ORIGINAL PAPER

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Students with Autism Spectrum Disorder and Their Parents in the Transition into Higher Education: Impact on Dynamics in the Parent–Child Relationship

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Abstract

This study examined how 34 senior students and first-year college students with autism spectrum disorder, their mothers ($n=34$) and fathers ($n=26$) navigate the higher education transition, and how this context impacts on dynamics in the parent–child relationships. Semi-structured interviews were analyzed based on grounded theory and dyadic analysis principles. Both parties were confronted with an abundance of challenges and experienced strong feelings of ambivalence, stress and anxiety. Differences in perspectives occurred regarding the construction of adulthood, the acquisition of autonomy, disclosure and subscribing to support services. These differences caused tensions in the parent–child relationship, hindering the transformation of the relationship into an adult-like mutual relationship. Clinical implications are extrapolated on the basis of these findings.

Keywords ASD · Higher education transition · Qualitative research · Challenges · Support needs · Parent–child relationship · Interpersonal influences

Introduction

Autism spectrum disorder (ASD) refers to a neurodevelopmental disorder associated with deficits in social interaction and social communication, combined with restricted or repetitive patterns of behavior and interests (American Psychiatric Association 2013). The prevalence of ASD has

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increased dramatically over the last two decades and varies worldwide from 0.6 to 1.47% (Brugha et al. 2011; Centers for Disease Control and Prevention 2016; Davidovitch et al. 2013; Elsabbagh et al. 2012; Fombonne et al. 2011). The rising numbers in prevalence, the improved provisions of effective, evidence-based treatment programs, and the introduction of disability legislation in education, have contributed to a growing contingency of students with ASD attending postsecondary education (Adreon and Durocher 2007; Barnhill 2014; Pillay and Bhat 2012; Van Bergeijk et al. 2008).

Although autism symptoms tend to improve over time (Howlin and Moss 2012), the transition from high school into higher education constitutes a precarious life event for students with ASD (Van Bergeijk et al. 2008; Van Hees et al. 2015). Compared to other disability groups, students with ASD in postsecondary education have reduced graduation rates (Sanford et al. 2011; Shattuck et al. 2012; Taylor and Seltzer 2011), and face difficulties with managing the competing social and academic demands in postsecondary education, achieving appropriate time management and self-advocacy skills, and difficulties with regulating emotions and sensory issues (e.g., Cai and Richdale 2016; Van Hees et al. 2015; White et al. 2016). In addition to these challenges, many young adults with ASD lose the entitlement

to formal supports services after they leave secondary education school (Cadman et al. 2012; Friedman et al. 2013; Pinder-Amaker 2014). Parents of students with ASD often continue to be an important source of support and care in the postsecondary environment to ensure success (Cadman et al. 2012; Hendricks and Wehman 2009; Taylor and Seltzer 2011). This situation where parents hold an important role to provide support to their child may have a significant impact on family life (Cadman et al. 2012).

While a growing body of literature has explored the higher education experiences from the viewpoints of young adults with ASD (e.g. Cox et al. 2017; Gelbar et al. 2015; Van Hees et al. 2015) and from the parents (e.g. Elias and White 2017; Morrison et al. 2009; Morrisson et al. 2009; White et al. 2016), only a limited number of studies have focused on the perspectives of both students and their parents about the higher education transition. Camarena and Sarigiani (2009) interviewed high school students with ASD ($n=21$), their mothers ($n=20$) and fathers ($n=13$) to assess postsecondary educational aspirations, perceived obstacles, and the resources needed for success. Findings revealed that adolescents and their parents had clear postsecondary educational goals, but were more concerned with non-academic situations (e.g., daily living skills, housing, campus life transition) rather than academic success. Parents also had significant concerns about the suitability of the institution for higher education to meet the specific needs of their child. The study by Cai and Richdale (2016), conducting focus groups with students with ASD in postsecondary education ($n=23$) and focus groups with family members ($n=15$; of which 14 were parents), confirms these concerns and indicates that students perceived receiving better educational than social support, whereas family members reported inadequate support in both the academic and social domains. Many parents, usually mothers, played an important and active role in their child's life, providing organizational, financial and emotional support. Hence, parents felt they did not have the opportunity to provide sufficient support within the academic setting. They complained of a communication breakdown between parents and staff, sometimes associated with privacy laws, which could lead to negative consequences for their children. Cheak-Zamora et al. (2015), who conducted focus groups with adolescents with ASD ($n=13$) and focus groups with their caregivers ($n=19$; of which 16 were mothers) about the transition into adulthood, highlight the fear and anxiety of both stakeholders' experience generally caused by a lack of service availability, as well as the significant unmet needs for adolescents with ASD and caregivers, leaving caregivers struggling to fill the gaps. Mothers reported feeling overwhelmed, anxious and in great need of a break. Hendrickson et al. (2017) examined student ($n=8$) and parent ($n=8$) perspectives on college adjustment across five dimensions (Student Life, Emotional Adjustment, Independent Living Skills, Interpersonal Relationships, and Self-Advocacy). Although both the students and parents perceived the transition to and exit from college positively, the perceptions of parents did not always align with those of the students. At the end of the first semester, for instance, parents felt more positively than the students about Student Life. These results suggest that family members experience the transition differently.

