

Using Mobile Phone Technology to Support Young Liver Transplant Recipients Moving to Adult Services: A Systematic Rapid Review

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Abstract

Background: The process and preparation of moving from child to adult services (transition) is a challenging period of time for young people and represents significant changes in care and support systems. The proliferation of mobile phone applications for health purposes suggests that it is an area for further investigation. **Objective:** The review explores the potential to use mobile phone technology to help support young liver transplant recipients moving to adult services. It represents the first review conducted in this specialism and considers a new model of support for young liver patients. **Methods:** A systematic rapid review of the published peer-reviewed literature. **Results:** Two searches were conducted: Search 1: the use of technology to support transition to adult services (6 studies) and Search 2: how best to support liver transplant recipients during transition (6 studies). **Discussion:** Research shows that to achieve positive transition young people need information about their condition and transition. The process needs to be guided by transition readiness, rather than the young persons' age. Although parents and support networks should be in place and are valued, transition should build upon self-management and independence. Results suggest that there appears to be scope to use mobile phone technology to support transition. This is the first time a review has explored the types of issues or concerns facing liver transplant patients and how these can be addressed through mobile phone technology.

Keywords

liver disease, transition, systematic rapid review, technology, young people, transplantation

Introduction

Approximately 2 young people (aged 16-24 years) a day are diagnosed with some form of liver disease.¹ Recent UK statistics² shows that more than nine out of 10 transplanted livers continue to function for at least 1 year posttransplant. 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 people's perceptions of transitioning can often create or heighten anxieties about the quality of health care,³ raising issues concerning engagement with services and self-management.⁴ The period of transition to adult services is noted as a period of vulnerability or deteriorating health. An example of this is nonadherence to medication being more common in young people⁵ and that is exacerbated after

transition to adult services.⁶ The result of a negative transition experience can undermine previous good practice during paediatric care.⁷

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In the United Kingdom, the process of transition has previously been seen as variable and inconsistent.⁸ Recent national guidelines from the National Institute for Health and Care Excellence (NICE)⁹ provide guidance for how health-care services should support young people transitioning from pediatric to adult services. However, this is a 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.⁴ Data from 2016 suggests there are around 259,000 health apps available, with 100,000 being launched since 2015.¹⁰ This suggests it 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 pediatric to adult health-care services.

Methods

A systematic rapid review approach to identify and summarize the evidence was used. In line with the definition by Grant and Booth,¹¹ the review was rigorous and systematic yet made allowances for the limited time of the project. Featherstone et al¹² 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 program¹³ shows that rapid reviews can produce “timely, user-friendly, and trustworthy evidence and transparently report these methods for the scientific community.”^{13(p1)}

Search Strategy

Two independent searches of 4 online databases (PubMed, MEDLINE, CINAHL, and PsychINFO) were undertaken. Search 1 aimed to identify literature pertaining to the use of technology to support young people transitioning to adult services. Search 2 aimed to capture the literature exploring transition for liver transplant recipients. Key search terms were used including: young people, technology, mobile, transition, and support for search 1; and young people, liver, transplant, transition, and crossing services for search 2. Only contemporary literature was sought, and therefore, searches were limited to articles published between 2005 and 2015 (for the search protocol, see supplementary material).

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 2 team members independently. Figures 1 and 2 outline the included articles by search category (search 1 or search 2, respectively). 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 3 research team members (J.C., A.T., and R.T.) before synthesizing the included articles into prominent themes.

Results

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

Search 1: The Use of Technology to Support Transition

Results from search 1 identified 6 articles that focused upon the use of technology to aid transition to adult services.^{3,15-17,19,20} 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, 2 main ways that technology could be used to assist with transition were identified 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 al³ noted that in order to manage disease, young people need to have good information, with importance placed on the quality of the information and its source. Young people wanted information from health-care professionals such as doctors whom they had built up a professional relationship.³ Information from online sources was not trusted and advice from friends was not valued.³ However, other studies suggest that the sharing of information among peers is an important activity and can offer an extra layer of support. Huang et al¹⁵ 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 al³ 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’.”^{3(p123)}

