



## The evaluation of pediatric-adult transition programs: What place for human flourishing?



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### ABSTRACT

Adolescents with chronic health conditions transitioning from pediatric to adult healthcare services experience a wide array of difficulties. In response, transition programs have been developed. Transition programs commonly embody goals such as autonomy and independence. However, these may not be highly valued by young adults and their families. To assess critically the current evaluation of goals and outcomes of these programs, the concept of human flourishing offers a promising alternative to concepts of quality of life. It grants that objectives pursued (e.g., health, social integration) stand to be interpreted by the agent as being valuable and coherent with their meaning-making narrative. Flourishing is also an indicator of physical and psychological health.

The purpose of this paper is to review the literature on transition care to assess whether and how flourishing is addressed in the evaluation of transition programs. We carried out systematic sampling of the literature and applied a qualitative thematic content extraction strategy. Based on Ryff and Singer's integrative concept of flourishing, we examined whether six key dimensions of flourishing (self-acceptance, positive relations with others, personal growth, purpose in life, environmental mastery, and autonomy) were present in current evaluation practices. We reviewed 105 relevant papers and found that (1) 44 out of 105 articles evaluated one or more dimensions of human flourishing; (2) there was considerable variation in the assessment of these dimensions, which was sometimes minimalistic; (3) no single evaluation was based on an explicit measure of human flourishing; (4) autonomy and positive relationships were the dimensions most investigated; (5) the evaluation of transition care mostly emphasized medical aspects of health. Considering its lifelong impact, it is crucial to better understand how transition care can support the flourishing of young adults. Open-ended views on flourishing based on participatory and collaborative research designs should be explored in this context.

### 1. Introduction

During their transition to adulthood, adolescents experience physiological, cognitive, psychological, and social changes. While adolescence is generally marked by particularly significant developmental transformations, young adults with chronic conditions and diseases must, in addition, adapt to their health conditions and to the multiple consequences that these imply in their daily lives (Pinzon et al., 2006). They generally have very few resources to guide them in the evolution of their needs and their living conditions (Blum, 2002; Wright et al., 2016), not to mention that they are often involved in the same process of transitioning to the adult system as adolescents without chronic health conditions.

Several international studies have documented difficulties with respect to information and preparation in transition from pediatric to adult healthcare systems. In response, and given the stakes at hand, significant attention is currently being granted to this transition period. Intervention programs have been developed to support young adults before and during their transition (Committee on Adolescence, 2016; Betz et al., 2016; Blum, 2002; Campbell et al., 2016; CAPHC, 2016; Commission for Social Care Inspection, 2007). However, most of the programs implemented in hospital contexts are focused on the transfer of care, rather than a genuine transition of care (Betz et al., 2016; Clemente et al., 2017). Here, a distinction has to be made between “transfer of care” and a “comprehensive plan for transition care”. Beyond a transfer of medical

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records from a system to another, a comprehensive plan for transition implies a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated. This process should address “the medical, psychosocial, educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems” (Rosen et al., 2003). This general suggestion brings up the question of the specific goals and outcomes to be sought within transition care.

The goals of transition programs generally embody concepts and values such as autonomy and independence (Gibson et al., 2014; Hamdani et al., 2015). However, these goals may not be shared or actually highly valued by young adults and their families, especially for individuals who have chronic conditions calling for more relational and contextual understandings of development. Hamdani et al. (2015) have remarked that “[t]ransitions best practices reflect dominant social values and assumptions about what constitutes a successful adulthood, embedded in goals such as independent living, self-management, and obtaining work” (Hamdani et al., 2015). This observation brings attention to the deeper values embedded in transition care and whether the goals of transition care are supporting young adults rather than the reverse. The concept of human flourishing provides a lens through which transition care can be evaluated in terms of its orientations and outcomes in this light.

