Building upon their previous work that focused upon transition readiness and tested young persons’ knowledge of their own health, the study sought to find out if participants knew the name of medications, the dosage required, the reason for taking certain medications, whether they could recognise when to seek medical attention and the ability to communicate with healthcare professionals.. Although 90% of the young people could name their

medication they struggled to provide the other information.<sup>20</sup> Knowledge of liver disease was also seen as an important factor for transition, although the research specifically on liver patients has tended to focus upon knowledge of the transition process itself over medical knowledge. Applebaum et al<sup>3</sup> however, stressed that accurate knowledge provided by professionals or recommended by professionals was important. It is important for young people; in this case those attending rheumatology clinics, to understand their diseases in order to manage them. Haung et al<sup>15</sup> noted that those who knew about their illness had better health outcomes.

### *Developing support networks*

The involvement of parents and/or a support network was seen as an important part of the transition process. Webb et al<sup>8</sup> stated that the process itself should involve families and that an individualised support service should be made available to those in the process. Although a key aspect of transition was to reduce the role of parents in young adult's healthcare, Huang et al<sup>15</sup> noted that this was often problematic for practitioners since 'overbearing' parents could prevent young people taking control of their own healthcare.

## **Discussion**

Similar to studies conducted in young people with diabetes<sup>18</sup> there was a clear emphasis on the role of the individual to take ownership of their care and to begin managing their medications. Internationally, this has been achieved through having an organised programme in place that promoted engagement with adult healthcare professionals whilst still under paediatric care. This long term approach prepared the young adult for the shift in care and ensured future health professionals delivering care were not strangers. Here technology can be used to assist and promote self-care. Currently, the majority of research exists with

regards to SMS systems that can be used as reminders to take medication. With gentle reminders, young people increased medication adherence and increased the chances for a successful transition but this was not a long-term strategy for teaching self-efficacy.

Education was a theme emerging from the existing literature with implications both for liver patients and for the emergent use of technology. Those who had access to information/education material were positioned to understand and be ready for transition. Transition readiness was measured by assessing individual's knowledge of their healthcare,<sup>19</sup> although there was no examination how such information was given to liver patients. Here technology could be used to send information to individuals to prepare them for the process of transition and for wider medical issues, such as their disease or the future implications for their health.

The issue of support underpinned the discussions of transition and technology. To date, the literature has focused upon where this support should come from and why certain support is more useful than others. There appears to be a tension in the literature with the suggestion that support of peers was perhaps unwelcome because friends do not understand the medical issues, or if they have similar medical backgrounds they were strangers.<sup>3</sup> Conversely such peer support through online services may be useful because of the anonymity and the ability to share stories with individuals with similar experiences.<sup>14</sup>

Recent NICE guidance<sup>22</sup> has produced a number of key recommendations with regards to transition that resonate with this review. The guidelines stated that young people must be involved in the 'service design, delivery and evaluation'<sup>22(p4)</sup> of transition. The guidance noted that transition should not be anchored to age; maturity, readiness and the stability of the young people should guide transition.<sup>22(p6)</sup> This was clearly reflected in the literature describing the needs of young liver patients. The guide also noted that transition should feature a named professional,<sup>22(p7)</sup> should build independence<sup>22(p9)</sup> and involve parents

and carers.<sup>22(p10)</sup> This publication supports the literature presented here, yet it is clear that there is a divide here between what currently happens in transition and what should happen.

Research focusing on transition for liver transplant patients noted the importance of having a structured and organized system in place and stressed the importance of transition readiness moving towards self-management. Technology to assist with transition was used to educate young people about the transition process and their disease, the overall goal being to provide support when moving towards self-management. Transition support programs seem to be most successful when taking the form of either mobile applications or web-based systems as they offer quick solutions to gain information, contact professionals, and access retrieve information about their own health records.

With the provisos outlined above in mind, there are benefits in the use of mobile technology to support young liver patients with transition. It is a time of confusion and great change and although there is no suggestion that a mobile application should replace their existing care, a mobile application could be used to supplement their care. This is increasingly important in terms of saving time and resources within the healthcare system. With careful management and administration a mobile phone application could be used to communicate information to young people, providing quick and timely access. This will reduce the need for expensive and time-consuming communication methods currently employed.

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*Table and Figures:*

Table 1: Articles included concerning technology and transition

Table 2: Articles included concerning transition for liver patients

Figure 1: Results of the search strategy: Technology to support transition

Figure 2: Results of the search strategy: Transition of liver patients

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