Huang et al¹⁵ 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

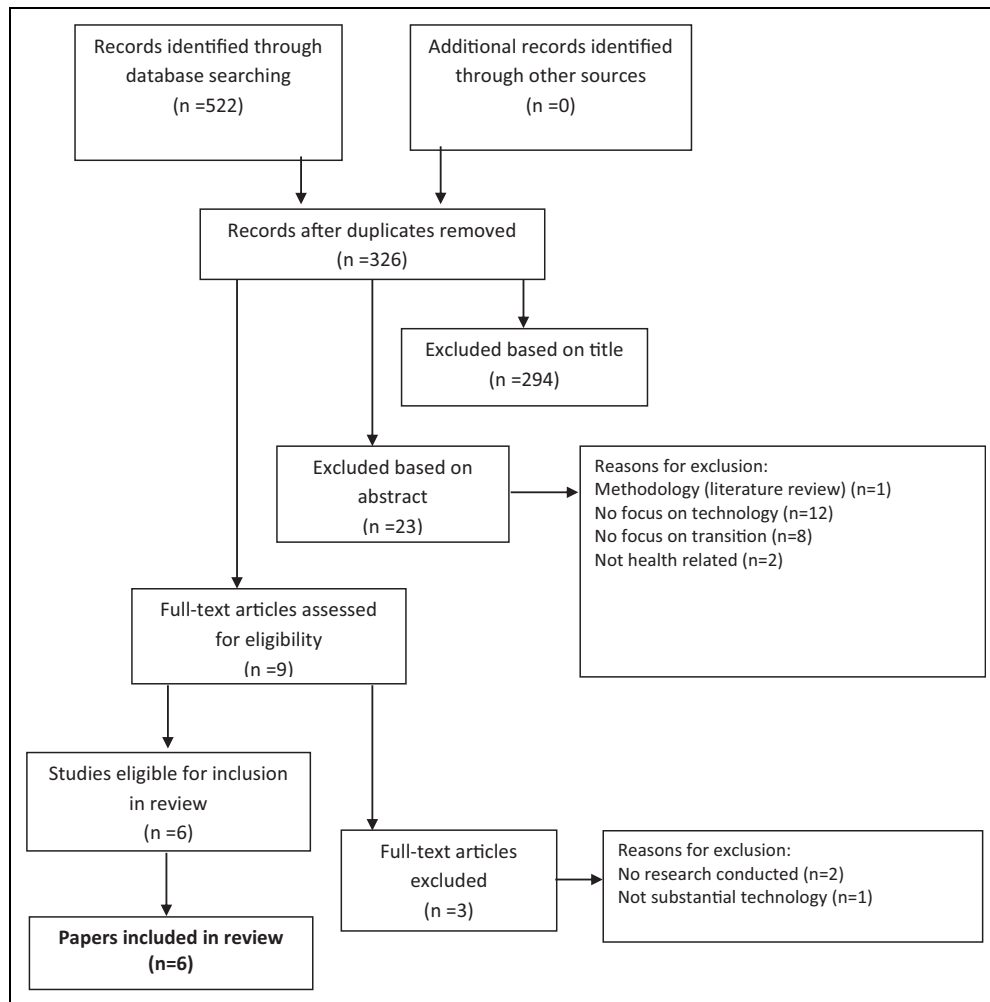


Figure 1. Results of the search strategy: technology to support transition.

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 that 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.”^{15(p1645)} Those with inadequate skills did not benefit significantly from the intervention. The issue of quality of information was not addressed, where the information originated was not stated.

Other research has linked education/information to transition readiness. Fredericks et al¹⁴ 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 health-care needs. Such information could easily be transmitted using technology such as web-based systems and mobile applications.

Self-management of health was seen as a vital for making a successful transition. Results suggested that this aspect could be supported through the use of technology. For example, Franklin et al,¹⁷ in their evaluation of the Sweet Talk SMS program, 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.¹⁷

For liver transplant patients, technology was seen as a useful method for facilitating independence in young persons, while still involving the parents. Miloh et al¹⁶ 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 al³ who reported that their participants welcomed receiving appointment reminders via SMS or e-mail.