Human flourishing is a contemporary rendition of the Greek concept of Eudaimonia, i.e., the good life. It designates both a state of being that is judged to be plentiful and satisfying but also a process by which an individual is enacting their potential as a human being (Witten, 2019). Although subject to multiple views and understandings, debates about the nature of human flourishing have staged tensions between pleasure-oriented (hedonistic) accounts for which contentment and happiness would be key and more meaning-oriented (eudemonistic) accounts where self-realization is central (VanderWeele, 2017). Flourishing incorporates autonomy but also other important dimensions of human self-realization such as positive relationships, meaning in life and acceptance of oneself (Ryff, 2014). Integrative models incorporating both aspects suggest that these are not mutually exclusive, and that human flourishing can be understood as the development of a pleasant and rewarding outlook and set of experiences. Ryff and Singer have proposed a useful integrative six-dimension model of human flourishing (i.e., self-acceptance, positive relations with others, personal growth, purpose in life, environmental mastery, and autonomy) which incorporates much of the insights of hedonistic and eudemonistic models of human flourishing (Ryff, 1989; Ryff & Singer, 2008). It has been used to inspire, investigate, and evaluate a wide array of interventions (Ryff, 2014).

As a construct to guide and evaluate health-related and social interventions, human flourishing provides additional layers than concepts of happiness and quality of life. It grants that whatever objectives pursued (e.g., better health, social integration, economic gain) stand to be interpreted by the agent as being a worthwhile goal that coheres with their meaning-making narrative. Importantly, flourishing is a remarkable indicator and predictor of physical and psychological health and represents a positive orientation to model health (and other) services (VanderWeele, 2017). There is now an emerging literature showing how key dimensions of Ryff and Singer's model are correlated with longevity with rather extensive findings on mortality as well as reduced morbidity through various physiological processes (Friedman & Ryff, 2012; Ryff & Singer, 1998; Urry et al., 2004) such as physiological regulation, specific gene expression, and emotion regulation.

While flourishing in adolescents and young adults is still poorly understood (Witten, 2019), the question of whether transition care is responsive to the concept and orientation of flourishing remains open. For example, is the flourishing of young adults considered in the implementation and evaluation of these transition programs? Are the values and orientations of young adults integrated in these programs in order to

promote their wellbeing and development? Which aspect of flourishing are transition programs most focused on? Are some aspects of flourishing neglected? As such, it is crucial to look at how transition programs are currently evaluated and examine how they envision an ideal and genuinely successful transition. Goals and outcomes are related since it is crucial to know what is targeted by a program in order to properly study the relevance of its outcomes. For example, the objectives of a program wishing to improve or maintain the general state of health of a young adult is different than the goal from a program aimed at empowering a young adult and giving them the means to express themselves and to assert their interests and preferences. Likewise, the way to assess the achievement of such objectives can take various forms. Changes in health and in individuals' levels of autonomy can be measured in different ways, whether quantitative or qualitative (e.g. by observing their behaviors, by asking them questions) (Clark et al., 2019; Deci & Ryan, 1985; Perkins, 1995; Ryan & Deci, 2000).

The purpose of this paper is to review the literature on transition care to assess whether and how flourishing is addressed in the evaluation of transition programs. Considering the lifelong impact of transition of youth and its contribution to shaping their lives, it is crucial to better understand how transition care can support the flourishing of young adults.

To the best of our knowledge, this scoping literature review is the first tackling health care transitions in light of the dimensions of human flourishing. We adopted Ryff and Singer's integrative account of human flourishing as a workable, widely used comprehensive model to guide our content extraction. We pursued a scoping-style review based on systematic sampling of the literature but qualitative content extraction.

## 2. Methods

We undertook a scoping review based on systematic sampling, qualitative content extraction guided by an integrative theoretical framework on human flourishing proposed by Ryff and Singer (2008).

### 2.1. Review questions

The guiding review and extraction questions were “Does transition program evaluation consider different dimensions of human flourishing, if so, how?” This question guided more precisely the scoping review but background information about the content of various features of evaluation programs was extracted to contextualize our findings and our analysis. More precisely, the question “Do evaluative approaches take into account the flourishing of transitioning young adults?” guided this scoping review.

### 2.2. Article search

A comprehensive literature search was conducted between August and September 2019 using the following databases: OVID Medline; OVID Embase (excluding Medline journals); EbscoHost (CINAHL) and Web of Science. The keyword combinations used in the review were the following: (“transition program\*” OR “transition clinic\*” OR “transition practice\*” OR “transition of care”) AND (“pediatric\*” OR “youth” OR “young adult\*” OR “adolescenc\*” OR “teen\*”) AND (“evaluation\*” OR “outcome\*” OR “measure\*” OR “assess\*” OR “questionnaire\*” OR “test\*” OR “trial\*”). The search yielded 1410 results. All results were imported into an EndNote library (v. X8). Duplicates were excluded ( $n = 287$ ), for a remaining number of 1123 results, screened by a member of the team (AL). The initial screening of articles was based on the relevance of their titles and available abstracts. A total of 164 publications were included for full-text appraisal, after which 105 met the criteria for final inclusion in the study. Therefore, a total of 105 publications were included in the review and a total of 59 were excluded. A flowchart of the process is represented in Fig. 1 below.

