**Decision-making experiences of young adults with long-term conditions**

**Abstract**

**Background**: Young adults with long-term conditions can struggle to accept their diagnosis and can become overwhelmed with managing their condition. Sub-optimal transfer from paediatric to adult services with a resultant disengagement with the service, can result in less involvement in care and decision-making. Shared decision-making can improve involvement in health decisions and increase satisfaction with treatment/therapy and care.

**Objectives**: An integrative literature review was conducted to explore and understand young adults’ experiences of decision-making in healthcare.

**Design**: An integrative literature review.

**Data sources**: CINAHL, EMCARE, PsycINFO, HMIC, EMBASE, Web of Science, PubMed, MEDLINE, EBSCOHOST and COCHRANE databases were searched for relevant literature published between January1999 to January 2020.

**Findings:** Thirteen primary research papers met the inclusion criteria. Four main themes were identified: (1) Information delivery and communication; (2) Participation in decision-making; (3) Social factors influencing decision-making; and (4) Emotional impact of decision-making.

**Conclusions:** Young adults with long-term conditions have specific decision-making needs which can impact on their emotional health. Research with a specific focus on young adults’ experiences of decision-making in healthcare is needed.

**Keyword list**: Chronic kidney disease, decision-making, long-term conditions, renal replacement therapy, young adults

**Introduction**

Decision-making is complex and multifaceted. It is a central part of everyday activity that people undertake consciously or unconsciously, to manage and coordinate their actions (Peterson, 2009). Shared decision-making (SDM) and enabling of choice have become pinnacles in personalised healthcare and are positively promoted within health care settings in the UK (NHS England, 2018; National Institute for Health and Care Excellence (NICE), 2016a). Although there are varied definitions of SDM, one commonly agreed definition is that SDM occurs where health professionals collaborate with patients and/or carers to deliberate and agree on a treatment/therapy choice (Charles et al.1997; Elwyn et al. 2012). In this model both the patient and the health professional share decision-relevant information, deliberate on a choice, agree, and then implement the choice (Charles et al. 1997). The drive for patients’ involvement in care decisions led to the development of international (Härter et al. 2011) and national guidelines (NICE 2016a); where *“no decision about me without me”* has often become the norm in the UK (Department of Health, 2012). Evidence suggests that SDM can promote patient satisfaction and improve health outcomes (Care Commission, 2017; Joseph-Williams et al. 2017).

Young adults with long-term conditions such as chronic kidney disease (CKD), often struggle to accept their diagnosis and can become overwhelmed with the burden of managing their condition and coping with the complex decisions they have to make during the trajectory of the illness (Bailey et al. 2018; Krischock et al. 2016). As a result, they can experience worse outcomes because of disruptions in their education and employment (Murray et al. 2014), growth development and building of relationships (Kaufman et al. 2010), depression (Kogon et al. 2013), and low quality of life (Gerson et al. 2010) compared with an age-related healthy population (Neinstein & Irwin 2013; Park et al. 2014).

The worsening of health outcomes is common around the time of transitioning from paediatric to adult services and for the first three years after transition (Ferris et al*.* 2016; Foster, 2015; Samuel et al. 2014). At this time, young people can often experiment and take risks but can also acquire skills to manage more complex tasks and become more independent (Kaufman et al. 2010; Murray et al. 2014). These studies and others have led to the development of transition guidelines to support adolescents and young adults (AYAs) to improve their knowledge and understanding of their long-term condition and enable participation in decision-making (British Association for Paediatric Nephrology (BAPN), 2009; NICE, 2016b).

Despite the above recommendations and policies (BAPN, 2009; NICE, 2016b) for AYAs involvement in decision-making and better transitioning, not all AYAs are able to participate in decisions about treatment/therapy (Care Quality Commission, 2017). Although young adults (YAs) in receipt of dialysis and kidney transplant appear to have worse outcomes compared with adolescents, and older adults with the disease (Bailey et al. 2018; Hamilton et al. 2018) there is little understanding of their decision-making experiences. The aim of this integrative literature review was to explore young adults’ experiences of making a treatment/therapy decision to provide a comprehensive body of evidence.

**Method**

An integrative literature review method (Whittemore and Knafl, 2005) was applied as a framework to synthesise knowledge from primary research studies to understand the decision-making experiences of YAs. The integrative literature review used a structured process to identify the relevant body of literature to explore the research question and offers a strong scientific body of evidence and holistic understanding of the topic or question (Whittemore and Knafl, 2005). Primary research studies in the review investigated or explored the views or experiences of YAs making diagnostic or therapeutic choices. It was necessary to use an approach that would allow the integration of different methodological approaches which can be critiqued and synthesised in an integrated way to generate new ideas, perspectives and knowledge on the topic reviewed (Torraco, 2005).

