REVIEW ARTICLE

BENEFITS AND CHALLENGES FOR YOUNG AUSTRALIANS WITH EPILEPSY TRANSITIONING INTO ADULT HEALTHCARE: A SCOPING REVIEW

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ABSTRACT

BACKGROUND

Transitioning from paediatric healthcare into an adult healthcare system is a high-risk time for people with complex epilepsy. This can be a period of significant upheaval as a young person moves away from familiar and safe paediatric environments into unfamiliar adult healthcare. This is compounded by normal adolescent development, the challenges of epilepsy and the lifestyle conditions it demands, including restrictions on driving and levels of independence. Such factors can contribute to suboptimal health engagement which result in increased seizure activity, hospital admissions and reduction in community participation [1-6]. Effective, well implemented transition programs are key to reducing risks, however little is known about which features of transition pathways define success or best practice.

A scoping review was used to examine a broad range of peer-reviewed literature published between 2017 and 2022. This review examined evidence-based literature relating to experiences of people with epilepsy as they transitioned between paediatric and adult healthcare environments. Specifically, exploring practices that offered benefits, recognising barriers, and identifying findings to inform future research and advance transition practices.

CONCLUSION

This review found that key to reducing transition-related health impacts for young people was patient-centred, engaging care that acknowledges their psychosocial and mental health needs specific to their level of development. Evidence suggests that engagement is built through multidisciplinary clinics that facilitate education and self-management. This review found that successful programs can deliver this by focusing on four key areas: relationships and continuity, capacity building, processes, and health services and systems. At a paediatric level this involves timely, age-appropriate preparation that builds skills and knowledge through tailored care-plans. At the transfer phase this means coordinated teams that work together across systems to ensure handover continuity, reduce stressors, and to aid navigation. At the adult level, care-teams that welcome young patients with protocols for continued capacity building are required.

KEYWORDS

adolescent, healthcare transition, epilepsy, paediatric to adult healthcare

INTRODUCTION

Transition to adult care from the paediatric health system is described as a high-risk time for patients with epilepsy who require ongoing specialised care and treatment [1-3]. For these adolescents and young adults (AYA) transition can be stressful as they leave familiar, facilitated, and safe paediatric centres for new adult orientated health environments [4]. While simultaneously, patient case management changes from being parent (or significant adult) led to being self-managed. This means patients must acquire the skills and abilities to manage their own care, sourcing and complying with medication, scheduling, navigating, and attending appointments, while also knowing how to react to changes in their condition [5]. In the paediatric system this health management is scaffolded by supportive adults, including parents and health practitioners. In an adult-orientated system there is a higher expectation that patients have the capacity and knowledge to do this unaided [4]. For AYA's deemed not to have this capacity, transition proceeds with their existing supports in place.

Transition is further complicated by normal developmental social and emotional changes experienced by all young people, including increases in general risk-taking behaviours and a desire for autonomy [6]. These emotional changes mean that some young people can struggle to make the lifestyle adjustments their condition requires. Collectively these factors contribute to suboptimal health engagement, resulting in decreases in adherence to medication, low appointment attendance and poor lifestyle behaviours [7, 8]. This leads to increased seizure activity, hospital admissions, injuries, risk of sudden unexplained death in Epilepsy (SUDEP) as well as disruptions to education, vocational and social participation [9]

BACKGROUND LITERATURE REVIEW

EPILEPSY

Epilepsy is a chronic neurological condition that is characterised by unpredictable and recurrent seizures. For some, childhood epilepsy is self-limiting, but others may require ongoing anti-seizure treatment and specialist care into adulthood [1, 10]. People with epilepsy experience differences in seizure severity, frequency, and type and as such require individualised ongoing treatment [10]. Australian healthcare expenditure for epilepsy in 2018-19 was calculated at $333 million, with people aged 15-19 years experiencing the highest burden of disease [11]. One in three people with an epilepsy diagnosis do not gain seizure control from anti-seizure medications (ASM) (1). In addition to this lack of seizure control, ASM treatments are complicated by negative side effects such as cognitive slowing, depressive symptoms, and behaviour disinhibition [1, 10].