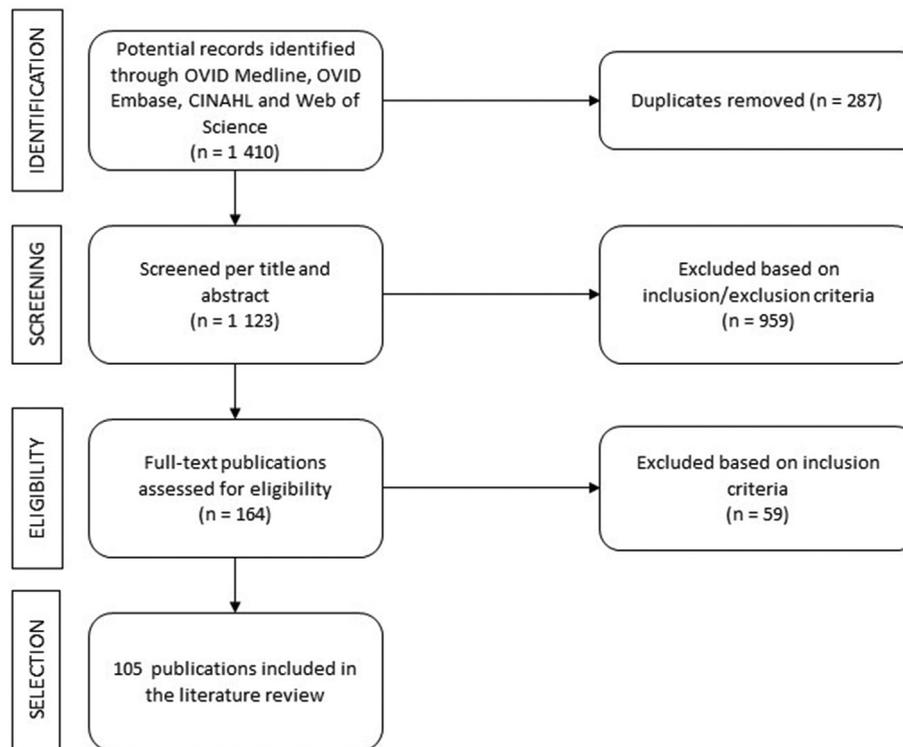


Fig. 1. Flow chart.

### 2.3. Inclusion criteria

For the purposes of this review, the criteria for final inclusion in the study were as follows: (1) publications in only English or French, (2) studies that reported on evaluations of transition programs from the pediatric to the adult healthcare system, (3) peer-reviewed publications, and (4) empirical studies.

### 2.4. Exclusion criteria

The exclusion criteria consisted of: (1) articles written in languages other than English or French; (2) unrelated article topics; (3) evaluation of healthcare professionals' transition practices or experience; (4) reviews; (5) editorials; and (6) letters to the editor. The remaining articles ( $n = 164$ ) were read and screened for final inclusion.

### 2.5. Data extraction

The data extraction table was developed to provide an overview of the studies and highlight key areas of human flourishing. Each article was analyzed to extract the following information: (1) authors and affiliation; (2) sample size and context; (3) transition care program evaluation; (4) presence or absence of a transition coordinator/navigator; (5) study design and follow-up time; (6) outcome measures; (7) methods; (8) results; (9) whether dimensions of human flourishing were evaluated, and if so, how; and (10) limitations and/or comments. Dimensions of human flourishing were based on Ryff and Singer's integrative framework (2008), see Table 1. Foreseeing that these dimensions could perhaps be elaborated upon minimally, we adopted a generous and charitable application of the content extraction categories. All included articles were thoroughly read, categorized, and summarized by AL and MG (Table 2). The content of the table was revised by ER (see online supplemental table for complete data).