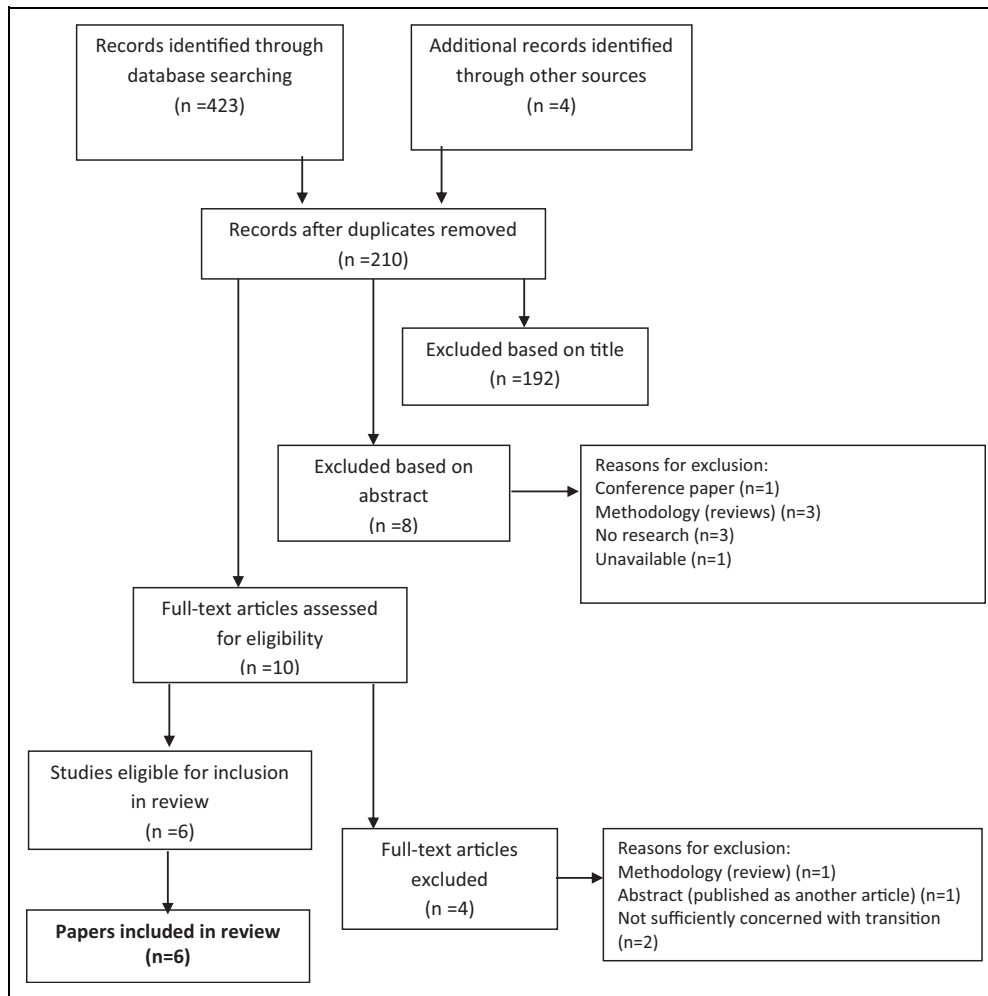


Figure 2. Results of the search strategy: transition of liver transplant patients.

The Benefits of Using Technology

Technology can have a unique impact because it is portable and easily assessable. Huang et al¹⁵ 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 al⁷ suggested that 1 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 2: Support for Liver Transplant 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.^{4,6-8,14,18}

Results were organized in 5 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 NICE⁹ 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).^{19(p996)}

This quotation highlights the responses from practitioners themselves who felt transition was not an organized process. It was suggested that a formal national framework was required, which would result in patients receiving optimal

Table 1. Articles Included Concerning Technology and Transition.