***Search Strategy***

A comprehensive search strategy was used to undertake searches across ten databases (CINAHL, EMCARE, PsycINFO, HMIC, EMBASE, Web of Science, PubMed, MEDLINE, EBSCOHOST and COCHRANE) for primary articles published from January 1999 to January 2020. An initial search for papers exploring the experiences of YAs with a kidney condition, retrieved a small number of papers therefore the inclusion criteria were broadened to include other long-term conditions. A combination of key words and terms (Table 1) to ensure relevant articles were identified were used for the search. Table 1 is provided as supplementary material. The title and abstract for all citations were screened for articles that met the inclusion criteria and duplicates removed. The reference list of relevant studies was screened for additional relevant papers. The retrieved articles were further screened using the inclusion and exclusion criteria detailed in the study selection. In this review the term treatment decision is used for studies on other long-term conditions (such as cancer, asthma, diabetes, cystic fibrosis, and sickle cell) and the term therapy decision is used for studies on kidney disease. This paper presents the findings of an integrative literature synthesis to understand young adults experiences of decision-making in healthcare.

***Study selection***

There is no consensus for the age range for young adulthood, so an age range of 16-30 years (inclusive) was used for this review, as this is accepted globally (United Nations Convention, 1990; European Union Agency for Fundamental Rights, 2017). This integrative review therefore included studies of YAs with long-term conditions, aged 16-30 years old, and explored views, experiences, or aspects of treatment/therapy decision-making. Studies that included other age groups <16 to >30 years were also eligible, but only where it was clear which data related to ages 16-30 years. Authors of studies published less than five years ago were contacted to clarify the actual numbers of YAs in the studies if they were not stated. All included studies were published in English. The Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flow chart is shown in Figure 1.

Insert Figure 1 PRISMA Flow chart here

**Data extraction and quality appraisal**

Data extracted from primary studies (Table 2) included aims, design, sample characteristics, variables measured, data collection methods, data analysis, findings/results, and limitations. Table 2 is available as supplementary material. The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework (Tong et al. 2007) was used. Data were initially extracted from one study using a line-by-line approach and coded into different categories of themes (Table 3) to create a coding framework.

Table 3 removed

The remaining twelve articles were then coded into the framework to create a matrix for each of the classification and new codes identified during the process added to the list. The coded data were grouped into clustering of codes, patterns or themes, the relationships across the data was noted setting the scene for comparation and interpretation of the data. The codes were then grouped according to patterns based on the commonalities, differences, and shared properties to form concepts to show the relationship between patterns and themes to provide clarity of the emerging themes to form higher clusters and enhanced a holistic interpretation (Whittemore and Knafl, 2005). The final themes were grounded in the data to confirm accuracy, credibility and confirmability of the themes and allowed the themes to be verified from the primary data sources.

**Results**

The thirteen studies (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al.2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016*;* Weaver et al.2015; Zee et al. 2018); nine qualitative and four quantitative studies, met the inclusion criteria. The studies were in three categories of long-term conditions: cancer (4), degenerative and other chronic illness (2) and kidney diseases (7) and conducted in seven countries (Australia (n=1), Europe (involved multiple sites n=36 countries including UK), UK (n=3), Ireland (n=1), New Zealand (n=1), South Korea (n=1), Taiwan (n=1), and USA (n=4). Studies reported 19-32 of the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist (Tong et al. 2007). The quality of the qualitative studies ranged between 7-10 for the Critical Appraisal Skills Programme (CASP) qualitative checklist (2018) and 7-12 of the Centre for Evidence Based Management (CEBM) checklist for survey studies (2014) with an overall quality range of moderate to strong quality (Table 2). The four main themes identified were: (1) information delivery and communication; (2) participation in decision-making; (3) social factors influencing decision-making; and (4) emotional impact of decision-making. See Figure 2

Insert Figure 2 Final themes here

Participants quotes reported in primary studies (Table 4) used to illustrate the themes are provided as supplementary material.

