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Abstract

Background Due to medical advances, growing numbers of adolescents with congenital heart disease (CHD) survive into adulthood, and transferring from paediatric to adult healthcare. This transfer is significant step in a young person's life and this study examines the views of Irish healthcare professionals' on how best to manage this transition.

Methods Purposeful sampling was used to invite participation by healthcare professionals (HCPs) from a variety of disciplines whose caseloads include adolescents and young adults with CHD. Fourteen professionals participated in semi-structured interviews regarding their experiences of the transition process and their recommendations. Data were collected during Spring 2016, and analysed using Thematic Analysis.

Results Results indicated that the current approach to transition and transfer could be improved. Professionals identified barriers hindering the transition process such as: cultural and attitudinal differences between HCPs dealing with child and adult patients, inadequate preparation and education of patients about their condition, parental reluctance to transfer, and concern about parents' role in on-going treatment. Measures such as better support and education for both the patients and their parents were recommended, in order to facilitate a smoother transition process for all parties involved. Additionally, HCPs identified the need for better collaboration and communication, both between paediatric and adult healthcare professionals and between hospitals, to ensure greater continuity of care for patients.

Conclusions Action is required in order to improve the current transition process. Measures need to be taken to address the barriers that currently prevent a smooth transition process for young adult CHD patients. Professionals recommended the implementation of a structured transition clinic to deal with the wide variety of needs of transitioning adolescent patients and their families. Recommendations for future research are also made.

Introduction

It is estimated that 90% of children born with congenital heart disease (CHD) will survive into adulthood (Schwerzmann, 2012) and manage to live meaningful lives (Knauth *et al.*, 2006). CHD ranges from simple to complex cases, but anyone born with CHD benefits from lifelong healthcare. For this reason, a number of studies (e.g. Mackie *et al.*, 2014; Schwerzmann 2012; Wacker *et al.* 2005) have highlighted the benefits of supporting adolescents with CHD to transfer from paediatric to adult healthcare in a timely and structured manner. Such transfer is a significant step for an adolescent marking the beginning of their journey as an adult, responsible for the management of their condition. It entails departure from familiar medical staff and hospital context, and learning to negotiate a new medical context. ‘Transfer’ refers to the event/series of events when the actual shift of care from paediatric to adult providers occurs (Knauth *et al.*, 2006), whereas ‘transition’ refers to an active and multi-faceted process that encompasses the medical, psychosocial, and educational needs of the adolescents as they move from paediatric to adult services (Blum *et al.*, 1993).

A poor transition can result in lapses in care and loss to follow-up, with consequences such as greater risk of needing urgent interventions, increased morbidity, greater likelihood of a diagnosis of a new cardiac condition, and emotional stress for the patient (Gurvitz & Saidi, 2014; Yeung *et al.* 2008). Internationally, it has been found that few adolescents with CHD successfully transfer to adult care (Bohun *et al.*, 2015; Moons *et al.*, 2010; Wacker *et al.*, 2005) and show a significant decline in clinic attendance after transferring to adult care (Heery *et al.*, 2015). This highlights the need for routine provision of transition programmes for adolescents with CHD in all paediatric units to facilitate a smoother transition to adult care.

The goal of transition programmes is to provide uninterrupted healthcare that is patient-focused and age-appropriate (Knauth *et al.*, 2006) while maximising the patient’s quality of life and future opportunities (Blum *et al.*, 1993). While the patient is the focus of transition, other significant participants include the patient’s family, paediatric and adult cardiologists, nurses, psychologists, and other healthcare professionals (HCPs; Bronheim *et al.*, 1995; McDonagh & Kelly, 2003). The America Heart Association (Sable *et al.*, 2011) accords HCPs a central role during the transition process. However, while many studies have focused on CHD patients’ experiences of transition, relatively few have focused on HCPs’ experiences. To our knowledge only four previous studies (Clariza *et al.*, 2009; Fernandes *et*

al., 2012; Hilderson *et al.*, 2009, Sparud-Lundin *et al.*, 2017) have explored the views and opinions of HCPs working with adolescents with CHD transitioning to adult care.

Those studies used surveys, eliciting useful information on the relatively unexplored topic of the professionals' role in the CHD transition process. The present study seeks to complement these previous survey studies, using qualitative methods to explore HCPs' experiences and views in greater depth. It also explores this topic in a previously less-examined context by looking at the CHD transition experience in the Republic of Ireland. Semi-structured interviews were used to elicit professionals' views on their role and involvement in preparing adolescents for adult services. Following the analysis of data, recommendations are made to facilitate the transition process.

Methods

Design

A qualitative research design was chosen in order to gain exploratory insights into transition for CHD in Ireland, where no "formal" transition programme was in place at the time of the interviews (Spring, 2016). The interview protocol was developed based on previous research carried out in the area of transition for CHD and other chronic illnesses (Clariza *et al.*, 2009; Fernandes *et al.*, 2012; Por *et al.*, 2004; van Staa *et al.*, 2011). A multidisciplinary group of HCPs working with adolescents and young adults with CHD took part in semi-structured interviews focused on transition for CHD patients. The study gained ethical approval from participating institutions.

Sample

Purposeful sampling was used to identify participants with particular expertise and experience with CHD patients up to, during and/or after they transferred to adult care. All invitees were either members of the cardiology team in a major paediatric hospital or linked to the cardiology team in a major adult hospital. In the Republic of Ireland, one paediatric hospital is responsible for the care of all CHD children in the state. Similarly, one adult hospital specializes in caring for all adults with CHD. However, if a young adult's CHD is mild in nature and they do not live in the area of the major adult hospital, their care is transferred to the cardiologist in a local hospital. In the paediatric hospital, the cardiology team at time of data collection comprised 23 HCPs, including seven cardiologists, three surgeons, six clinical nurse specialists, two social workers, two psychologists, one SLT and two dieticians. The main congenital heart team in the adult hospital consisted of one cardiologist, two surgeons,

and two clinical nurse specialists. All (23) HCPs were sent an information sheet describing the study and invited to participate. Fourteen HCPs were interviewed, including cardiologists, surgeons, psychologists, social workers and clinical nurse specialists. Twelve participants worked in the paediatric hospital and two in the adult hospital. Participants were assigned a code to protect their identity and these are used when reporting the results.