Authors	Country	Population	Technology Program	Conditions	Overall Aim	Outcomes	Results	Conclusion
Applebaum et al 2013 ³	United States	Aged 13 to 21 years	Not specific: Investigated what an effective technology program would look like	Chronic disease. The young people were attending a rheumatology clinic so mainly arthritis and lupus	To explore what an effective technological program would look like	<ul style="list-style-type: none"> All concerned transitional care: <ul style="list-style-type: none"> 1. Disease perception and understanding or health information 2. Concern about independently managing disease 3. Degree of independence in health-related tasks 4. Ideas for transition tools with an emphasis on technological aids 	<p>A web-based system was felt to be the best and would include:</p> <ul style="list-style-type: none"> - Easy ways to learn about disease and medication - Capability to contact health care - Methods to retrieve medication and lab information <p>The participants felt that the information needs to come from medical professionals</p>	<p>The participants were concerned with the move to adult services.</p> <p>Future research should explore using web-based transition programs</p>
Franklin 2006 ¹⁷	United Kingdom	8 to 18 years (126 patients)	Sweet Talk: An SMS system to support young people with diabetes	Diabetes	To evaluate the Sweet Talk SMS system	<ul style="list-style-type: none"> - HbA1c - Diabetic ketoacidosis (DKA) – Ketones are poisonous chemicals which build up and, if left unchecked, and will cause the body to become acidic—hence the name “acidosis.” - Hypoglycemia - BMI, SD - Visual analogue adherence score - Diabetes knowledge scales - Diabetes Social Support Interview (DSSI) which includes insulin, blood-glucose testing, diet, and exercise. - Hotline contact - Clinic visits 	<p>HbA1c did not change in patients on conventional therapy without or with Sweet Talk: 10.3 (0.7%) versus 10.1 (1.7%) It did improve in patients randomized to intensive therapy and Sweet Talk: 9.2 (2.2%), 95% CI: -1.9 to -0.5, P < .001.</p> <p>Sweet Talk was associated with (1) improvement in diabetes self-efficacy: conventional therapy 56.0 (13.7), Sweet Talk 62.1 (6.6), 95% CI: +2.6 to +7.5, P = .003 and (2) self-reported adherence: conventional therapy 70.4 plus Sweet Talk 77.2 (16.1), 95% CI: +0.4 to +17.4, P = .042.</p> <p>When surveyed, 82% of patients felt that Sweet Talk had improved their diabetes self-management and 90% wanted to continue receiving messages</p>	<p>Sweet Talk was associated with improved self-efficacy and adherence; engaging a classically difficult to reach group of young people. While Sweet Talk alone did not improve glycemic control, it may have had a role in supporting the introduction of intensive insulin therapy. Scheduled, tailored text messaging offers an innovative means of supporting adolescents with diabetes and could be adapted for other health-care settings and chronic diseases. (1332)</p>
Huang et al 2011 ¹⁹	United States	Ten young adults. Aged 18 to 25 (mean 20) years	None. Qualitative research exploring transition and technology	Chronic illnesses. Inflammatory bowel disease (IBD), cystic fibrosis (CF), or type 1 diabetes	To examine the transition process using qualitative methods	<ol style="list-style-type: none"> Transition experiences in the context of relationships among patients, parents, and health-care providers. Differences between pediatric and adult-oriented medicine and how these differences inhibit or facilitate transition. 	<p>Parental involvement in the process is important. Over involvement can lead to a poor experience but there needs to be support.</p> <p>Transition should start when the young person is mature and not at a prespecified age</p>	<p>Transfer of disease management needs to be gradual.</p> <p>Communication between adult and pediatric services needs to improve. The authors suggest that technologies might be used to improve user experiences</p>

(continued)

Table 1. (continued)