**Information delivery and communication**

The delivery and communication of treatment/ therapy information varied across studies and was considered as integral to the understanding of diagnosis and available treatment/therapy options, participating in decisions and also managing the long-term condition (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al.2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016;Weaver et al.2015; Zee et al. 2018). Verbal and written information were the main source of communicating information and was often provided by a health professional (Calestani et al. 2014; Coyne and Gallagher, 2011; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016*;* Weaver et al.2015), although perceived sometimes as biased (Coyne and Gallagher, 2011; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018). The situational context, timing of information, the content and how information was communicated enhanced or hindered YAs ability to absorb and understand the information received (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Mark et al.2019*;* Pyke-Grimm et al. 2018).

The quantity and quality of information varied; where more was received, sometimes less was desired (Calestani et al. 2014; Mitchell, 2014; Walker et al.2016) and vice versa (Calestani et al. 2014; Pyke-Grimm et al. 2018). Providing too much information over a short period caused fear, confusion, and lacked depth (Calestani et al. 2014; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016). Preference for slower and just enough information to gain understanding of treatment/therapy and make right decisions was highlighted (Calestani et al. 2014; Coyne and Gallagher, 2011; Mitchell, 2014; Pyke-Grimm et al. 2018). Explaining information in a way perceived to enhance easy understanding was associated with positive information experiences and satisfaction with communication (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Mark et al.2019*;* Mitchell, 2014; Walker et al.2016; Zee et al. 2018). Two sub-themes encompassing knowledge and understanding of information and information seeking as subthemes is now discussed.

*Knowledge and understanding of information*

Studies highlighted experiences of limited knowledge, which was due to the lack of information, difficult engagement and understanding of treatment/therapy options (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016*;* Weaver et al.2015). When information was perceived to be communicated very quickly, or the content found to be too complex or technical with medical jargons this hindered YAs understanding of treatment/therapy options (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016;Weaver et al.2015). Patients receiving in-centre haemodialysis therapy felt less informed (Chen et al. 2018; Devitt et al. 2017; Zee et al. 2018) compared with those on peritoneal dialysis (Zee et al. 2018). Culturally appropriate information and communication were considered enabling to engage people from indigenous background (Chen et al. 2018; Devitt et al. 2017; Zee et al. 2018). These participants felt either uninformed or lacked understanding of aspects of information received such as the practicalities of dialysis therapy and kidney transplant option (Chen et al. 2018; Devitt et al. 2017; Weaver et al.2015). Lack of awareness of the kidney transplant listing process for example eligibility, the implications of receiving a kidney transplant and whether or not they were listed on the national transplant register were reported (Calestani et al. 2014; Coyne and Gallagher, 2011; Walker et al.2016). Health professionals were sometimes perceived to use their power to restrict access to information (Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Mitchell, 2014; Walker et al.2016). The lack of information and understanding was associated with the inability to participate in treatment/therapy decision-making (Calestani et al. 2014; Chen et al. 2018; Devitt et al. 2017; Hart et al*.* 2020; Pyke-Grimm et al. 2018; Walker et al.2016).

*Information seeking*

The desire to conduct one’s own research on treatment/therapy options such as searching the internet or using alternate information sources like family opinions were highlighted (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016). YAs appeared to improve their knowledge on the options and the practicalities involved through their information seeking, which in turn enhanced their understanding and involvement in decision-making. YAs with kidney failure (Calestani et al. 2014; Walker et al.2016; Zee et al. 2018) and degenerative conditions (Mitchell, 2014) found talking to peers beneficial in enabling their understanding of treatment/therapy options and the practicalities involved compared with YAs in cancer studies (Coyne and Gallagher, 2011; Pyke-Grimm et al. 2018). The receipt of valuable information and understanding of options was associated with satisfaction of therapy choice (Chen et al. 2018; Mitchell, 2014; Walker et al.2016; Weaver et al.2015; Zee et al. 2018).

**Participation in decision-making**

Although many participants in all the studies felt involved in the decision-making, their preference of decision type, decisional role and level of involvement varied across studies. Three sub-themes encompassing perceptions about choice, decision-making preferences and roles of significant others is now discussed.

*Perception of choice*

The perception of choice varied across studies; not all YAs felt choice was offered (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al*.* 2020; Mark et al.2019; Mitchell, 2014; Weaver et al.2015) and others lacked choice or were not involved in decision-making (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al.2019;Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016; Zee et al. 2018). Choice was framed as supporting or inhibiting independence and/or autonomy (3,8). Reports of choice already decided before conversations on options were held was highlighted (Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020). Limited interaction time between healthcare professionals and patients resulted in a lack of depth during choice discussions (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020). Decisional conflict and decisional regrets following commencement of therapy were highlighted (Chen et al. 2018; Mark et al.2019; Zee et al. 2018). The degree of decisional conflict was associated with age, the level of education, work status and education of therapy but not with gender or marital status (Chen et al. 2018; Mark et al.2019). Dialysis knowledge, decisional self-efficacy, family, and clinician support were predictors of decisional conflict while uncertainty of implementing a dialysis choice was associated with higher decisional conflict score (Chen et al. 2018).