Data Collection

After receiving the information sheet, staff members interested in taking part contacted the researcher to organise an interview. All but one of the interviews took place in the hospital setting. The remaining interview was done by phone for that participant's convenience. The interview protocol addressed both the current and ideal transition practices in Ireland, as well as changes that HCPs would recommend. The first author carried out all interviews in order to maximize consistency between participants. All participants were asked the same set of 10 pre-determined open-ended questions as set out in the protocol granted ethical approval. These covered three areas: (1) general information such as participant's role and involvement in the transition process; (2) their knowledge and perception of current transition practices in the hospital; and (3) their views on ideal transition practices. The semi-structured aspect of the interview facilitated focus and comparison between interviewees' data by ensuring consistency in the topics covered and the wording of the questions. However, discussion of related issues was also accepted, ensuring that issues considered relevant by interviewees, but not in the interview protocol, could be included, maximising the richness and breadth of the data. Interviews lasted on average 24 minutes (range 10 -30 minutes) and were audio recorded.

Data Analysis

Each interview was transcribed verbatim and the data were analysed using Thematic Analysis (TA), a method of qualitative data analysis well suited to healthcare research (Braun & Clarke, 2014). TA does not require adherence to any particular theory of language, or explanatory meaning framework for human beings or experiences (Clarke & Braun, 2013). Data analysis followed the steps outlined by Braun and Clarke (2006), including familiarisation with the data, label/code generation for meaningful units, identification of themes by grouping codes, and checking themes for overlaps and comprehensiveness. Following O'Driscoll et al. (2015) and Rubin & Rubin (2005), a combined inductive and deductive approach was considered most appropriate for the analysis. This meant that the

researchers identified themes as the data were analysed, and sought to apply a sensitive and comprehensive coding to the data, but that theories and previous research findings were also used in a deductive manner to help interpret themes emerging from the inductive analysis.

To enhance the trustworthiness of the analysis, both researchers were involved in the development of the coding frame and its first application to a number of transcripts, resulting in revisions to the frame. The first author then applied the revised coding frame to the entire data set. To assess inter-rater reliability, we followed Ridge and Guerin (2010) in having the second author code two randomly selected interviews using the revised coding frame; this comparison showed an inter-rater reliability level of 72%, meeting Guerin and Hennessy's (2002) recommendation of at least 70% agreement. Following discussion of the non-agreement, the coding frame was further amended to enhance clarity in coding the remaining transcripts.

Results

Analysis of the interviews identified 8 main themes (see Figure 1) related to three topics: Current approach to transition and transfer, Barriers to transition and transfer, and Recommendations for future action to support positive transition. The main themes are explained in greater detail below, supported by quotes from the interviews.

Insert Figure 1 about here

Topic 1: Current approach to transition and transfer

Participants' opinions of the current transition practices for CHD in Ireland formed the core of the first topic. While some positive elements were noted about the current approach, there was a consensus that the process could be improved (see Table 1).

Insert Table 1 here

Theme 1.1: Current versus ideal approach to transfer

Professionals considered the current approach to transfer of adolescents with CHD as somewhat disorganised, and tending to be managed on an "ad-hoc" basis. Participants observed that this can confuse and disempower the adolescents and their parents, resulting in what one participant (P24) described as "*a feeling of un-safeness*" and another as "*disenfranchising for the family*" (P7).

Participants overwhelmingly noted the need for a decisive plan for the transfer process, as well as consistency in its implementation. Over half recommended a gradual approach to

transition, with preparation for transfer beginning with the child and family in an age-appropriate way, some years before it occurs. It was emphasised that transition should not be “*an overnight thing*” where the patient “*lands in suddenly, no notes, no nothing, and nobody knows who they are*” (P12).

Theme 1.2: Timing of transfer

Currently transfer to the adult hospital is judged mainly on the patient’s age, with the appropriate age deemed to be between 16 and 18 years, or the end of second-level education. However, participants stressed that flexibility is needed so that an adolescent’s ability, readiness and maturity, both emotionally and physically, as well as their health status can also be taken into account.

“[so] that they (the adolescents) would have the maturity to be able to bring themselves to be looked after and not depend on their families,...be able to access care and go to clinics on their own”

(P18)

However, four participants pointed out that resources influence the timing of the transfer, including the availability of personnel in the adult hospital to take over care, or waiting list length. They saw this as an inappropriate way to judge the timing of the transfer.

Topic 2: Barriers to transition and transfer

Participants identified a number of barriers to a smooth transition process that need to be addressed, summarised in Table 2.

Insert Table 2 here

Theme 2.1: Cultural differences between the two systems

Interviewees identified significant “cultural differences” between the paediatric and adult services that can make the transfer challenging for patients and parents, noting that adult services can appear impersonal and business-like compared to children’s services. The level of support from social work and psychology may decline in the adult system, depending on the patient’s condition, which can be “*quite isolating*” (P7) for patients. It was particularly noteworthy that adult HCPs expect considerably less involvement from parents, and this can lead to problems when the patient is not prepared and fully informed of his/her condition, and parents feel suddenly excluded.

However, while acknowledging differences between the two systems, some participants reported that many adolescent patients welcome the move to adult services and see it as a “*graduation for them*” (P13). It was noted that the two adult HCPs emphasised this positive side of transition significantly more than the paediatric HCPs, who tended to focus on the challenges of transition. This suggests that another cultural difference between the two systems is the differing view of transition among paediatric and adult HCPs, and points to the value of promoting greater collaboration between the two groups.

Theme 2.2: Protection of CHD patients by parents and paediatric system

All participants acknowledged that transition can be stressful for the adolescent and his/her family. However, a strong theme emerged regarding their perception that patients are “*over-protected*” by their parents, with a parallel “*over protection*” of both parents and patients by the paediatric staff combining to make transition more difficult for all involved (see Table 2).