TRANSITION PRACTICES

Healthcare transition involves the staged process of preparation and purposeful planned movement between healthcare systems. Differences between paediatric and adult healthcare models are marked and therefore require a strategic approach to maximise patient outcomes.

This paper defines people aged between 10-24 as adolescents and young adults (AYA's) (People aged between aged 10-14 are young adolescents, 15-19 are older adolescents and young adults are 20-24) [12, 13]. The goals for this process should be for uninterrupted, comprehensive, developmentally appropriate, psychologically sound, and coordinated healthcare [14]. Research is clear that discontinuity of adequate epilepsy healthcare poses risks for poor health related quality of life as well as lifestyle and occupational restrictions [10, 15, 16]. In other words, transition programs that do not meet a young person's needs increase the incidence of disengagement and increase risks of treatment failure which exacerbates the disease.

Published work acknowledges this complex time with consensus that little is known about which features of transitional care define success [17, 18]. Transitional pathways for chronic disease are an expanding area of practice, with much of the published literature recognising the need for established, widespread service models [16]. To date, much of the published work pertains to specific disease states, for example HIV or diabetes. As yet common protocols or programmes for epilepsy transition have not been established [18]. In addition to this, research indicates there is a need for a consensus driven approach as to how transition readiness is measured and how success is evaluated.

Existing transition research indicates higher age was associated with transition readiness. Positive correlations were also found with factors such as high levels of knowledge, cognitive ability, and psychosocial function [1, 2]. This is significant because it is recognised that AYA's with epilepsy can have deficits in all these areas, which further complicates their transition [1, 2, 10, 17]. They found that successful transition was aided by care that managed seizures and actively acknowledged psychosocial and mental health needs. Collectively these studies concluded that further understanding and transition programs based on identified best practice models were still needed.

Additional studies converge to highlight the research gap for more knowledge around transitional needs and program design. Research states that AYA's need a process that recognises their individual needs delivered by upskilled clinicians to ensure a smooth transition and optimal care [18, 19]. Authors found that despite national recommendations transition discussions and processes were not routinely happening [1]. A significant finding was that adult health providers reported low-levels of confidence in dealing with complex forms of childhood-onset epilepsy. This finding was supported by Tirol and Kumar [20] whose qualitative study of resident doctors found most respondents rated their transition knowledge as very minimal. Respondents reported a lack of exposure to transition processes and the need for improved training.

These findings indicated there are common factors that provide benefits and challenges which this review study sought to further explore.

AIM

The aim of this project was to conduct a scoping review of published literature to examine what is known about current transition practises. Specifically, to understand what is beneficial and what are the ongoing challenges experienced by AYA's at this time. It is important to clarify and define these findings so they can then be generalised or transferred to further benefit Australian youth with epilepsy. This is crucial because transition programs that do not meet a young person's needs increase the incidence of disengagement leading to an increased risk of treatment failure and increased disease burdens.

METHOD

A scoping review was conducted using the Arksey and O'Malley [21] framework in conjunction with PRISMA ScR methodology [22]. These are both established conventions that provided stand-alone systematic methodology for mapping literature on a broad topic from a broad range of study types [21, 23]. The following sections describe the process used.

RESEARCH QUESTION IDENTIFICATION

Early investigations indicated that there were several potentially relevant studies, but each examined different elements of transition and were not overarching in their findings. For example, some studies assessed a singular trial transition program, or mental health experiences of patients. This paper therefore sought to review several studies for a holistic understanding of the issues and benefits effecting these young people by asking: "What are the benefits and challenges for paediatric patients with epilepsy as they transition into the adult healthcare system in Australia?"