*Decision-making preferences*

Preference for decision-making, roles and level of involvement varied across the studies. Decision-making was perceived to have lesser or greater consequences depending on the threat to life and categorised into small or minor, intermediate, big or major or life threatening in relation to its outcome, impact on life and future (Calestani et al. 2014; Coyne and Gallagher, 2011; Hart et al*.* 2020; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016; Weaver et al.2015).Passive, shared/collaborative or active decision-making preferences were highlighted (Coyne and Gallagher, 2011; Hart et al*.* 2020; Mark et al.2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Weaver et al.2015). However, not all were able to participate in their preferred level and role (5-7,9). Decision-making preferences and roles were dynamic as preference for involvement changed overtime (Calestani et al. 2014; Hart et al*.* 2020; Mitchell, 2014; Pyke-Grimm et al. 2018).

*Role of significant others in decision-making*

Studies reported parents/family, partners, peers, and health professionals played supportive roles in decision-making and were valued, although on some occasions their involvement were considered inhibiting (Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al.2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016;Weaver et al.2015; Zee et al. 2018). However, not all YAs wanted parental involvement in decision-making (Coyne and Gallagher, 2011; Hart et al*.* 2020; Mitchell, 2014; Pyke-Grimm et al. 2018). Trusting the source of information and building relationships with health professionals provided some degree of certainty or assurance especially where outcome was uncertain or carried serious risks and consequences (Calestani et al. 2014; Chen et al. 2018; Hart et al*.* 2020; Pyke-Grimm et al. 2018; Walker et al.2016; Weaver et al.2015). Health professionals perceived to be trustworthy were able to help participants with a limited support network to overcome the vulnerability associated with performing home dialysis therapy (Walker et al.2016). Positive support enhanced their coping with treatment/ therapy (Coyne and Gallagher, 2011; Hart et al*.* 2020; Pyke-Grimm et al. 2018; Weaver et al.2015).

**Social factors influencing decision-making**

A desire for normality, ability to work, independence, and quality of life influenced treatment/therapy decision-making (Calestani et al. 2014; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Kim and Choi, 2016; Mark et al.2019; Mitchell, 2014; Pyke-Grimm et al. 2018; Walker et al.2016;Weaver et al.2015). Perceived independence, invasiveness of procedure and its impact on life influenced decision-making of medical devices needed to sustain life (Mitchell, 2014). Therapy was rejected when the risk outweighed the benefits (Mitchell, 2014). Some participants preferred to keep their social life rather than having a therapy that prevented them from socialising. Family and friends influenced dialysis choice (Walker et al.2016) and living donor kidney transplant decisions (Calestani et al. 2014; Devitt et al. 2017; Kim and Choi, 2016). Normalcy in life and avoidance of constraints of dialysis therapy drove the desire for a kidney transplant (Calestani et al. 2014; Devitt et al. 2017). Participants from indigenous backgrounds negotiated cultural and social beliefs for community leaders and family to accept kidney donation as it was considered a taboo and associated with bad omen (Devitt et al. 2017; Walker et al.2016). Health professionals influenced dialysis modality decision based on their advice and framing of discussions (Calestani et al. 2014; Walker et al.2016; Zee et al. 2018).

**Emotional impact of decision-making**

Emotional impact of decision-making was not directly explored except for one study reporting assessment of baseline psychological level of participants in addition to other areas (Mark et al.2019). Reports of shock, fear, anxiety, distress, and mixed feelings following receipt of a cancer diagnosis due to the fear of possible death were highlighted (Coyne and Gallagher, 2011; Hart et al*.* 2020; Pyke-Grimm et al. 2018). Fear and lack of understanding hindered the ability to engage with treatment/therapy options when information was perceived to have the potential to cause emotional distress (Coyne and Gallagher, 2011; Hart et al*.* 2020). Others struggled to build lasting relationship due to their perceived self-image (Coyne and Gallagher, 2011; Kim and Choi, 2016; Mitchell, 2014). Cultural and religious beliefs and fear of kidney donor outcome due to beliefs of donor risk affected the ability to discuss kidney transplant donation with family members (Calestani et al. 2014; Devitt et al. 2017). Concerns of not wanting to be perceived as a “spoiler” or “taker” of another person’s life (Devitt et al. 2017; p 6) should the donor come to harm or suffer problems later in life or be indebted or controlled by their kidney donors for the rest of their life were highlighted; therefore, these participants opted for deceased kidney donation (Calestani et al. 2014; Devitt et al. 2017).