HCPs commented on what some perceived as ‘over-protection’ of CHD patients by their parents, limiting their developing independence. They reported that some adolescents are not aware of the reality of their condition or involved in treatment decisions, due to parents’ protective desire to offer a ‘normal childhood’. Interviewees noted that this can cause significant difficulties when these patients transfer to adult care, as they are insufficiently informed to consent in matters of their healthcare and are “*not empowered to be thinking of taking care of their own medical care.*” (P20).

Not only did some HCPs claim that CHD patients are “over-protected” by parents, but some also noted that parents can, in turn be over-protected by paediatric services’ culture of holistic care which “*fosters over-dependence*” (P18) on the hospital. One interviewee described this over-dependence as the paediatric hospital becoming “*their life and their bubble*” (P12). While such support is critical at certain junctures, it makes leaving the paediatric hospital both practically and emotionally challenging for families.

Theme 2.3: Parental resistance versus adjustment to transition and transfer

Participants identified a central role for parents in the transition process, but a significant theme to emerge (see Table 2) related to the observation that the transition can actually be “*much more difficult for the parents than for the child*” (P24).

Some HCPs identified benefits for patients in transferring to an adult service that supported their own sense of self-efficacy, but acknowledged that parents may fear being marginalised by their changed role in the adult hospital. Consequently, some parents respond

negatively to transitioning to adult services, showing reluctance to leave, resistance to change, and lack of trust in the unfamiliar adult service. Participants commented on the struggle of “*convincing parents to begin to handover care to their child for their medical condition*” (P8) after years of bearing this responsibility. There was agreement among HCPs that parents need to “*recognize that they [patients] are mature enough to understand their own condition*” (P16), but their reports of parents’ difficulties with transition point to the need for a more phased approach to family preparation. A greater understanding among HCPs of factors that contribute to this struggle among parents would be helpful in facilitating positive transition, and such adjustments are considered below (see Figure 2).

Insert Figure 2 about here

Topic 3: Recommendations for future action to support positive transition

Participants recognised that the quality of the transition services provided to adolescent CHD patients and their families could be improved.

Insert Table 3 about here

Theme 3.1: Preparation: the need for education, and support

Eleven participants agreed that, currently, adolescents are not sufficiently prepared to transfer to adult hospital, and require better education and support during transition (see Table 3). Professionals reported that it is common for CHD adolescents to be unable to describe their condition and to lack important information about their medication, relying unduly on their parents in this regard. Incomplete knowledge and understanding of their condition can be problematic when entering into adult services. Thus, it was judged to be critically important that CHD patients are educated by HCPs and parents to assume responsibility for their own healthcare in a gradual and age-appropriate fashion to prepare them for adult services where “*the spoon-feeding will be over*” (P17).

It is important that medical information provided is age-appropriate and accessible, and can be reviewed and consulted regularly. Some participants suggested providing patients’ medical information in a small pack or on an encrypted memory stick so that he/she can access it as necessary. Given the age group involved, another option would be to prepare a mobile application with this information in accessible format. Two participants noted that web-based information is effective in engaging adolescents, as “*teenagers quite like [that], rather than the face to face or phone call*” (P14). Another practical method of providing

information suggested by three participants was providing a 'Health Passport' for patients, briefly listing interventions and treatment.

Along with the provision of education, it was recognised that patients must also be supported through transition. . Five participants emphasised the importance of providing “*a lot of psychological care, as it is a big change*” (P11). Some suggested that patient groups and charities could provide welcome guidance and support to adolescents. Hospital staff are under resource- and time-pressure, so the possibility of sourcing support from support organisations could be investigated further.

Theme 3.2: Need for greater coordination and collaboration

Participants noted that without coordination between professionals and institutions involved in transition, transition will not proceed smoothly (see Table 3). The preferred transition model appeared to be a multidisciplinary approach that fosters collaboration between professionals and hospitals, leading to the formulation of a gradual, age-appropriate and individualised transition plan. While some collaboration already occurs, over half the participants highlighted the need for “*better communication between the two hospitals*” (P9) to improve transition practices. Some participants suggested that this could be achieved by ‘*Outreach clinics*’ allowing staff from the adult hospital to meet patients in the paediatric hospital before transfer. Additionally, participants advocated adopting a combined care approach between the two hospitals, in which professionals from both hospitals come together to discuss a plan for patients’ future care before transfer.

Theme 3.3: Policy and practical changes needed

Participants maintained that policy and practical changes are required to improve transition services for adolescent CHD patients (see Table 3). Professionals are aware of the importance of transition planning becoming the norm, and a process that parents and patients are aware of early in treatment. Promoting children’s involvement in their care would benefit from a multidisciplinary approach monitored by the paediatric hospital’s psychologists, so that children or parents who experience difficulties can be supported.

Participants identified changes that would facilitate transition but would require a joint commitment by both paediatric and adult hospitals. Half of the participants believed that providing a ‘*Transition Clinic*’ in the familiar setting of the paediatric hospital would make transition easier for patients. Other proposals centred on promoting familiarity with the adult

hospital: seven participants recommended introducing visits by adolescent patients to the adult hospital before they transferred, to orient them and help them feel more comfortable there.

Finally, some participants argued that, before transfer, patients need to see HCPs without their parents, so that sensitive issues “*you don’t want to discuss in front of parents*” (P14) such as “*what alcohol they can drink, smoking, exercise, sexual health*” (P13) can be addressed without embarrassment. Not only would this help to offer important health information to the adolescent, this practice would prepare the adolescent for how adult services are run, and develop their independence and autonomy. Figure 3 summarises the principal recommendations identified by HCPs.

Insert Figure 3 here

Discussion

This study aimed to explore Irish HCPs’ experiences and views of the transfer from paediatric to adult care for adolescents with CHD. The data indicated that the current approach to transition and transfer could be improved, and participants identified some of the barriers to successful transition to adult care. They also recommended a number of measures that could improve the process, including provision of better education and support to the adolescents and their families and improving levels of collaboration between professionals and hospitals.

The overall findings of this study are consistent with previous research on this topic. Adolescent patients with chronic illnesses have repeatedly been found to have poor knowledge of the specifics of their condition (Clariza *et al.*, 2009; van Staa *et al.*, 2011). This is despite research showing the need for patients to have detailed knowledge of their medical condition and history and the signs of possible complications in order to be able to function independently in adult healthcare (Williams, 2015). International guidelines recommend the provision of comprehensive education regarding their condition to the adolescent patient from a young age (Hilderson *et al.* 2009; Webb *et al.*, 2015).