STUDY IDENTIFICATION

Date Collection:

This study reviewed published literature using a search criterion based on key words from credible, peer-reviewed articles published in the last five years. This time frame was chosen because transitional care is an expanding area of research as increasing numbers of children with chronic health needs age out of paediatric systems [16, 18, 24]. At the same time, modern healthcare has increasingly separated children and adults' hospitals with purpose built paediatric hospitals. Transition processes, therefore, now effect a larger group of people across a wider chasm. Consequently, it was, important to explore contemporary literature to examine this emerging area of practice.

Data Bases:

This search used online data bases; WorldCat.org, ABI/INFORM Collection, Gale Academic OneFile, and ERIC. They were selected because they offer a wide range of peer reviewed articles that have been tested by experts and validated to ensure credibility.

Search Terms:

Transitional care for young adults with epilepsy in Australia and Transitional care for young adults with epilepsy. These terms target key words of transitional, young adults, epilepsy, and Australia. The search was then broadened by removing the word Australia to capture international articles that could offer commonalities and generalisable themes.

STUDY SELECTION

Inclusions

This review included all forms of empirical research concerning people with epilepsy aged 10-24 transitioning between paediatric and adult health systems. To ensure a complete examination this project placed no limits on the study types included. Where possible, the project sought to examine literature describing the Australian healthcare system but as this information was limited, international studies were also reviewed for transferable findings. All forms of healthcare and allied healthcare services for people with epilepsy were included as were all forms of service delivery such as, face-to-face, telehealth, hospital, etc.

EXCLUSION CRITERIA

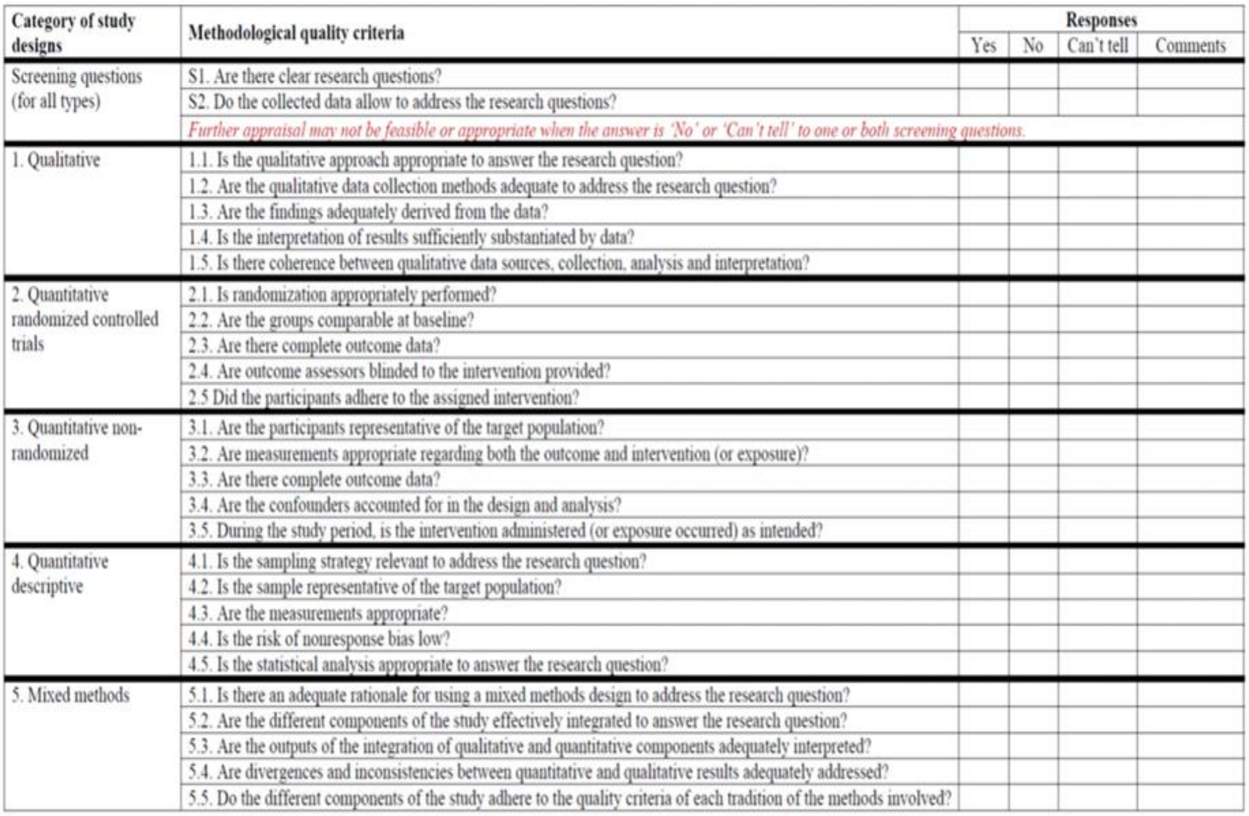
This study excluded articles not published in English due to time factors associated with translation. To further exclude unsuitable articles this study used the PRISMA ScR flow method for selection.