**Discussion**

YAs in the selected studies were diagnosed with different long-term conditions, yet all faced life-saving decisions despite their different situational and social context for the treatment/therapy decision-making. The focus of this discussion is to compare young adults’ experiences with older adults in relation to the themes identified: information delivery and communication; participation in decision-making; social factors influencing decision-making and emotional impact of decision-making.

*Information delivery and communication*

Information delivery and communication was a pivotal part of receiving/understanding the diagnosis, prognosis, and treatment/therapy. Despite this, suboptimal information delivery and understanding was highlighted across studies. Participation in decision-making was dependant on YAs’ understanding the need for decision-making, the type of decision and the roles they preferred to play. The framing of treatment/therapy information, the content, timing of delivery, the situational contexts and how information is communicated influenced YAs ability to absorb, make sense of, gain understanding and be able to participate in the decision-making. The integrative review highlights the unmet decisional needs of YAs and the lack of understanding of how elements in the decision context affects the emotions of YAs.

YAs health literacy contributes to the understanding of their illness, its progression, available treatment/therapy options and decisions they need to make during the journey of the disease (Levine et al. 2018; Morsa et al. 2018). YAs tend to be provided with information without a consideration of their literacy level which may have contributed to their dissatisfaction of information delivery and communication in the decision-making context. YAs’ literacy levels should be assessed prior to or during information delivery so that information is provided at the appropriate literacy level, which in turn can enhance their understanding. Assessing the knowledge and understanding of YAs prior to, during and post treatment/therapy education could highlight their information needs and enable health professionals to reinforce their understanding of treatment/therapy options. Provision of simple and non-technical information less of medical jargon was perceived as enabling the understanding of choice and the practicalities involved. Coulter and Collins (2011) argue that patients who are less informed about available treatment/therapy options are less involved in health decisions and become dissatisfied.

*Participation in decision-making*

Reports of lack of choice, feeling rushed, and lack of understanding in decision-making have been highlighted by other studies among older patients (Dahleruset al. 2016; Morton et al. 2010a and b; Robinski et al. 2016). In Dahleruset al’s (2016) study, one third of the participants perceived that they lacked choice. The complexity of the treatment/therapy decision-making process can bring some degree of emotional stress which relates to the concerns YAs may have about what matters to them. The decision-making context was perceived by YAs as choosing between lifesaving treatment/therapy verses death or giving up autonomy or independence of areas of their life and reported among older people with the disease (Harwood and Clark, 2013; Morton et al. 2010a; Tong et al. 2013).

YAs are still developing their autonomy and independence, and some may not feel confident to make decisions (Davies et al. 2015) therefore, the elicitation of their decisional preferences and roles are vital. Providing YAs support to feel more in control and independent to make an informed or shared decision could enhance their self-esteem and self-actualization which is a basic element of human need (Maslow, 1943). A person can make competent informed health decision only if that person understands the purpose of the treatment/therapy, the procedures involved, the possible risks, alternative options and likely outcomes (Halpern-Felsher and Cauffman, 2001).

*Social factors influencing decision-making*

YAs decision-making does not always involve two people nor is it linear but can be a triad, cyclical, multi-relational and/or contextual depending on the situational and social context (Umeh, 2009). The type of decisional task, situational context, relationship and trust with health professionals, family, impact of therapy on life (short and long term) and quality of life influenced YAs involvement in decision-making. These factors highlighted in this integrative review are echoed by other studies (Dahlerus et al. 2016; Harwood et al. 2013; Morton et al. 2010b; Murray et al. 2009). Although studies (1-2,5,9,11,12) in this review highlighted that YAs trusted their parents and health professionals to look after their best interest based on their experience and expertise due to the uncertainty of choice, they were unable to determine whether YAs were willing to take higher risk and this reflects a notion of trust.

The notion of trust is when a person tends to rely on others when there is uncertainty about choice (Zinn, 2015). Harrington and Morgan, (2016) asserts that having a notion of trust does not always mean that people are willing to take higher risk. YAs who experienced uncertainty about choice relied on parents and/or health professionals support and collaborated with them to conclude their decisions. Trust in health professionals was associated with the quality of information delivery and communication on treatment/therapy options and influenced acceptance and recommendations about a choice. However, where aspects of information were found lacking following decision-making and commencement of treatment/therapy it resulted in a feeling of betrayal.