There has been extensive research on the issue of timing in the transfer of care. Here, participants’ views are in line with international recommendations, in seeing age as a general indicator of when transfer should occur, but also taking each adolescent’s physical and emotional maturity into account, and their medical and developmental status (Warnes *et al.*, 2008; Sable *et al.*, 2011; Stout *et al.*, 2015). The importance of flexibility was emphasized

when judging when transfer of care should occur, and the need to adjust the timing to patients and their family.

The barriers to the transition process identified here, such as ‘over-protection’ of patients by parents, and parents’ reluctance to transfer, are similar to those found in previous studies (Clariza *et al.* 2009; Fernandes *et al.* 2012). Parents need to be informed and supported by HCPs in promoting their child’s partnership in their own healthcare and sharing the responsibility with them, to shifting that responsibility to their adolescent. Clariza *et al.* (2009) found that parents who took complete responsibility for their child’s healthcare inhibited the child’s development of confidence and independence regarding their own healthcare.

However, there is clearly a need to strike a balance between encouraging independence in the adolescent patient and keeping parents involved in their care. Parents’ fears may, in fact, be well-grounded regarding their son/daughter’s inability or unreadiness to manage their condition and care independently (Knauth *et al.*, 2006). Furthermore, research has shown that the development of effective self-management skills in adolescents is positively influenced by parents’ involvement in their healthcare (De Lambo *et al.* 2004; Reed-Knight *et al.* 2011). Additionally, involving parents in the transition process eases their concerns and creates a feeling of security (Bratt *et al.*, 2016). What HCPs identify as ‘overprotective’ parenting practices needs further exploration, in order to understand better *why* parents act as they do, how parents construe the role of parenting a child with a significant chronic illness, and how they can adjust that role as the child develops. The facilitation of communication and education fostering a more collaborative approach between HCPs and parents during the transition process is likely to be more productive than what appeared among some HCPs to be a somewhat oppositional approach to parents currently.

An interesting aspect of transition revealed in this study related to the identification of cultural differences in approaches to paediatric and adult care. Van Staa *et al.* (2011) also noted that patients struggle to adjust to cultural differences between the two services, with paediatric care being seen as family-oriented and friendly, while adult services were seen as sterile and business-like. Furthermore, Sparud-Lingen *et al.* (2017) found that paediatric and adult staff differ in their opinions about the sufficiency in the level of support provided in adult healthcare, with paediatric HCPs rating it as considerably less sufficient than adult HCPs. Similarly, the data here indicated that paediatric HCPs had a more negative view of transition than staff in adult services. This difference may be conveyed unintentionally to adolescent patients, and shape their expectations of adult services. The findings here support

Van Staa et al's identification of HCPs' differing attitudes towards transition and adult healthcare as part of the cultural differences between paediatric and adult services that adolescent patients grapple with while transitioning. Ideally, therefore, it would ease the transition if staff in both paediatric and adult hospitals were enabled to present a more congruent view of transition and of adult services to patients. Bridging that contrasting cultures between paediatric and adult care is one of the key challenges for HCPs (van Staa et al., 2011).

Anthony et al. (2009) and Valenzuela et al. (2011) maintain that communication and collaboration between HCPs in both hospitals is vital for bridging this gap more effectively. This view is reflected in this study, and HCPs called for an increase in collaboration between disciplines in order to facilitate a multidisciplinary and holistic approach to transition as is recommended by international guidelines (Deanfield et al., 2003; Warnes et al., 2001; Webb et al., 2015). Professionals recognised the roles that various disciplines could play in transferring the adolescent. The significant impact that psychological support can play in the process was emphasized, recognising the need during the transition process to support the young person through any psychosocial issues that may emerge.

It is important to examine how the knowledge garnered from this study could be applied to clinical practice, particularly in contexts where establishing a transition clinic/programme remains to be addressed. There was general agreement that a transition clinic/programme for adolescents with CHD should be established promptly. Despite this, only one-third of paediatric services internationally provide structured preparation for patients with CHD (Hilderson et al., 2009). HCPs in this study are well aware of the benefits of a transition programme, and indicated that a transition clinic would be of maximum benefit if a number of factors were in place. These included that the transition clinic would run in conjunction with the adult and paediatric hospital, and that both paediatric and adult staff would be present. It was noted that adolescent patients should attend the clinic for a number of years prior to transfer. Additionally, professionals believed that the clinic should be multidisciplinary, with a staff of doctors, nurses, social workers and psychologists. These suggested practices are very much in line with international guidelines and with the findings of recent research (Sparud-Lundin et al., 2017) regarding increasing patient knowledge of their condition, improving treatment compliance, limiting high-risk behaviours and improving quality of life and psychosocial well-being (Moons et al., 2009).

Strengths and Limitations

This study explores the views and recommendations of HCPs in one hospital in Ireland, and the extent to which these findings can be applied to other settings is unknown. Additionally, there was limited representation of the adult side of transition with only two HCPs linked to an adult centre taking part. Given that paediatric providers sometimes overestimate reluctance to transfer and anticipated difficulties (van Staa *et al.*, 2011), this study may therefore over-emphasize the negative aspects of transition and transfer.

Nonetheless, this exploration of the views of a significant sample of the professionals working with adolescents with CHD in Ireland offers valuable insights, in taking into account the opinions of those working on the ground with the patients and their families. Combining these findings with other research findings and guidelines from international organisations makes the strongest case for change. A combination of the two levels of research examines the situation from the top down and bottom up, marrying the voice of those who design policy approaches with those who implement the system.

Future Research

This research points to the value of conducting a closer examination of the differences between paediatric HCPs' and adult HCPs' expectations and opinions of transition. Contrasts in HCPs' expectations about young adults' autonomy, self-efficacy and the role of parents causes cultural gaps between the two systems, making transition more challenging for adolescent patients. A better understanding of the expectations of adult HCPs would help guide paediatric HCPs when preparing patients for transfer. A study of parents' attitudes and expectations of transition would also help to identify how parents can be supported most effectively to facilitate transition and allow HCPs better understand parents' experiences, challenges and needs during the transition process.