Authors	Country	Population	Technology Program	Conditions	Overall Aim	Outcomes	Results	Conclusion
Huang et al 2014 ¹⁵	United States	12 to 20 years (17 median)	MD2Me: A web-service and SMS system with an education angle	Chronic Disease (adolescents and young adults with chronic disease [ACD])	To evaluate the effectiveness of the MD2Me system	<p>3. Identification of transition services that should be provided to young patients who have chronic disease.^(9,94)</p> <p>1. Health literacy. 2. Disease management and self-efficacy. 3. Patient-initiated health communication. Disease status and global health status were also recorded</p>	<p>Significant improvements in performance of disease management tasks, health-related self-efficacy, and patient-initiated communications compared with controls. Improvement in all outcomes Assistive technology can prevent young people with spina bifida to feel less isolated. The type of technology is specific to spina bifida, for example speech recognition, wheelchairs, memory assistants, text pagers, cell phones, etc.</p>	Technology used to aid transition is cost-effective and positively benefits young people
Johnson et al 2007 ²⁰	United States	Aged 13 to 27 years diagnosed with myelomeningocele	Looking at forms of assistive technology	Spina bifida	To explore how young people can use assistive technology	<p>1. Independent self-care. 2. Participation in structured activities. 3. Home-life (whether they live with their parents)</p>	<p>Utilization of the assistive technology could improve transitions to independent living and to participation within communities</p>	
Miloh et al 2009 ¹⁶	United States	Age range of patients: 1 to 27 years	SMS texts to improve medical adherence	Liver transplant recipients	To evaluate the effectiveness of an SMS system which aimed to increase medical adherence	<p>1. Medical adherence: Consecutive tacrolimus blood levels. Greater fluctuation between individual blood levels indicates lower levels of adherence.⁽⁸⁴⁵⁾ 2. Medical outcomes: Biopsy proven, acute rejection episodes were recorded</p>	<p>The service reduced the risk of rejection (12-2) and improved adherence, shown by "a reduction of the tacrolimus level SD from 3.48 to 1.36 g/L with the use of TM."⁽⁶⁸⁴⁸⁾ However, it is noted that adherence is hard to measure. The SMS system was noted as being discreet and not intrusive</p>	The study shows that SMS systems significantly improve medical adherence and reduce rejection episodes

Abbreviations: BMI, body mass index; CI, confidence interval; HbA1c, hemoglobin A1c; SD, standard deviation.

Table 2. Articles Included Concerning Transition for Liver Patients.

Author	Country	Population	Technology Program	Conditions	Overall Aim	Outcomes	Results	Conclusion
Annunziato et al 2007 ¹⁸	United States	Pediatric: 12 to 20 years. Adult: 21 to 35 years	NA (liver transition)	Liver transplant patients	To examine whether adherence changes during transition	Medication adherence, measured through the use of standard deviations of tacrolimus blood levels	The authors propose that the 3 most important aspects of changing the system are: 1. redesigning the transfer process 2. addressing health-care management support for patients prior to transfer 3. adopting a long-term care approach to transition	The transition period is a vulnerable one and results in lower rates of adherence to medication
Annunziato et al 2010 ⁶	United States	For the review/case study: 14 recently transitioned. For the survey: 52 (26 adolescents of ages 14 to 17 and 26 and young adults of ages 18 and older)	None. Explores transition for liver transplant patients. A survey was conducted.	Liver transplant patients	The authors state that the overall aim is: to (1) describe systemic changes made in our clinical practice to facilitate transfer of transplant recipients from the pediatric to the adult service and (2) provide the rationale for instituting these organizational changes. ^(8,23)	Medical and psychosocial outcomes: no further detail is given in the article	The targets to improve the process are to: 1. redesign the process 2. address care management and support prior to transfer 3. adopt a long-term care approach to transition	Transition is a long and complex process. The authors felt that the most problematic point is the move out of pediatrics
Fredericks et al 2010 ¹⁴	United States	Young people: 11 to 20 years parents.	None. Looking at readiness skills and adherence in pediatric liver transplant recipients	Liver disease (transplant)	To explore how ready young people are for transition	Transition readiness (TRS), adherence (measuring immunosuppressant level), clinic attendance, health outcomes (liver test panels, biopsies, rejection episodes, and hospitalizations.) TRS: They assessed "readiness" using a scale (TRS: AYA). It asked whether the young person knew: - Medication name - Dosage - Prescription timing between dosage - Drug functions (why they are taking the drugs)	Results indicate that all domains of transition readiness, with the exception of demonstrated skills, and nonadherence were positively correlated with age. Proportion of immunosuppressant blood levels below target range was positively correlated with self-management skills and increased responsibility for medication tasks. Parent regimen knowledge was associated with clinic attendance. Health outcomes were significantly related to medication nonadherence, but not to transition readiness domains. ^(9,14)	Chronological age is associated with self-management skills, but older age results in increased risk of nonadherence. Therefore, age alone should not govern when young people transition. The promotion of self-management skills is an important part of transition and interventions which promote these are essential