Cultural and religious beliefs can influence autonomy (Halpern-Felsher et al. 2016). Cultural and religious beliefs negatively influenced acceptance of dialysis and kidney transplant choice as it did not always encourage decisional autonomy among people from indigenous population (4 &11) and has been highlighted by Jones and Cornwall, (2018) and Sheu et al.(2012). The informational needs of YAs, their perception of the decisional context and how it impacts on the personal, social and psychological well-being are different compared with older people who have the same disease. Without understanding what matters most to YAs, alongside their informational and decisional needs, health professionals are likely to get it wrong.

*Emotional impact of decision-making*

The thought of choosing between lifesaving treatment/therapy or death can bring emotional and mental distress for YAs during decision-making. However, the studies ( Calestani et al. 2014; Chen et al. 2018; Coyne and Gallagher, 2011; Devitt et al. 2017; Hart et al*.* 2020; Mark et al.2019*;* Mitchell, 2014; Pyke-Grimm et al. 2018; Van Biesen et al.2014; Walker et al.2016*;* Weaver et al.2015; Zee et al. 2018) in this review focused on the decision itself and less consideration were given to how the decision-making is perceived by YAs and the impact of these perceptions on the decisional context, the practicalities involved and the performance of the treatment/therapy. The anticipation of significant changes that the treatment/therapy choice will bring into YAs life adds to already heightened fears. Compared to the emotional stress experienced during decision- making by older adults’ (Joseph-Williams et al. 2014; 2017), YAs may be different because they are yet to have a future. The personal, material and subjective losses that could occur when a person is faced with decision-making also has the potential to lower self-esteem and can affect the person’s ability to make a good or bad decision.

Although older people’s decision-making needs are well documented (Dahleruset al. 2016; Harwood and Clark, 2013; Morton et al. 2010a; Robinski et al. 2016), the same cannot be said of YAs. Less attention is given to the issues that mattered most to YAs in the decisional context and is less understood how the decision-making impacts on their personal, social, and psychological well-being.

*Strength and weaknesses*

The strength ofthis integrative review lies in the ability to combine studies with different methodological approaches that have explored the decision-making experiences of young adults with kidney disease and other long-term conditions. As the majority of the studies were retrospective and relied on participants’ ability to recall experiences, it is subject to recall bias. Selection biased could have resulted to an unbalanced representation of age groups, as most studies had either more adolescents and/or older adults compared with young adults. The findings cannot be generalised but are transferable to similar situations.

**Implications for practice**

YAs have unmet information and decision-making needs that are vital to develop their knowledge and understanding that could enhance their ability to participate in therapy decision-making. Assessing and evaluating YAs informational needs could highlight their knowledge gap. The provision of simple information with less medical jargon is vital to improve YAs understanding and to reduce the emotional burdens experienced during their interactions (Jackson, 2014). Good clinician-patient interpersonal relationships can act as a safe zone for YAs to feel confident to share what matters most to them.

YAs’ decision-making is complex with many different facets intertwined with personal, emotional, and cultural sensitivities which must be navigated. Planned preparation of YAs is important in ensuring that they are ready to receive information and be supported to participate in decision-making. YAs have unmet decisional needs such as sub-optimal communication, knowledge and understanding the decision-making process, the practicalities involved in performing treatment/therapy and psychological support. Eliciting feedback from YAs and/or their family to ascertain their understanding of information can improve clinician’s awareness of their knowledge and understanding and address any knowledge gap. Empathetic communication and timely preparation of YAs and parents/family prior to receiving therapy information and offering psychosocial support could promote absorption of information and engagement with the decision-making process.

**Conclusion**

YAs with kidney disease and other long-term conditions have specific decision-making needs which can impact on their emotional health. This integrative review found that YAs experience suboptimal information delivery and communication on the available therapy options and lacked understanding of the practicalities involved with the treatment/therapy. The lack of consideration of YAs’ situational and personal circumstances, appropriate timing of information delivery hindered their development of knowledge, understanding and involvement in decision-making. The desire for independence, the ability to work, normalcy and trust in health professionals also influenced YAs’ decision. How the decisional context affects YAs’ emotional health is less understood which must be elicited to address their unmet decision-making needs. There is less literature on YAs’ experiences on decision-making therefore research with a specific focus on YAs’ experiences of health decision-making is needed.