Conclusion

This study highlights the urgent need for the establishment of a formal transition programme for adolescents with CHD, and the need for a more coordinated approach to transition, with better communication between HCPs involved in the process. This study provides important information about HCPs' views on transition and transfer that could serve to inform future transition practices.

Key messages

- Current transition practices are unsatisfactory and must be changed in order to prevent gaps in care and loss to follow up among adolescent patients.
- The transition period can be a difficult and challenging time for adolescent patients and their families. It is important that they are provided with education and support to equip them to navigate the process efficiently.
- Collaboration and communication between professionals and between hospitals needs to improve to ensure a multidisciplinary and holistic approach is taken to transition and transfer.
- The implementation of a structured transition programme or clinic with dedicated staff would significantly improve the transition experience for all parties involved.

References

- Anthony, S. J., Kaufman, M., Drabble, A., Seifert-Hansen, M., Dipchand, A. I., & Martin, K. (2009). Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *American Journal of Transplantation*, *9*, 614-619. DOI:10.1111/j.1600-6143.2008.02515.x
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, *14*, 570-576. DOI:10.1016/1054-139X(93)90143-D
- Bohun, C. M., Woods, P., Winter, C., Mitchell, J., McLarry, J., Weiss, J., & Broberg, C. S. (2015). Challenges of intra-institutional transfer of care from paediatric to adult congenital cardiology: the need for retention as well as transition. *Cardiology in the Young*, 1-7. DOI:10.1017/S1047951115000220
- Bratt, E-L., Burström, A., Hanseus, K., Rydberg, A. and Berghammer, M. (2016). Adolescents with congenital heart disease - Parents' perceptions and expectations about transition and transfer to adult care. Paper presented at 46th Nordic Meeting in Paediatric Cardiology, 21-23 September 2016. Båstad, Sweden
- Braun, V. & Clarke, V. (2006). Using thematic analysis in Psychology. *Qualitative Research in Psychology*, *3*, 77-101. DOI: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers?. *International Journal of Qualitative Studies on Health and Well-being*, *9*. DOI: 10.3402/qhw.v9.26152
- Bronheim, S., Fiel, D., Schidlow, D., MaGrab, P., Boczar, K., & Dillon, C. (1995). *Crossings: A manual for transition of chronically ill youth to adult health care*. Washington: Georgetown University.
- Clarizia, N. A., Chahal, N., Manlhiot, C., Kilburn, J., Redington, A. N., & McCrindle, B. W. (2009). Transition to adult health care for adolescents and young adults with congenital heart disease: perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology*, *25*, S317-S322. DOI:10.1016/S0828-282X(09)70145-X
- Clarke, V. & Braun, V. (2013) Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*, 120-123.
- Deanfield, J., Thaulow, E., Warnes, C., Webb, G., Kolbel, F., Hoffman, A., Sorenson, K., Kaemmerer, H., Thilen, U., Bink-Boelkens, M., Iserin, L., Daliento, L., Silove, E., Redington, A., Vouhe, P., Priori, S., Angeles Alonso, M., Blanc, J.J., Budaj, A., Cowie, M., Deckers, J., Fernandez Burgos, E., Lekakis, J., Lindahl, B., Mazzotta, G., Morais, J., Oto, A., Smiseth, O., Joachim Trappe, H., Deckers, J., Klein, W., Alonso, M.A., Blömstrom-Lundqvist, C., de Backer, G., Hradec, J., Mazzotta, G., Parkhomenko, A., Presbitero, P. & Torbicki, A. (2003). Management of grown up congenital heart disease. *European Heart Journal*, *24*, 1035-1084. DOI:10.1016/S0195-668X(03)00131-3
- DeLambo, K. E., Levers-Landis, C. E., Drotar, D. & Quittner, A. L. (2004) Association of observed family relationship quality and problem-solving skills with treatment adherence in older children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, *29*, 343–353. DOI:10.1093/JPEPSY/JSH038

- Fernandes, S.M., Khairy, P., Fishman, L., Melvin, P., O'Sullivan-Oliveira, J., Sawicki, G.S., Ziniel, S., Breitingner, P., Williams, R., Takahashi, M. & Landzberg, M.J. (2012). Referral patterns and perceived barriers to adult congenital heart disease care: results of a survey of US pediatric cardiologists. *Journal of the American College of Cardiology*, **60**, 2411-2418. DOI:10.1016/j.jacc.2012.09.015
- Foster, E., Graham, T.P., Driscoll, D.J., Reid, G.J., Reiss, J.G., Russell, I.A., Sermer, M., Siu, S.C., Uzark, K., Williams, R.G. & Webb, G.D. (2001). Task force 2: special health care needs of adults with congenital heart disease. *Journal of the American College of Cardiology*, **37**, 1176-1183. DOI:10.1016/s0735-1097(01)01277-3
- Guerin, S. & Hennessy, E. (2002). Pupils' definitions of bullying. *European Journal of Psychology of Education*, **17**, 249-261. DOI:10.1007/bf03173535
- Gurvitz, M., & Saidi, A. (2014). Transition in congenital heart disease: it takes a village. *Heart*, **100**, 1075-1076. DOI:10.1136/heartjnl-2014-306030
- Heery, E., Sheehan, A. M., While, A. E., & Coyne, I. (2015). Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: A systematic review. *Congenital Heart Disease*, **10**, 413-427. DOI:10.1111/chd.12251
- Hilderson, D., Saidi, A.S., Van Deyk, K., Verstappen, A., Kovacs, A.H., Fernandes, S.M., Canobbio, M.M., Fleck, D., Meadows, A., Linstead, R. & Moons, P. (2009). Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. *Pediatric Cardiology*, **30**, 786-793. DOI:10.1111/chd.12251
- Knauth, A., Verstappen, A., Reiss, J., & Webb, G. D. (2006). Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiology Clinics*, **24**, 619-629. DOI:10.1016/j.ccl.2006.08.010
- Mackie, A.S., Islam, S., Magill-Evans, J., Rankin, K.N., Robert, C., Schuh, M., Nicholas, D., Muhll, I.V., McCrindle, B.W., Yasui, Y. & Rempel, G.R. (2014). Healthcare transition for youth with heart disease: a clinical trial. *Heart*, **100**, 1113-1118. DOI:10.1136/heartjnl-2014-305748
- McDonagh, J. E., & Kelly, D. A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics of North America*, **50**, 1561-1583. DOI:10.1016/s0031-3955(03)00131-7
- Moons, P., Meijboom, F. J., Baumgartner, H., Trindade, P. T., Huyghe, E., Kaemmerer, H., & ESC Working Group on Grown-up Congenital Heart Disease. (2010). Structure and activities of adult congenital heart disease programmes in Europe. *European Heart Journal*, **31**, 1305-1310. DOI:10.1093/eurheartj/ehp551
- Moons, P., Pinxten, S., Dedroog, D., Van Deyk, K., Gewillig, M., Hilderson, D., & Budts, W. (2009). Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *Journal of Adolescent Health*, **44**, 316-322. DOI:10.1016/j.jadohealth.2008.11.007
- Por, J., Golberg, B., Lennox, V., Burr, P., Barrow, J., & Dennard, L. (2004). Transition of care: health care professionals' view. *Journal of Nursing Management*, **5**, 354-361. DOI:10.1111/j.1365-2834.2004.00428.x
- Reed-Knight, B., Lewis, J. D. & Blount, R. L. (2011) Association of disease, adolescent, and family factors with medication adherence in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*, **36**, 308-317. DOI:10.1093/jpepsy/jsq076