(continued)

Table 2. (continued)

Author	Country	Population	Technology Program	Conditions	Overall Aim	Outcomes	Results	Conclusion
Fredericks et al 2011 ⁴	United States	Patients Age range: 12 to 21. Mean 16.6 years. More than 6 months after transplantation. Plus 31 parents	None. Transition for liver transplant patients	Liver transplant	To explore patient and parent perspectives on the transition from child to adult services	1. Level of prior thought; 2. level of interest in transition; 3. knowledge of the transition process; 4. perceived importance of tasks related to transitioning to adult care; 5. concerns about the transfer. ⁽⁴¹⁵⁾	Few participants have thought about transition, 42% not at all. (416) Moderate levels of interest in learning about the transition process. Poor knowledge of the transition process Moderate levels of concern about transition. Older patients (16+) had greater knowledge/understanding	Overall, results suggest that adolescent and young adult Liver Transplant Recipients (LTR) and their parents perceive the importance of transitional care but demonstrate poor knowledge of the process. There remains a need for improved transition planning for both adolescents and parents
Taylor et al 2010 ⁷	United Kingdom	12 to 18 years	None. Transition of young liver patients (after transplant)	Liver disease (transplant)	To explore, through qualitative methods, experiences with transition for liver patients	Six themes emerged from the data: 1. Impact of transplantation on their relationships with friends, family, and peers; 2. effect on education; 3. development of tiredness and fatigue; 4. burden of medication; 5. communication with health-care professionals; 6. the impact on the future. ⁽¹⁰⁸⁷⁾	The young people in the study tried to form their identity based upon the self rather than their transplant. There was a strong desire to be "normal" although the desire to appear well had detrimental health consequences through nonadherence to medication for example. Transition is not a linear process which further exacerbates this situation. Involving young people in decision-making and asking them about their experience is important as it increases the confidence of young people and improves communication pathways. The authors suggest that understanding young people's experiences will encourage personalized care plans. Health professionals need to ensure care is age appropriate and understand that young people are striving for normalcy. Information should be provided about the transplant but also about how to cope and adapt	Although the themes are presented as being distinct, in reality, there was considerable overlap. The authors provide an example: "... an inability to make and maintain friends also manifest in a poor school experience, which can increase the perception of medication burden and a negative view of the future." ⁽¹⁰⁸⁸⁾ The article concludes with a revised Quality of Life concept model for life after liver transplantation

(continued)

Table 2. (continued)

Author	Country	Population	Technology/Program	Conditions	Overall Aim	Outcomes	Results	Conclusion
Webb et al 2010 ⁸	United Kingdom	Not specific	None. Looking at transition for those with chronic illness	Chronic illness. More specifically cardiac, hepatic, and renal	Looking to build a consensus around transition for transplant patients	Seven consensus statements were drafted	Summaries of the statements (too lengthy for inclusion in full): (1) There should be a formal national framework. (2) Transition should not be governed by age. (3) Transplant recipients should be able to stay in young adult clinic until 24 years. (4) Each department should have a clinical lead for transition. (5) Patients, parents and families should be consulted about the process. (6) Tailored support should be offered. (7) Transition standards should be established for monitoring by the Care Quality Commission (CQC)	The statements should be seen as recommendations for best practice

care.⁸ This process would be regulated through best practice and improve standards of care throughout the transition process. Taylor et al⁷ noted that a formalized program would improve continuity of care in line with Royal College of Nursing 2007²¹ guidelines that suggested poor transition experiences negate positive pediatric memories.