**Table 1**

Dimensions of human flourishing following Ryff and Singer (2008).

*Self-acceptance:* This dimension is a long-term self-assessment involving a certain level of self-awareness, with the intention of accepting one's own personal strengths and weaknesses. Self-acceptance goes beyond the concept of self-esteem. Maintaining positive attitudes towards oneself appears to be a central characteristic of maturity and optimal psychological functioning.

*Positive relations with others:* This dimension is related to the capacity for affection, empathy, friendship, and love towards other human beings. These abilities are indicative of good psychological health and are defined as criteria of maturity. Theories about the stages of adult psychosocial development also emphasize the achievement of unions with others (intimacy) and the concern for contribution to society (generativity).

*Personal growth:* This dimension is the closest to the meaning of Aristotle's *Eudaimonia* since it explicitly includes the idea of individual self-realization. Personal growth is a continuous process of developing one's own potential as a human. Openness to experience, for example, is characteristic of a fully functional individual.

*Purpose in life:* This dimension refers to having goals, intentions, and a sense of direction in one's own life. Mental health is defined as comprising healthy beliefs that there is a purpose and a meaning to life. Theories of development refer to a variety of changing goals, associated for example with productivity and creativity, or the achievement of some emotional integration.

*Environmental mastery:* This dimension is defined by the management of complex environments through mental or physical activities, in other words, having the ability to act. An individual's ability to choose or create environments suited to one's mental conditions is a characteristic of mental health. Maturity also requires participation in a sphere of activity outside oneself. Successful aging is associated with an individual's ability to seize the opportunities of their environment.

*Autonomy:* This dimension revolves around the notions of independence, self-determination, and behavior regulation. The authors associate autonomy with the idea of freedom from the norms governing daily life. A fully functional person is described as having an internal locus of assessment, against which they assess themselves according to personal standards and do not turn to others for approval.

### 2.6. Data synthesis

Data were synthesized while keeping in mind the heterogeneity of studies, as well as the relevance of the studies regarding our objectives.

We analyzed the studies included in this review by observing, on the one hand, how each dimension of human flourishing is evaluated, and on the other, according to the methods used. A critical interpretative synthesis review approach was utilized to critically appraise and synthesize the literature, in order to target what is put forward as well as what is missing in the evaluation studies of transition programs (McDougall, 2015). Given the heterogeneity of study designs and instruments used, no quality evaluation of included studies was conducted.

### 3. Results

#### 3.1. Sample characteristics

Only a limited number of studies exist on the evaluation of transition program, and the literature on the subject is recent. The majority of the 105 articles found and reviewed articles originated from North America: 36 studies were conducted in the USA and 18 in Canada. Table 2 presents an overview of the sample as well as the content extracted. The underlying conditions of youth was wide-ranging but primarily focused on chronic health conditions such as congenital heart disease, Type 1 diabetes, spina bifida, sickle-cell disease, thalassemia, transplant recipients (kidney, heart), Crohn's disease, cystic fibrosis, and epilepsy (see Table 2).

#### 3.2. Methods used by studies reviewed

The evaluative methods used by studies reviewed were scales, questionnaires, chart review, clinical measures, surveys, semi-structured individual interviews, observations, and focus groups. The most common method for the evaluation of transition programs was that of a chart review. The use of qualitative methods with open questions (such as semi-structured interviews) (Beaufils et al., 2019; Gorter, 2015), as well as the combination of focus groups and individual interviews (Bundock et al., 2011), or focus groups alone (Weigensberg et al., 2017), were seldom used. The studies that assessed the greatest number of dimensions of human flourishing (Freeman et al., 2015) used a variety of methods: self-reported scales, questionnaires with closed questions, and open questions.

#### 3.3. Evaluation of the dimensions of human flourishing during transition

##### 3.3.1. Self-acceptance

Eight studies evaluated the dimension of self-acceptance (Table 2). The criteria underlying self-acceptance in the study of Bachelot et al. (2017) were the feelings experienced about one's own physical appearance, and self-confidence. Craig et al. (2007); Paine et al. (2014), and Weigensberg et al. (2017), put the emphasis on young adults' acceptance of their medical condition and the evaluation of its impact on their emotions and their body image. Weigensberg et al. (2017) also explored self-discovery and personal identity, and highlighted the component of self-realization, similarly to Freeman et al., 2015; Mora et al. (2017); Weigensberg et al. (2018), and Zoni et al. (2018). Conversely, Steinbeck et al.'s study (2015) addressed self-acceptance by assessing the global self-worth of young adults rather superficially.