- Ridge, K., & Guerin, S. (2011). Irish clinicians' views of interventions for children with autistic spectrum disorders. *Autism*, **15**, 239-252. DOI: <https://doi.org/10.1177/1362361310364141>
- Sable, C., Foster, E., Uzark, K., Bjornsen, K., Canobbio, M.M., Connolly, H.M., Graham, T.P., Gurvitz, M.Z., Kovacs, A., Meadows, A.K. & Reid, G.J. (2011). Best practices in managing transition to adulthood for adolescents with congenital heart disease: The transition process and medical and psychosocial issues a scientific statement from the American Heart Association. *Circulation*, **123**, 1454-1485. DOI:10.1161/cir.0b013e3182107c56
- Schwerzmann, M. (2012). Congenital heart disease clinics: How to keep the adult patients on board. *Progress in Pediatric Cardiology*, **34**, 113-117. DOI:10.1016/j.ppedcard.2012.08.010
- Sparud-Lundin, C., Berghammer, M., Moons, P., & Bratt, E. L. (2017). Health care providers' attitudes towards transfer and transition in young persons with long term illness—a web-based survey. *BMC Health Services Research*, **17**, 260. DOI: 10.1186/s12913-017-2192-5
- Stout, K., Valente, A. M., Bartz, P. J., Cook, S., Gurvitz, M., Saidi, A., & Ross, R. D. (2015). Task force 6: pediatric cardiology fellowship training in adult congenital heart disease. *Journal of the American College of Cardiology*, **66**, 723-731.
- Valenzuela, J. M., Buchanan, C. L., Radcliffe, J., Ambrose, C., Hawkins, L. A., Tanney, M., & Rudy, B. J. (2011). Transition to adult services among behaviorally infected adolescents with HIV—a qualitative study. *Journal of Pediatric Psychology*, **36**, 134-140. DOI: 10.1093/jpepsy/jsp051
- Van Staa, A., Jedeloo, S., van Meeteren, J., & Latour, J. M. (2011). Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: Care, Health and Development*, **37**, 821-832. DOI:10.1111/j.1365-2214.2011.01261.x
- Wacker, A., Kaemmerer, H., Hollweck, R., Hauser, M., Deutsch, M. A., Brodherr-Heberlein, S., Eicken, A. & Hess, J. (2005). Outcome of operated and unoperated adults with congenital cardiac disease lost to follow-up for more than five years. *The American Journal of Cardiology*, **95**, 776-779. DOI:10.1016/j.amjcard.2004.11.036
- Warnes, C.A., Liberthson, R., Danielson, G.K., Dore, A., Harris, L., Hoffman, J.I., Somerville, J., Williams, R.G. & Webb, G.D. (2001). Task force 1: the changing profile of congenital heart disease in adult life. *Journal of the American College of Cardiology*, **37**, 1170-1175. DOI: 10.1016/s0735-1097(01)01272-4
- Webb, G., Mulder, B.J., Aboulhosn, J., Daniels, C.J., Elizari, M.A., Hong, G., Horlick, E., Landzberg, M.J., Marelli, A.J., O'Donnell, C.P., Oechslin, E.N. Peardon, D.D., Pieper, E.L.G., Saxena, A., Schwerzmann, M., Stout, K.K., Warnes, C.A. & Khairy, P. (2015). The care of adults with congenital heart disease across the globe: current assessment and future perspective: a position statement from the international society for adult congenital heart disease (ISACHD). *International Journal of Cardiology*, **195**, 326-333. DOI: 10.1016/j.ijcard.2015.04.230
- Williams, R. G. (2015). Transitioning youth with congenital heart disease from pediatric to adult health care. *The Journal of Pediatrics*, **1**, 15-19. DOI:10.1016/j.jpeds.2014.09.054
- Yeung, E., Kay, J., Roosevelt, G. E., Brandon, M., & Yetman, A. T. (2008). Lapse of care as a predictor for morbidity in adults with congenital heart disease. *International journal of Cardiology*, **125**, 62-65. DOI: 10.1016/j.ijcard.2007.02

Tables

Table 1: Current approach to transition and transfer (themes, sub-themes and illustrative quotes)

<i>Theme</i>	<i>Subtheme</i>	<i>Illustrative Quote</i>
Current v. ideal approach to transfer	Current approach to transfer	Lack of organisation <i>“It’s very ad-hoc, there’s not a set up, established one (approach) (P16)”</i>
	Ideal approach to transfer	Formulation of clear plan implemented over time with individual child and family <i>“It’s a matter of slowly preparing families for that (transfer) (P19)”</i>
Timing of transfer	Determined by age/school stage	Transfer occurs between 16 and 18 years or end of second level education <i>“Usually...it’s when they leave school so that’s generally at about 17 or 18 years of age” (P18)</i>
	Relevance of other factors	Variation in emotional, developmental and physical maturity requires flexible approach <i>“I think there should be other factors included, such as psychological readiness and emotional maturity” (P24)</i>