ARTICLE QUALITY ASSESSMENT

To ensure the quality of included articles a quality assessment was conducted using the Mixed Methods Appraisal Tool (MMAT), 2018 version 17 [25]. The assessment tool is reproduced below in Figure 1.

To achieve consensus for article quality, a dual review was undertaken. Studies considered for selection were reviewed independently by each author to determine appropriateness for inclusion or exclusion. This process examined and scored the search results against the MMAT to ensure unison for article quality and integrity.

FIGURE 1. QUALITY ASSESSMENT TOOL



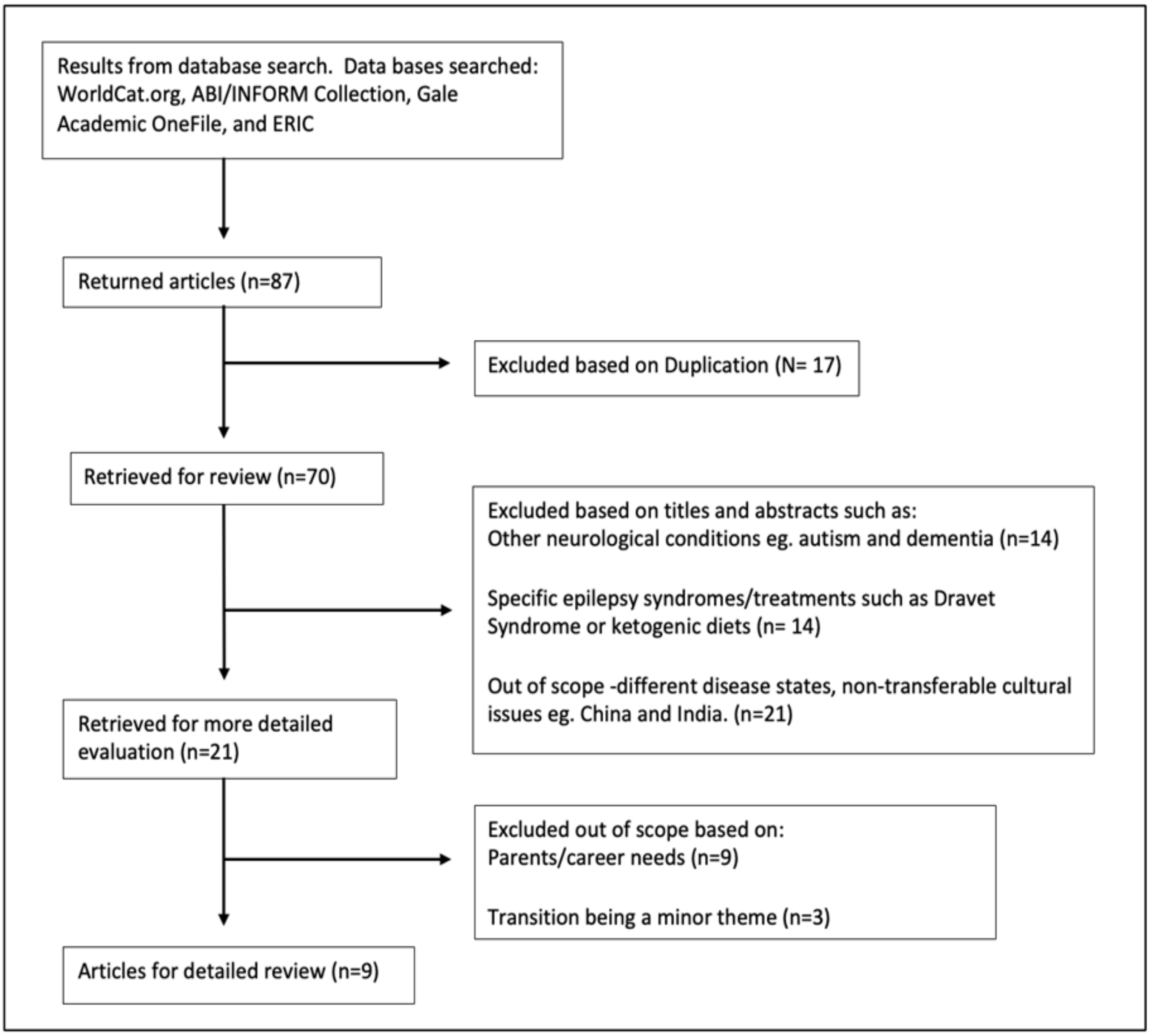
Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Sourced: Methods Appraisal Tool (MMAT), 2018 version 17.