##### 3.3.2. Positive relationships

Fifteen studies evaluated the dimension of positive relationships (Table 2). This dimension was most often approached in terms of social support, namely whether the young adult in question had access to someone to rely on and someone to speak with. Often one or more family members were involved (Bachelot et al., 2017; Geerlings et al., 2016; Harhuis et al., 2018; Kelly et al., 2017; Smith et al., 2019; Stringer et al., 2015; Weigensberg et al., 2017; While et al., 2016). This dimension was also often approached through positive relationships with health professionals (Gorter et al., 2015; Van Staa et al., 2013; Zoni et al., 2018). However, only one study, namely Freeman et al., 2015, assessed this

dimension more in-depth by evaluating not only the effectiveness of these relationships for the well-being of the young adult in question but also the active role played by mentors in the young person's life throughout their transition. Lastly, Sam-Agudu et al. (2017), for their part, assessed the solidity of social networks.

##### 3.3.3. Personal growth

Only three studies evaluated personal growth (Table 2). Freeman et al., 2015 developed and evaluated the Youth KIT, which involves the assessment of the developmental experiences lived by young adults; this was found to be useful and impactful regarding young adults' self-discovery. The study of Gorter et al. (2015) included questions assessing the performance and satisfaction of goals fixed by young adults during their transition. Evans et al. (2006) measured self-realization in transitioning young adults.

##### 3.3.4. Purpose in life

In total, four studies evaluated matters related to purpose in life (Table 2). Freeman and colleagues (2014) assessed how young adults experienced their individual transition differently while focusing on their developmental progress with respect to purpose in life. These researchers were also interested in other types of transition involved in these young persons' journey, in particular that of high school through post-secondary studies, all the way up to transitioning into the job market. Harhuis (2018) as well as Kelly et al. (2017) explored questions assessing whether or not the future of young adults is discussed during consultations. Finally, Schmidt et al. (2016) implemented questions related to work-preparedness, education, and job qualifications.

##### 3.3.5. Environmental mastery

As previously described, this category is related to autonomy but designates the ability to act on one's environment. Eight studies in our sample evaluated environmental mastery (Table 2). In Acuña Mora and colleagues' study (2017), the criteria related to environmental mastery were: feeling of control, self-efficacy, and ability to achieve change over one's condition. For Bachelot et al. (2017), environmental mastery was translated as financial freedom, physical security, and the possibility of learning a variety of new skills. Three studies were concerned with the empowerment of young adults. These studies addressed the capacity to act rather than being autonomous by focusing on productive activities and the accomplishment of tasks, as well as helping others and community participation (Evans et al., 2006; Freeman et al., 2015; Mora et al., 2017). Mora et al. (2017) approached this dimension of human flourishing by putting forward the capacity of helping others. Smith et al. (2019), on the other hand, were interested in the extracurricular implications of young persons, including their hobbies and professional skills. Weigensberg and colleagues (2017) emphasized the idea of motivation and the desire to give back to others.

##### 3.3.5. Autonomy

Thirty-nine studies evaluated the autonomy of young adults (Table 2), most often focused on the independence of young persons, as well as self-management, self-regulation, self-medication, alongside education and health knowledge. In several instances, empowerment was assessed with a focus on being more autonomous (Evans et al., 2006; Mora et al., 2017; Pyatak et al., 2017; Sequeira et al., 2015). Some researchers assessed more specific components of the dimension of autonomy, such as cooking skills (Bashore & Bender, 2016) or taking care of oneself in terms of household tasks or in relation to personal hygiene (Geerlings et al., 2016). Other than the dimensions listed above, the independence of young persons was assessed mainly by taking into account decision-making, as opposed to the foreground position of the parent (Geerlings et al., 2016; Junge et al., 2017). More closely related to the medical condition, Michaud and colleagues (2017) were interested in the motivation of young persons in terms of how it underlies perceptions of their own autonomy, while Sattoe et al. (2016) were interested in the goals set by young adults based on their particular condition.