Table 2: Barriers to transition and transfer (themes, sub-themes and illustrative quotes)

<i>Theme</i>	<i>Subtheme</i>		<i>Quote</i>
Cultural differences between the two systems	Environmental & professional differences	Adult hospital is business-like, HCPs expect more from patients.	<i>“You’re getting to know a whole new service, it’s run very differently and it has to be run very differently”</i> (P11)
	Changes in role of parents	Difference in attitudes of paediatric and adult staff to parents	<i>“When they are in the children’s hospital, I think the parents get spoken to a lot. But in [the adult hospital] we start speaking to the patient and that’s different.”</i> (P14)
Protection of CHD patients by parents and paediatric system	Parental protection	Can restrict empowerment as patients develop	<i>“They’re [the patients] kind of under the umbrella of their parents, and they don’t become independent for longer.”</i> (P20)
	Paediatric services protection	Can lead to over-dependence on paediatric service.	<i>“I think that they’re over-dependent on us for all aspects of their care. You see we don’t just look after their heart conditions -because they’re often so complex we look after...many other problems of theirs, so they become over-dependent on us.”</i> (P18)
Parental resistance versus adjustment to transition and transfer	Parents’ response to impending transfer	Difficult for families/parents to leave familiar service	<i>“I think the barrier would possibly be the lack of trust they might have in an unknown service.”</i> (P7)
	Need to manage parents’ needs and expectations	Difficult for parents to hand over care	<i>“For the parents, it’s hard [...] to get the idea that the person is now an adult and they’re going to become responsible for themselves, particularly if they’ve had complex problems.”</i> (P20)

Table 3: Recommendations for future action to support positive transition (themes, sub-themes and illustrative quotes)

<i>Theme</i>	<i>Subtheme</i>		<i>Quote</i>
Preparation: the need for education and support	Education	Need better preparation to educate/inform patient with age appropriate information	<i>“I definitely think they need to be educated to take responsibility. Some of these children still don’t know their own medication, you know?” (P 12)</i>
	Support	Provide psychological support, including via external organisations and peers	<i>“That’s where Clinical Psychology would come in, that there is a team there that you can ring and say ‘look I’m not doing well with this’ or ‘I’m finding it hard’ or ‘I’m not sleeping’ [...] Often it’s issues that can be dealt with fairly quickly, if there is somebody to deal with them.” (P18)</i>
Need for greater coordination & collaboration	Between professionals	Formalise communication in a coordinated multi-dsicplinary approach	<i>“In order to successfully support and transition a family, you need to have a multidisciplinary approach.” (P7)</i>
	Between hospitals	Combined care approach: Adult staff visits paediatric hospital	<i>“That the last clinic visit in the children’s hospital be one that is attended by the Adult as well as the Paediatric service [...] a clinic where it’s like ‘Now we’re going to close out your paediatric care.’...Then at the first appointment in the adult hospital you might have the same teams on both visits” (P8)</i>
Need for policy and practical changes	Policy changes	Transition becomes the norm, with preparation beginning earlier	<i>“Transitioning should start here [children’s hospital], I think here in the earlier teenage years, to prepare them and empower them” (P16)</i>
	Practical changes	Transition clinic and staff - visit to adult hospital prior to transfer	<i>“I think the practical thing would be a specific transition clinic with the personnel there so there would be the paediatric cardiologist, the adult cardiologist who’s going to take over, and the transition nurse so that both the teams together would be able to meet.” (P18)</i>