SEARCH RESULTS

The initial search term returned only 65 articles, after removing the term Australia this increased to 87 peer-reviewed articles. The small number of articles generated is indicative of the limited information available on this emerging topic. Duplicates were excluded as were a further 28 studies as they were out of scope for example, relating to other neurological conditions, or relating only to specific epilepsy conditions or treatments. 21 studies were removed as they were outside of scope discussing: different disease states, or non-transferable international issues. Abstracts of the remaining 21 were read and a further 12 were deemed out of scope, for example: focusing on parents/carer needs or discussing transition as a minor theme. This produced nine remaining articles suitable for inclusion, see Figure 2.

FIGURE 2. ARTICLE SELECTION



Source: Adapted PRISMA flow diagram (2020) https://prisma-statement.org/PRISMAStatement/

CHARTING, SUMMARY AND REPORTING

The selected articles were read for in-depth analysis and interpretation. Data were extracted from each paper in accordance with key findings and comparable themes. This information was charted in a spreadsheet as seen in Table 1.

Continued analysis of themes allowed for categories to be charted as commonalties and overlapping findings were identified and summarised. These were identified and coded according to five categories focusing on factors that benefited transition. They were relationships and continuity, capacity building, process, health services and systems, mental health, and comorbidities, as seen in Table 1.

These categories were then further condensed into four key area that grouped common elements in accordance with factors that contributed to successful transition for AYA's as seen in Table 2. This process of data analysis and charting produced a descriptive account of transitional elements that contribute clarity to the research topic.