The call for a standard nationwide transition program was echoed through the research specifically focusing upon liver transplant patients, particularly by Fredericks et al⁴ who argued that a formalized 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 pediatric professionals. This area was explored by Annunziato et al⁶ who evaluated a transition program of liver patients. The study recommendations included: encouraging communication between the pediatric-adult areas, using a designated transition coordinator, and having a transfer checklist to ensure details such as primary care provider, insurance, and compliance history would be recorded.

Annunziato et al⁶ 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.¹⁴ Thus, despite increased independence over health-related tasks, age alone should not determine readiness to transfer from pediatric to adult-focused health care given the risk of medical complications. Rather, the timing of transfer from pediatric to adult-focused care should be individualized and based on the acquisition and mastery of self-management skills.^{14(pp950-951)}

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 the consensus statement 2 of Webb et al.⁸ 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 al¹⁸ suggested that promotion of self-management must occur while the young adult is still

under pediatric care to minimize disruption. The issue of self-management was complicated by the role of the parents. Fredericks et al¹⁴ 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.¹⁸ The authors compared medication adherence across 3 different cohorts: those receiving pediatric care, those receiving adult care, and those who were in the process of transitioning. During the study, 4 who had recently transitioned died and 2 from suspected nonadherence. The cohort with the worst levels of adherence was the transitioning group. The authors concluded that nonadherence in transitioning young people was not only 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 nonadherence were seen as being outside the scope of the study, they hypothesized that “nonadherence is treated more aggressively in the pediatric clinic, which has a more hands-on approach to treatment.”^{18(p612)}

Providing Information on Both the Transition Process and Health

Fredericks et al¹⁴ 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.¹⁴ 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 whether participants knew the name of medications, the dosage required, the reason for taking certain medications, whether they could recognize when to seek medical attention, and the ability to communicate with health-care professionals. Although 90% of the young people could name their medication, they struggled to provide the other information.¹⁴ 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,³ 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 al¹⁵ 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 al⁸ stated that the process itself should involve families, and that an individualized 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 health care, Huang et al¹⁵ noted that this was often problematic for practitioners since "overbearing" parents could prevent young people taking control of their own health care.

Discussion

Similar to studies conducted in young people with diabetes,¹⁷ 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 organized program in place that promoted engagement with adult health-care professionals while still under pediatric 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 regard 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 health care,¹⁸ although there was no examination how such information was given to liver transplant 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 unwelcomed because friends do not understand the medical issues, or if they have similar medical backgrounds they were strangers.³ 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.¹⁹

Recent NICE guidance⁹ has produced a number of key recommendations with regard to transition that resonates with this review. The guidelines stated that young people must be involved in the "service design, delivery and evaluation"^{9(p4)} 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.^{9(p6)} 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,^{9(p7)} should build independence,^{9(p9)} and involve parents and carers.^{9(p10)} 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 toward 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 toward self-management. Transition support programs seem to be the 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 to 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 health-care 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 used.

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Authors' Note

This review is part of a wider project in the United Kingdom funded by the Children's Liver Disease Foundation (CLDF) using qualitative methods to construct a mobile phone app for young liver patients in transition. Using data collected from interviews and focus groups with young people and professionals, the project will design and make an app for young people constructed with the assistance of young people. It will be important to explore the findings of this wider project in relation to results of this literature review and relate this to the growing international evidence of young people in transition between pediatric and adult services.

Declaration of Conflicting Interests

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Supplemental Material

The online [appendices/data supplements/etc] are available at <http://journals.sagepub.com/doi/suppl/10.1177/1526924817699958>

References (* denotes manuscripts included in the rapid review)