Although these studies offer relevant insights into the perceived challenges and the perspectives of students and their parents, they focus predominantly on the impact a young adult with ASD has on the mother, consider less how fathers make sense of this transition, and largely ignore bidirectionality in intergenerational transmission. The bidirectional approach acknowledges that children and parents influence each other reciprocally and have equal agency, i.e., "the human capacity for initiating purposeful behavior to influence the other, and the ability to interpret and construct meanings out of relational experiences" (De Mol 2008, p. 164). Furthermore, when analyzing both perspectives, a holistic approach needs to be used as the parent–child relationship is not only influenced by the complex bidirectional relationship between the child and his parents, but also by the wider social and cultural context (Hinde 1997; Kuczynski and De Mol 2015). As more and more students with ASD are attending postsecondary education and students rely on their parents during the higher education transition, it is important to have a thorough understanding of how this transition impact on parent–child relationships.

In general, the transition from high school to college is often a period of change for the relationship. Studies on the transition into college in neurotypical families indicate that the relationship between students and their parents changes in different ways, including more open communication, feeling more equal, and acquiring independence (Aquilino 1997; Kenny 1987; Lefkowitz 2005; Rice and Mulkeen 1995; Thornton et al. 1995). College students perceive establishing oneself as an equal compared to one's parents as an important marker of becoming an adult (Arnett 1997; Chickering and Reisser 1993; Erikson 1974). They want to gain autonomy from their parents and solve problems on their own. However, they are also nervous about their transition and want to hold on to the sense of dependency. In fact, parents hold higher expectations for autonomy than their emerging-adult children themselves. This demonstrates the complexity of emerging adulthood and reveals that this transition may be a particularly important one for parents and young adults (Kenyon and Koerner 2009).

Study Aim

The purpose of the present exploratory study was to investigate how youngsters with ASD and their parents cope with the higher education transition and how this context impacts

on dynamics in the parent–child relationship in the scope of this study. Because of the limited work in this area, no specific hypotheses were predetermined. In accordance to the aim of the study, we systematically investigated from a dialectic perspective both parents' and students' perceptions on college attendance, the perceived obstacles and the support needs, while focusing on the processes of interpersonal influences (Kuczynski and De Mol 2015). Following Van Hees et al. (2015), we defined the college or university experience broadly, including the domains of education, student life and daily (independent) living. This wide perspective allowed us to enter the families' lives to understand their daily struggles and uplifts, as well as to identify possible support services that may help students with ASD and their parents during this transition. A better understanding of the dynamic processes in the parent–child relationship will allow for the development of interventions that are tailored to the specific needs of students and their parents.

Methodology

Theoretical Framework

Social relational theory (SRT; Kuczynski and De Mol 2015) formed the conceptual framework for this study as it represents an open-ended dialectical framework regarding dynamics in the parent–child relationship and provides guidance for exploring underlying micro processes of social transactions. According to SRT, parents and children are addressed as full and equal agents in their interdependent relationship, which is embedded in social and cultural contexts. These contexts influence bidirectional transmission in the parent–child relationship. Although the model draws attention to the separate goals and interpretations of parents and children, both parents and children are assumed to cope with or resolve conflicting views because they share a continuing interdependent relationship. Contradictions give rise to uncertainty that creates opportunities for novel syntheses, which sets the context for further developmental change. Considering parents and children as equally agentic, we conducted multi-family member interviews (MFMI) separately with students with ASD, their mothers, and their fathers. This allowed us to focus on the meaning and thoughts of each family member by giving each of them possibility to speak freely about their own experiences and to reflect upon the relationship with the other family members (Eisikovits and Koren 2010; Reczek 2014). Since only limited theoretical and empirical research exists on the transition into higher education in families with students with ASD, the grounded theory approach was used as a guiding framework for data collection and analysis (GTA, Bogdan and Biklen 1998; Corbin and Strauss 2008). Furthermore, the principles of dyadic interview analysis