TABLE 1. ARTICLES SELECTED

	Author/Year	Design	Title/Objective	Outcome/Findings	Benefits/Strengths	Challenges/Barriers
1	Smith et al., 2020 USA	Qualitative cross sectional	Modifiable factors related to transition readiness in adolescents and young adults with epilepsy	Need for epilepsy specific transfer readiness to identify targets for intervention. Age must be matched with factors such as knowledge, psychosocial/cognitive functioning Target modifiable social-ecological factors	Start transition conversations early Target modifiable factors Work with families Gradual process Individualised plans	Low cognitive function Insufficient knowledge Provider discomfort Family concerns
2	Reger et al., 2021 USA	Mixed methods	Development of the transition-age program (TAP): Review of a pilot psychosocial multidisciplinary transition program in a level 4 epilepsy centre.	Screen for readiness, and neurological comorbidities. Develop skills of selfcare and decision making. Build lifestyle factors for participation. Effective communication. Develop targeted individualised care plans before transition begins.	12 -13 start discussions Initiate plan 14 -15 years Individualised plan	Anticipatory anxiety Untreated neurological comorbidities
3	Stefanidou et al., 2020 USA	Literature Review	Mental health issues in transition-age adolescents and young adults with epilepsy.	Transition programs are promising methods for improving patient engagement and empowerment	Span 13 – 19yrs Educate, Build relationships Screen for mental health	Depression and anxiety Intellectual disability
4	Goselink et al., 2022 Sweden	Systematic review	Transition to adult care in epilepsy: A systematic review	Found gaps in knowledge for what constitutes efficacious transition. More study required to understand patient and family need of services Needs of AYA with ID vs needs of normal ID function without comorbidities. Start transition early 12-16 years, meet with adult team before transition	Planned transition enhances outcomes Multidiscipline teams Central coordinator Patient centered communication	Behavioural and cognitive problems effect transition more that epilepsy Anxiety and depression
5	Baca et al., 2018 USA	Longitudinal Qualitative study	The epilepsy transition care gap in young adults with childhood-onset epilepsy.	Only 15% of all cases had transition care discussion with provider before 18yrs. Higher rates for those with active epilepsy 31% compared to 4% for inactive. Participants would have expected earlier discussions. Epilepsy transition includes management of seizures, mental health and psychosocial needs. Presence of ID does not change the need for discussion, just the nature of discussion.	Early discussions Multipronged care Joint clinics Structured models	Low relationships Lack of definition Low knowledge
6	Le Marne 2018 Australia	Quantitative Likert-type scales Qualitative questions	Implementing a new adolescent epilepsy service: Improving patient experience and readiness for transition.	Age-appropriate education, self-management strategies and mental health support improve patient outcomes. 45 teens mean age 15.7yrs, 44 parents/care givers. Reduce attendance burden, create social opportunities	Upskilled staff Start transition early Include mental health	Attendance burden Lack of understanding Mental health stigma
7	Mc Govern et al., 2018 France	Qualitative OYOF-TES questionnaire and visual analogue scales	Making a 'Jump' from paediatric healthcare: A transitional program for young adults with chronic neurological disease.	Multidisciplinary and coordinated approach to transition leads to high satisfaction among patients and families. Coordinating nurse specialists were key to success. 111 patients, mean age of 19.7yrs 33% had epilepsy, 23% had etiology that didn't fit the main categories of neurological disease including: undiagnosed epilepsy, work ups in progress and functional symptoms. Study conducted in large hospital setting and may not transfer to smaller facilities, but guiding principles are still beneficial.	Multidiscipline teams Nurse coordinators Holistic Allied health team Tailored transition plans	Diverse neuro conditions How to quantify satisfaction and measurement Transition timing difficult for AYA
8	Burke et al. 2018 UK	Scoping review Includes papers from 2001 - 2016	The transition of adolescents with juvenile idiopathic arthritis or epilepsy from paediatric health-care services to adult health-care services: A scoping review of the literature and a synthesis of the evidence.	Found – lack of definition for a successful transition and lack of research evaluating effectiveness of interventions to support YP transitioning. Consensus on need and importance but no model. Study included Epilepsy and Juvenile Idiopathic Arthritis (JIA) epilepsy was a significant theme.	Strong relationships Continuity of health professionals Individualised approach Programme coordinator Education	Paucity of information Different protocols across hospitals Poor coordination between services
9	Tirol et al., 2020 USA	Qualitative	Resident training in transitioning youth with epilepsy into adult care	Educational interventions will improve transition process for patients.	Health professional Training and mentorship	Lack of/gaps in training and experience