### 3.4. The role of the transition coordinator

Several studies reported on the challenges of clinical follow-ups with young individuals undergoing transition. Transition coordinators have been proposed as a way to achieve stability during the transition in addition to bridging the pediatric care system and the adult care system.

In the context of this review, there was a transition coordinator in 45 cases, and none in 46 studies (Table 2). For example, the study of Annunziato et al. (2013) – a pilot study of using a transition coordinator to improve transfer from pediatric to adult services – suggests its promises as a method to improve the process. Mc Govern et al. (2018) emphasized the role of the nurse coordinator: “[t]he key role played by the coordination nurse specialists throughout the transfer process is a likely key determinant in satisfaction levels”. Hankin et al. (2012) stated that nurse case managers (coordinators) were the most important element of pilot programs, increasing the chances of successful retention. The study of Dogba et al. (2014) underlined the importance of the transition coordinator in the program evaluated in their study: the coordinator addressed transition-related issues such as employment, education, living, and social and community life during regular meetings with patient/family, care practitioner, and transition coordinator. Overall, many studies greatly favored the presence of a coordinator given its alleged beneficial impact on the transition process. However, some of these claims were made without clarity and further specification on the actual role and responsibilities of the transition coordinator.

A lack of consistency was found between the responsibilities and professional backgrounds of the coordinators across programs. For example, in the study of Annunziato et al. (2013), the coordinator is a psychologist, but this seems quite rare. Most of the time, the coordinator is a specialized nurse. Despite this lack of standardization, studies examining the impact of transition programs with dedicated coordinators are yielding generally positive results. The role of the transition coordinator is typically to: act as a pivot between the old and new members of the care teams, in addition to supporting patients and families in their preparation; to ensure the continuity of care between the two systems by ensuring that appointments are made; to discuss how patients are progressing toward self-managed care or barriers to this (e.g., medication); to ensure communication between the pediatric and adult systems, and referencing (Annunziato et al., 2015; Betz and Redcay, 2005; Ciccarelli et al., 2015; Flocco et al., 2019; Levy-Shraga et al., 2016; Nieboer et al., 2014).

## 4. Discussion

The purpose of this review was to identify whether and how dimensions of human flourishing were used to evaluate transition programs in healthcare systems. Our results reveal that 44 out of 105 articles evaluated one or more of the dimensions of human flourishing previously outlined – however, the ways of assessing these dimensions varied greatly from study to study and were sometimes minimal. No study used specific and explicit measures of human flourishing. In contrast, medical aspects (e.g., clinic attendance, medical outcomes, medication compliance) were emphasized in the evaluations reported. Given that transition care – and the challenges encountered therein – has considerable impact on youth, understanding how that care and associated services support their flourishing is quintessential. It is a promising terrain to develop broader ideas for collaborative ethics research, intervention, participatory and inclusive models of human flourishing. For example, consistent with tenets of pragmatic ethics, growth and human flourishing should be thought of as being the realization of one's own potential and capabilities (Pekarsky, 1990; Racine et al., 2019; Sen, 1989). This orientation cannot be imposed from outside, but most come deep personal aspirations. We discuss methodological and practical aspects of our findings, particularly the shortcomings of the current literature, the current focus on specific dimensions such as autonomy, and the need for more participatory and open-ended evaluations of flourishing.

No scales designed to specifically assess dimensions of human flourishing were used to evaluate transition. Methods that came closest to doing so were evaluations based on young adults' quality of life. The majority of the quality of life scales used took into consideration social support and autonomy, though neglected the objectives, passions, and ambitions that contribute to the development of the young adult in question. Several studies used quality of life scales as a validation of quantitative criteria without further investigation. For example, Strijbosch et al. (2016) acknowledge that 7% of patients had complex psychosocial problems but did not dig deeper into these aspects. Annunziato et al. (2013); Chaudhry et al. (2013); Flocco et al. (2019); Skov et al. (2018); Strijbosch et al. (2016), all assessed quality of life in terms of life satisfaction in general, including anxiety disorders and depression/emotional/psychosocial disorders, focusing on either their presence or absence, without taking interest in understanding young adults' plans, passions, motivations in life, etc. While it is important to know whether young patients have specific mental health problems, what about understanding the reasons for these problems? Where do these issues stem from? How do they affect the daily life of young persons within the context of care transition?