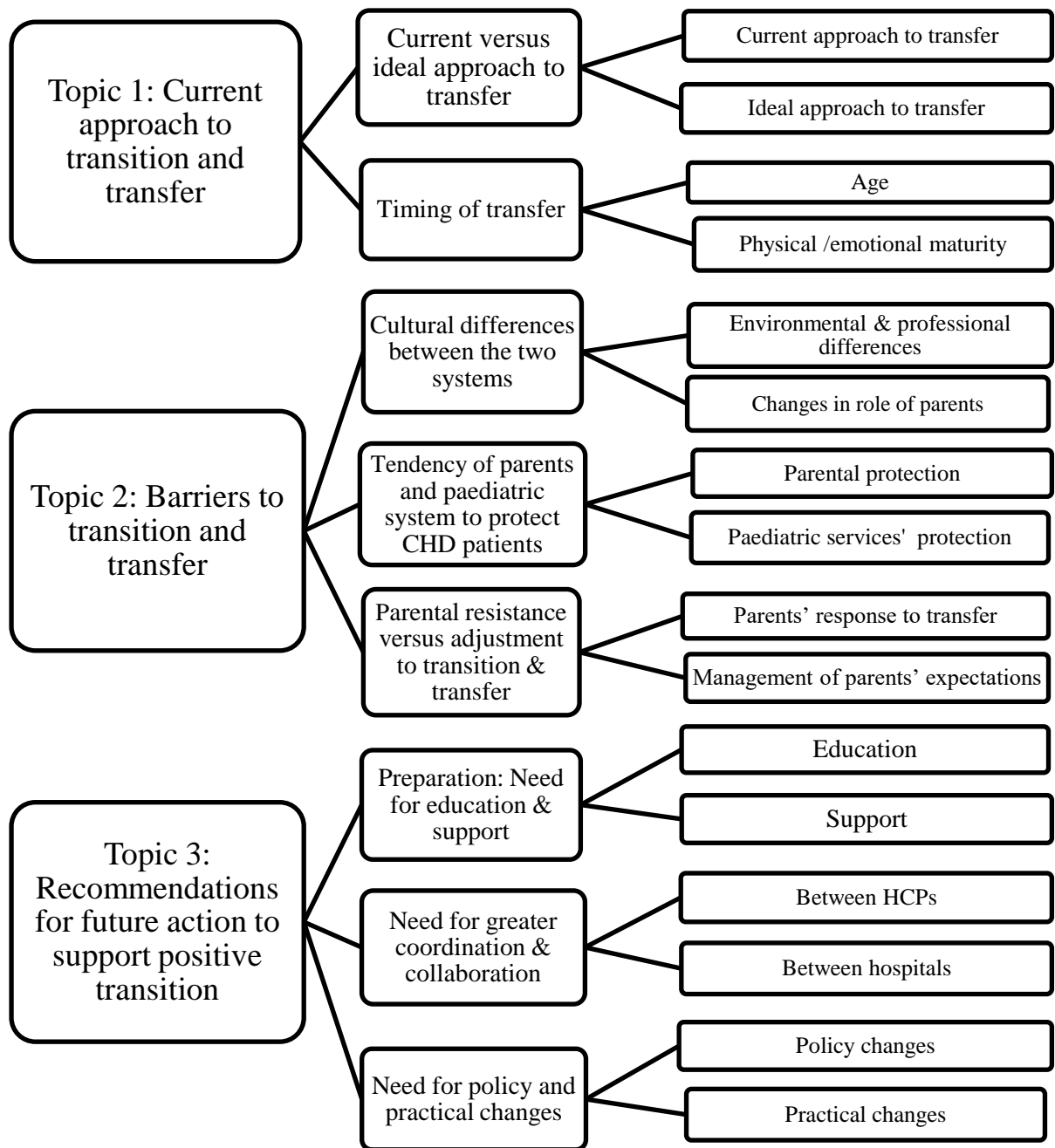


Figure 1. Summary of topics, themes and sub-themes

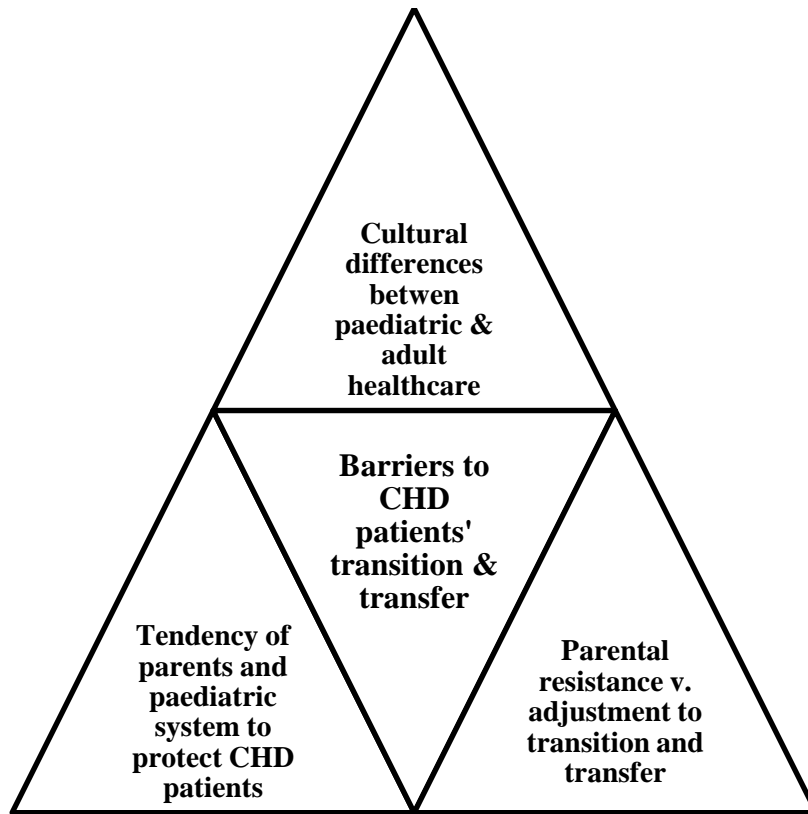


Figure 2. Themes within Topic 2 'Barriers to transition and transfer'

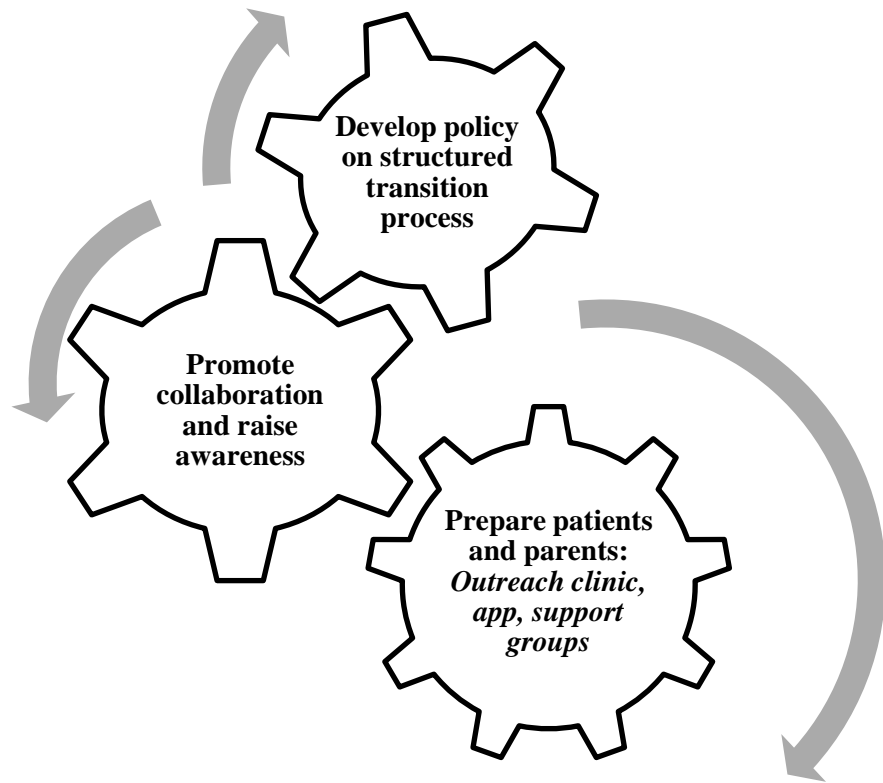


Figure 3. Themes within Topic 3 ‘Recommendations for future action to support positive transition’