TABLE 2. KEY CATEGORIES AND ELEMENTS OF SUCCESS

Theme	Elements of success
Relationships and Continuity	Patient centred care Include caregivers High quality relationships Confident practitioners Designated program coordinators
Capacity Building	Address comorbidities eg. cognitive deficits, mental health Provide epilepsy education and care Address psychosocial needs – school, vocation, housing, social Individual plans Create social opportunities
Process	Patient age and readiness Patient needs and goals Preparation and timing Multidisciplinary teams Joint transition plans
Health Services/systems	Upskilled clinicians Multidisciplinary teams Measurement scales/frameworks eg. readiness and outcomes Resourcing Utilise NGO's and support groups

RESULTS

RELATIONSHIPS AND CONTINUITY

An early theme to emerge in this review was the emphasis on high-quality relationships and continuity of care. Researchers consistently stated the importance of building relationships, working collaboratively, and understanding the viewpoints of patients and parents/care givers [1, 15, 17, 18]. It was stated specifically that nursing kindness and health professionals' interpersonal care were key predictors of patient satisfaction as were designated programme coordinators [18, 26]. These coordinators (often nurses) were credited with providing a consistent point of contact that facilitated and strengthened connections [15, 17, 18]. Authors' recommendations focused on building strong interpersonal relationships as a means of building trusting connections that foster AYA empowerment [3]. Multiple studies noted the importance of working collaboratively with AYA's families and care givers as key stakeholders in conjunction with the AYA patient, care provider and care system [1, 18]. This can be done by including families during the transition process to ensure their concerns are addressed and they are involved in capacity building education [15, 18]. Also noted was the importance of effective communication between treating practitioners, for example paediatric and adult teams [19].

CAPACITY BUILDING

Another strong theme in the analysis, was the need to recognise comorbidities commonly experienced by AHA's with epilepsy. This was included within the capacity building category to recognise that AYA's with epilepsy experience higher rates of intellectual disabilities, conduct disorders, and psychiatric comorbidities that amplify transition difficulties [2, 3, 17]. In particular, researchers noted that behavioural and cognitive problems affect AYA's transition more than epilepsy [17]. As such, this should take priority. Research states that programmes should screen for comorbidities and include treatment pathways as part of transition preparation. They state that capacity building was strengthened by developing self-esteem and including protectors against psychiatric conditions [15, 17, 19]. Further capacity is enhanced through education, self-management, and skill building by focusing on modifiable factors such as knowledge, psychosocial, and cognitive capacity [2, 3, 26]. Importantly, it is recommended that transition programs are adapted for AYA's with cognitive impairment whilst considering behavioural and emotional problems of all participants [1, 15, 17].

Further analysis concluded that transition preparation should be a gradual process of age-appropriate, goal orientated education, and skill building [2, 18, 19]. Recommendations focused on building individualised and tailored plans that could respond holistically to AYA's psychosocial needs as part of their epilepsy healthcare. Participants were reported as requesting 'teen-friendly' clinics and opportunities for social and peer support from other teens [2]. Researchers concluded that transition is challenging but critical and education and self-management strategies can improve patient outcomes [2, 15, 19, 26].

PROCESS

Another consistent theme in the data chart was that of patient age and readiness. The research recognised that transition processes were dependant on the patient being prepared for transition according to their individual needs and goals. The findings stated that successful transition was enhanced by organised, multidisciplinary teams who worked together on joint plans. Studies concur that plans individually tailored and delivered by teams reduce anticipatory anxiety and enhance transition processes [19]. For example, these teams may consist of neurology specialists, epileptologists, clinical nurses, coordinating staff and include allied health such as sexual health nurses, occupational therapists, and social workers [2, 19].

Significantly, patient age was frequently discussed within the research. Authors noted that there was no fixed age for transition, rather, transition is a process that should span several years and is dependent on the individual [1, 3, 15]. Studies found that higher age was associated with readiness and that preparation discussions should begin between 10-13 years [3, 19]. Further research supported the introduction of transition discussions beginning at 12-13 years with initiation by 14-16 years. Studies concluded that benefits were gained by early planning followed by more targeted interventions just prior to actual transition at or around of 18 years [1, 3, 17, 19].