Studies reviewed focused particularly on the dimensions of autonomy (39 articles) and positive relationships (15 articles). Personal growth (3 articles) and purpose in life (4 articles) were the least addressed dimensions, followed by self-acceptance (8 articles). This emphasis on autonomy potentially reflects a Western context in which the majority of the studies are conducted, given the great importance granted to individual autonomy. However, it is important to note that autonomy's contribution to human flourishing is typically encountered, contrary to some interpretations, as relevant to a very broad range of human cultures (Chirkov et al., 2003). Nonetheless, it is true that well-being and human flourishing tend to be interpreted as being essentially about autonomy and this could explain the literature's emphasis on this dimension of flourishing. Another reason could be that the transition period evokes important questions about autonomy (De-Juanas et al., 2020) although here again, broader views about flourishing in young adults would bring a more expansive perspective (Witten et al., 2019). Likewise, the recently developed theory of contextualized autonomy emphasizes that autonomy is an ability that contributes to flourishing but needs to be supported and cultivated as well as understood developmentally (Bogossian et al., 2020; Racine & Dubljević, 2016; Racine et al., 2017; Racine et al., 2021). Otherwise, Freeman et al., 2015 was the only study that assessed purpose of life in-depth. For the other studies, when mentioned, purpose in life was often assessed superficially, usually touching only on educational and employment statuses. Surprisingly very little was said about taking into account the life projects, passions, and ambitions of young adults, which are essential in the perspective of human flourishing. Moving forward, more integrative perspectives on transition care would be welcomed. Here we have in mind the personalization of transition care to the values of youth. This cannot be done by simply using a boilerplate understanding of human flourishing. It means being open to learning what matters for a given person and why, including the social and cultural dimensions of a person's existential goals and orientations, akin to person-centered care (Gordon, 1934; IOM, 2001; Laine & Davidoff, 1996) and person-oriented models of research ethics (Cascio et al., 2020; Cascio & Racine, 2018). In this regard, rehabilitation psychology offers insights into the promotion of the well-being of people with disabilities or chronic health conditions (Nierenberg et al., 2016). In addition, the recent advent of ultrabilitation signals a renewed interest in thinking about well-being and flourishing in this context beyond the perspective of restorative rehabilitation (Buetow, 2020; Buetow et al., 2019).

As mentioned previously based on Table 2, there were sometimes questions seemingly related to one or more dimensions of human flourishing, though the studies did not assess them *per se* and the impact of these dimensions. For example, in Annunziato et al.'s study (2015), the components of intensive pediatric preparation of the program, such as self-management and sharing of fears and concerns, were significantly

related to dimensions of human flourishing but they were not part of the evaluation measures. In other cases, certain aspects of the dimensions of human flourishing were reported freely by the participants though not evaluated by any specific measures. There were also some asymmetries between transition programs and their evaluation. While some transition programs take into account one or more dimensions of human flourishing, studies that assess the effectiveness of these programs after their establishment do not address these issues of human flourishing. It would have been interesting to know if the integration of these dimensions in the program had a beneficial effect on the life of young adults, or on the development of their life plan. This could have consisted of outcome measures. For instance, the study of Cadogan et al. (2018) mentioned SMART principles (relating to the dimensions of positive relationships, purpose in life, environmental mastery, and autonomy), though these principles were not evaluated in the final study. Similarly, even though the pilot program of Grady et al. (2019) included more than one dimension of human flourishing, the goal of the study was mostly to see whether TRANSIT medically improved patients' transition or not. Additionally, it would be useful to know if flourishing is envisioned similarly across chronic health conditions and whether there are common or specific needs and aspirations. At this time, the literature has advanced the practical relevance of establishing common core support across different conditions (e.g., in neurodevelopmental conditions) given the scarcity of resources (Racine et al., 2014) while at the same time flourishing has been described as different for some (e.g., neurodiversity in autism) (Cascio et al., 2021; Hilton et al., 2019; Jaswal & Akhtar, 2019).