(DIA) were used to analyze the interview data from different members of the family unit into an integrated systemic perspective (Eisikovits and Koren 2010). The DIA made it possible to carefully compare, reflect on, and integrate the perspectives of the participating family members and in this way lifted our systemic understanding of the dynamics in the parent–child relationship in families with a youngster with ASD. The combination of these approaches offered us the potential to generate a framework of how students with ASD and their parents navigate the higher education transition as a family. In accordance with the GTA and SRT we selected sensitizing concepts (Bowen 2006; Charmaz 2006; Corbin and Straus 2008; Miles and Huberman 1994). Since we were interested in how the transition affects dynamics in the parent–child relationship, interpersonal influences and perceived partner responsiveness were selected as sensitizing concepts. Perceived partner responsiveness represents the ability of an individual to respond to another with behaviours (e.g., disclosures, expressions of emotion) that address the communications, needs, wishes, or actions of the person with whom they are interacting (Miller and Berg 1984). Interpersonal influences have been defined as instances in which events in one partner's chain are causally connected to events in the other's chain (Huston 2002, p. 170). It is through these processes that family members affect and change each other's thoughts, feeling and actions (Huston 2002).

Participants and Recruitment

Convenience sampling was used to recruit families who were eligible to following inclusion criteria: (1) senior students attending the last year of high school and freshman students attending the first year at university (offering academic bachelor and master programmes) or university college (offering practice-oriented bachelor programmes) (hereinafter called 'colleges'); (2) with a formal diagnosis by a multidisciplinary team of experienced clinicians; and (3) fulfilled established DSM-IV-TR (APA 2000) criteria for autistic disorder, Asperger's disorder or PDD-NOS or DSM-5 criteria for Autism Spectrum Disorder (APA 2013); and (4) their mothers and their fathers. Recruitment was conducted through the Flemish user organization for ASD, ASD counseling services and several schools for secondary and higher education from different regions in Flanders. The study was conducted among 34 families with a youngster with ASD (94 individuals). The parent-reported diagnosis age of the student identified with ASD ranged from 3 to 16 years. The sample of students included 25 boys (73.5%) and 9 girls (26.5%) with an average age of 17 years, living in Flanders. Twenty-three students were attending high school (67.6%), while 11 were attending the first year of higher education (32.4%; 6 university and 5 university colleges). All institutions were publicly

funded and had open access. No application process applies in institutions for higher education in Belgium, save medical professions. The field of study varied, both in the high school settings (e.g., arts, general, technical and vocational education) as in the higher education setting (e.g., Art and History, Health care, Education, Business Sciences, Law and Criminology and Industry and Technology). Twenty-three students permanently lived at home with their parents, while 11 students (32.4%) lived on campus during the week and went home during weekends. Since distances in Belgium are small, it is common practice that residential students go home for the weekend. All students received specific support from the agency through which the recruitment took place. More specifically, all students were registered as students with a disability as they applied for academic accommodations. Sixty parents of the 34 students participated in this study, of which 26 were fathers (43.3%) and 34 were mothers (56.7%). The average age of fathers and mothers was 48 and 47 respectively. The majority of parents (65%) possessed a college or university degree (18 fathers and 21 mothers), 31.7% had completed high school (12 mothers and 7 fathers), and 3.3% had less than a high school level of education (one mother and one father). Six families had one child (17.6%), and 28 had multiple children (82.4%).

Interview Guides and Data Collection

Specific interview guides with complementary questions for parents and students were developed focusing on the experiences of each family member. An extract of both interview guides is presented in Appendix A in Supplementary material. The content was developed on prior research involving interviews on ASD (Van Hees et al. 2015) and family functioning (De Mol 2008; Kuczynski and De Mol 2015). The interview guide was revised by two researches, one in the field of ASD and one in the field of family research. Each topic had an introduction explaining the purpose and focus of the topic and consisted of a series of open-ended questions on college attendance, the perceived obstacles and the support needs, while focusing on the processes of interpersonal influences and perceived partner responsiveness that occur in the parent–child relationship during this stage of life. For each content area, probing questions were used to receive the relevant information and to prompt the participants for additional information or deeper explanation.