In an Australian setting, it is important to note that transfer taking place at 18 years coincides with the final year of school for most students. This may involve study commitments, exams, vocational preparation, tertiary study transition and end of school rites of passage. This is a complex and busy time that highlights timing and scheduling as a potential barrier for appointment attendance and engagement.

HEALTH SERVICES AND SYSTEMS

The management of health services and systems is another key element in the successful transition to adult care. Health system continuity issues were found to contribute to shortfalls in transition services [1, 26]. This presents as different treatment protocols, working methods, infrastructure, and priorities between service providers [2, 20, 26]. For example, it was noted that paediatric and adult health professionals may not know each other or understand each other's protocols and treatment models [18, 26]. These observations provide transferable cautions for health service providers and managers in Australia as a lack of coordination and appointment delays risk eroding patient engagement.

Further barriers to transition came from discordance between care models and low confidence levels of health providers [1]. Cautions for service providers came from findings that despite national recommendations, transition discussions and processes were not routinely happening. Some providers reported low-levels of confidence in dealing with complex forms of childhood-onset epilepsy [1]. This finding was supported in a qualitative study of resident doctors that found most respondents rated their transition knowledge as very minimal [20]. Respondents reported a lack of exposure to transition processes and the need for improved training. However, both studies were American and drew from small cohorts. Further evidence is needed to determine how prevalent these findings are and to what degree they apply to Australia.

Another theme identified as a barrier in AYA transition, was how transition readiness or success is measured and reported. Studies have noted that empirical data on transitional best practices is limited, and outcome measures are inconsistent, for example, how and when are transition outcomes measured [18, 26]. Transition is an ongoing process which means programmes may need longitudinal assessment to gauge their effectiveness [2].

Detailed analysis of the papers included in this study provided clear evidence of common themes that can be used to guide transition practice. A summary of these benefits and challenges can be seen in Table 3.

TABLE 3. KEY THEMES OF BENEFITS AND CHALLENGES.

Benefits – What works	Challenges – What hinders
High quality relationships	Comorbidities – mental health, cognitive deficits
Addressing psychosocial needs Capacity building through education	Psychosocial burdens
Individualised, tailored, and targeted programs	Parental/care giver transition anxiety
Multidisciplinary teams with designated coordinators	Practitioner inexperience or confidence gaps
Correct preparation and timing	Appointment burdens, time, access, expense
Continuity of care	Absence of measurement frameworks and empirical care models

FUTURE DIRECTIONS

This scoping review identified several elements that aide in answering the research question to understand the challenges and benefits for young Australians with epilepsy as they transition between healthcare systems. The results indicate the main categories to consider as health service managers are the timing and preparation of programs, which must be delivered by multidisciplinary joint teams with designated coordinators. Programs need to collaborate with patients and families to build individualised plans. In addition, these programs need to include strategies and adjustments to address the high prevalence of psychological, behavioural, and cognitive issues experienced by this cohort. While progress is being made in the transition area there is opportunity for further research as to how transition readiness is assessed and how successful transition is measured particularly in Australia. Investing in well-developed upstream transition programs will contribute to closing detrimental and expensive treatment gaps while improving long term health outcomes [10, 27, 28]

LIMITATIONS

A limitation for this study is the exclusion of disease states other than epilepsy. It is acknowledged that other disease areas could offer insight and value for improving transition processes but fall outside the scope of this review. A further limitation is that studies reviewed had a low prevalence of minority groups and transition data was drawn from metropolitan areas in well-resourced countries. As such the findings may not reflect the impacts for people living with different sociodemographic factors or in remote or regional areas. Further research is needed to understand the health and access disparities for people in these groups, particularly for First Nations Australians.

DECLARATION OF CONFLICTING INTERESTS

The Authors declare that there is no conflict of interest.

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