1. CLDF. Facts and Figures. 2014. <http://www.childliverdisease.org/Media/Facts-and-figures>. Accessed November 15, 2016.
2. NHS Choices. Liver Transplant. Risks of a liver transplant. 2015. <http://www.nhs.uk/conditions/Liver-transplant/Pages/Introduction.aspx>. Accessed March 10, 2017.
- *3. Applebaum MA, Lawson EF, von Scheven E. Perception of transition readiness and preferences for use of technology in transition programs: teens' ideas for the future. *Int J Adolesc Med Health*. 2013;25(2):119-125. doi:10.1515/ijamh-2013-0019.
- *4. Fredericks EM, Dore-Stites D, Lopez MJ, et al. Transition of pediatric liver transplant recipients to adult care: Patient and parent perspectives. *Pediatr Transplant*. 2011;15(4):414-424. doi:10.1111/j.1399-3046.2011.01499.x.
5. Berquist RK, Berquist WE, Esquivel CO, Cox KL, Wayman KI, Litt IF. Adolescent non-adherence: prevalence and consequences in liver transplant recipients. *Pediatr Transplant*. 2006;10(3):304-310.
- *6. Annunziato RA, Hogan B, Barton C, et al. A translational and systemic approach to transferring liver transplant recipients from pediatric to adult-oriented care settings. *Pediatr Transplant*. 2010;14(7):823-829. doi:10.1111/j.1399-3046.2010.01348.x.
- *7. Taylor RM, Franck LS, Dhawan A, Gibson F. The stories of young people living with a liver transplant. *Qual Health Res*. 2010;20(8):1076-1090. doi:10.1177/1049732310368405.
- *8. Webb N, Harden P, Lewis C, et al. Building consensus on transition of transplant patients from paediatric to adult healthcare. *Arch Dis Child*. 2010;95(8):606-611. doi:10.1136/adc.2009.176255.
9. National Institute for Health and Care Excellence. Transition from children's to adults' services for young people using health or social care services. 2016. <https://www.nice.org.uk/guidance/ng43>. Accessed November 15, 2016.
10. Research2guidance. mHealth App Developer Economics 2015: The current status and trends of the mHealth app market. 2016. <http://research2guidance.com/r2g/r2g-mHealth-App-Developer-Economics-2016.pdf>. Accessed March 10, 2017.
11. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J*. 2009;26(2):91-108. doi: 10.1111/j.1471-1842.2009.00848.x.
12. Featherstone RM, Dryden DM, Foisy M, et al. Advancing knowledge of rapid reviews: an analysis of results, conclusions and recommendations from published review articles examining rapid reviews. *Syst Rev*. 2015;4:50. doi:10.1186/s13643-015-0040-4.
13. Khangura S, Konnyu K, Cushman R, Grimshaw J, Moher D. Evidence summaries: the evolution of a rapid review approach. *Syst Rev*. 2012;1:10. doi:10.1186/2046-4053-1-10.
- *14. Fredericks EM, Dore-Stites D, Well A, et al. Assessment of transition readiness skills and adherence in pediatric liver transplant recipients. *Pediatr Transplant*. 2010;14(8):944-953. doi: 10.1111/j.1399-3046.2010.01349.x.
- *15. Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. *Pediatrics*. 2014;133(6):e1639-e1646. doi:10.1542/peds.2013-2830.
16. Miloh T, Annunziato R, Arnon R, et al. Improved adherence and outcomes for pediatric liver transplant recipients by using text messaging. *Pediatrics*. 2009;124(5):e844-e850. doi:10.1542/peds.2009-0415.
- *17. Franklin VL, Waller A, Pagliari C, Greene SA. A randomized controlled trial of Sweet Talk, a text-messaging system to support young people with diabetes. *Diabet Med*. 2006;23(12):1332-1338.
- *18. Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA, Shemesh E. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant*. 2007;11(6):608-614.
- *19. Huang JS, Gottschalk M, Pian M, Dillon L, Barajas D, Bartholomew LK. Transition to adult care: systematic assessment of adolescents with chronic illness and their teams. *J Pediatr*. 2011; 159(6):994-998.e2. doi:10.1016/j.jpeds.2011.05.038.
- *20. Johnson KL, Dudgeon B, Kuehn C, Walker W. Assistive technology use among adolescents and young people with spina bifida. *Am J Public Health*. 2007;97(2):330-336. doi:10.2105/AJPH.2004.050955.
21. Royal College of Nursing. *Lost in Transition: Moving Young People between Child and Adult Health Service*. London, UK: Royal College of Nursing; 2007.