Transition care is perhaps currently viewed in narrow ways such that a young adult's meaningful activities and orientations may seem superfluous to more clinical health-related questions such as medication compliance. However, the ability to envision transition care in ways that take into account the life goals and life preferences of young adults could be paramount, including for clinical efficacy. The life of some young adults with chronic disease may not correspond to the goals embedded in many clinical programs that emphasize autonomy (Racine et al., 2014). If this is the case, there is a real risk that transition programs do not engage with the values and outcomes important to young adults at a time in life where such questions bear considerable identify-development importance (Hamdani et al., 2015). This brings attention to the deeper values embedded in transition care and whether the goals of transition care are in service of young adults instead rather than the reverse. While flourishing in adolescents and young adults is still poorly understood (Witten, 2019), the question of whether transition care is responsible for the concept and orientation of flourishing remains open.

Moreover, considering the documented difficulties with regard to follow-ups, preparation, and well-being of young adults while transitioning from the pediatric system to the adult system, there is a need for more studies and more promotion of human flourishing in transition programs. Given that the studies reviewed were mostly quantitative, more studies using qualitative and participatory methods are necessary to explore human flourishing in order to fully understand the sources of the difficulties experienced by young adults and to be able to guide them in their own path. In order to forge their own identity, young adults question their skills, beliefs, and values. If young adults are able to make sense of themselves, they will forge a solid identity for themselves rather than trying to become what they are not. As pointed to already, some implicit and explicit views of transition and good transition care can embed ideals such as autonomy and independence which are not those of youth with chronic health conditions (Cascio & Racine, 2019; Hamdani et al., 2015). What can be done to support young adults in their quest for identity through the transition process? How to ensure their well-being in a life context of their own? How to ensure that the needs of young adults are continuously met in both pediatric and adult care systems, despite the change of the healthcare team? These critical questions need to be considered in research and in clinical practice. Embedding the various dimensions of human flourishing in transition programs could thus be beneficial. Furthermore, being open to various ways in which individuals

find equilibrium between various aspects such as favoring positive family relationships over autonomy *sensu stricto* should be part of personalized care (Bogossian et al., 2020; Racine et al., 2013).

Finally, and although this was not the main focus of our review, the generalized difficulty in maintaining clinical attendance and compliance with young individuals undergoing care transition is undoubtedly important to explore. This issue may explain why researchers are less interested, in general, in carrying out research on the development of young adults. However, targeting the sources of uncertainty and difficulty for young adults may help researchers understand why they so often fail to show up for their daily medical appointments. This is undoubtedly a line of thought worth pursuing to improve transition services, especially as to whether transition care more sensitive to how young adults see the world and their purpose in life could be a promising avenue.

## 5. Limitations

While we attempted to provide a first critical interpretative literature review on the consideration of human flourishing in transition programs for young adults with chronic conditions, our efforts were limited in several ways. To guide our search, we consulted a professional librarian to refine our keywords and search strategy. However, our search was limited to the French and English languages and the choice of keywords. Relevant content could be encountered using different search strategies. Another important limitation to note is that this study was conducted with an end date in 2019. New studies evaluating transition programs have been published since then. In addition, it is difficult to draw precise boundaries to the concept of human flourishing. What constitutes flourishing may vary from person to person and is based on norms and social context. In this sense, the fact that human flourishing is subjective, although effectively operationalized following Ryff and Singer's model in the context of this review, may represent a limit. It is possible that the use of another model would have changed slightly the overall results but most likely some of the key messages would remain rather intact because of the lack of attention to the topic of human flourishing in this literature. We adopted a generous data extraction strategy which could give the impression that there is more content than there actually is.

## 6. Conclusion

We set out to review whether and how transition evaluation takes into account important aspects of human flourishing based on an integrative and open-ended model of flourishing proposed by Ryff and Singer. Although our searches were rather extensive and the application of our content extraction rather generous, we are left with the general observation that the transition literature has not squarely addressed the topic and the orientation of flourishing as it bears on young adults, a population where aspects of flourishing such as autonomy, purpose in life, and positive relationships with others would seem to be of paramount, potentially lifelong, importance. To be fair some dimensions are integrated in quality of life evaluations and important efforts are currently made to expand transition care beyond clinical outcomes *sensu stricto*. However, we suggest that it would be beneficial to take into account more explicitly the literature on human flourishing and to consider adopting a clinical gaze that opens-up to broader visions of well-being. There lies a promise for increasing the relevance and impact of transition care in ways that meets the needs and preferences of young adults.

## Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssmmh.2021.100007>.

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