The interviews took place at the university or in the participant's home. To maintain sufficient openness for the participants to speak freely about their experiences and to give them the opportunity to come up with unanticipated topics and generate new discussion, the interview guides were handled flexibly. Interviews lasted between 39 min and 117 min ($M = 54$ min) and were digitally recorded. They were transcribed verbatim after which transcripts were made anonymous and checked for accuracy. Field notes provided details and descriptions of each interview and the participant.

Data Analysis

Although interviews were conducted separately, they were analyzed both individually, based on GTA methods (Bogdin and Biklen 1998; Corbin and Strauss 2008) and dyadically for overlaps and contrasts between the perspectives of students with ASD and their parents (Eisikovits and Koren 2010). After each interview, the verbatim transcript was subjected to a process of open coding with the sensitizing concepts in mind by two independent researchers. After a thorough first reading of the interview transcript, each researcher carefully read the transcript line-by-line several times noting nodes and comments in the right-hand margin. Emerging insights, data, themes and categories were recorded in the left-hand margins. Researchers regularly discussed preliminary findings in order to achieve consensus (researcher triangulation). When consensus was reached, the first author conducted intensive analyses. This process of open and axial coding resulted in a list of themes and categories representing and explaining the students', the mothers' and the fathers' experiences. The GTA of the students' texts yielded six themes: the construction of adulthood, the urge for autonomy acquisition, the reluctance for disclosure and formal support, complex tensions in the parent child-relationship, stress, anxiety and ambiguity and difficulties to redefine the parent–child relationship. Parents' reports yielded six themes: losing accustomed position, difficulties to handle their child' wish for autonomy, the need for disclosure and extensive support services, complex tensions in the parent–child relationship, stress, anxiety and ambiguity, and difficulties to redefine the parent–child relationship. Next, informed by Eisikovits and Koren's (2010) guidance for dyadic interview analysis, the two researchers carefully compared, reflected on and integrated the perspectives of both students with ASD and their parents. First, an overarching analysis within each family unit was conducted to construct potentially new thematic categories at a family level. Therefore, the researchers addressed how each individual participant, as part of a dyad, addressed each cross-case theme and category. Next, the researchers conducted an overarching analysis across families in order to look for convergences between the different families. The combination of these analyses allowed us to build up a conceptual framework that represents an integrative family perspective on how students with ASD and their parents navigate the higher education transition (Fig. 1). Table 1 represents an abstract of the coding book, showing the frequency of each theme and category.

Ethical Standards

The Ethical Committee of the faculty of Psychology and Educational Sciences of Ghent University granted ethical approval to the study. Prior to data collection, the purpose of the study and ethical issues regarding anonymity and confidentiality were discussed with each participant, after which full voluntary informed consent was obtained from all individual participants included in the study. If the student was a minor, parents also provided consent. Participants were given the right and freedom to withdraw at any time during the study. Interview data was stored securely and transcripts were made anonymous. Information provided by a family member was not'disclosed to other family member's. In the presentation of responses in the member checks, personal details such as names, places, occupation were changed or deleted in the interview excerpts to maintain confidentiality.

Trustworthiness

Two researchers conducted data collection and analysis, and regularly discussed their findings in order to achieve consensus on themes, as well as to reduce inherent biases in the personal interpretation of interview transcripts. Data triangulation was enhanced both by including participants from different geographical regions of the country and different institutions of secondary and higher education, and by ensuring participants reflected a variety of characteristics (e.g., senior students, first-year, students, gender, field of study). Debriefing was achieved by an academic colleague familiar with qualitative methods. His provocative questions relating to the analysis, provided additional insights beyond those of the researchers (Eisikovits and Koren 2010). Further, dyadic analysis served to ensure trustworthiness similar to triangulation (Eisikovits and Koren 2010). In order to enhance participation validation, we presented the results to the participants in individual member checks to receive their feedback and refine the figure. After analyzing 20 families in this way, we reached saturation on the topic, that is, no new themes emerged.

Results

The dyadic interview analysis made it possible to carefully compare, reflect on and integrate the perspectives of the participating family members and in this way lifted our systemic understanding of the complexity of the transition process for families with a youngster with ASD. Figure 1 represents how the transition impacts on dynamics in the parent–child relationship in families with a youngster with
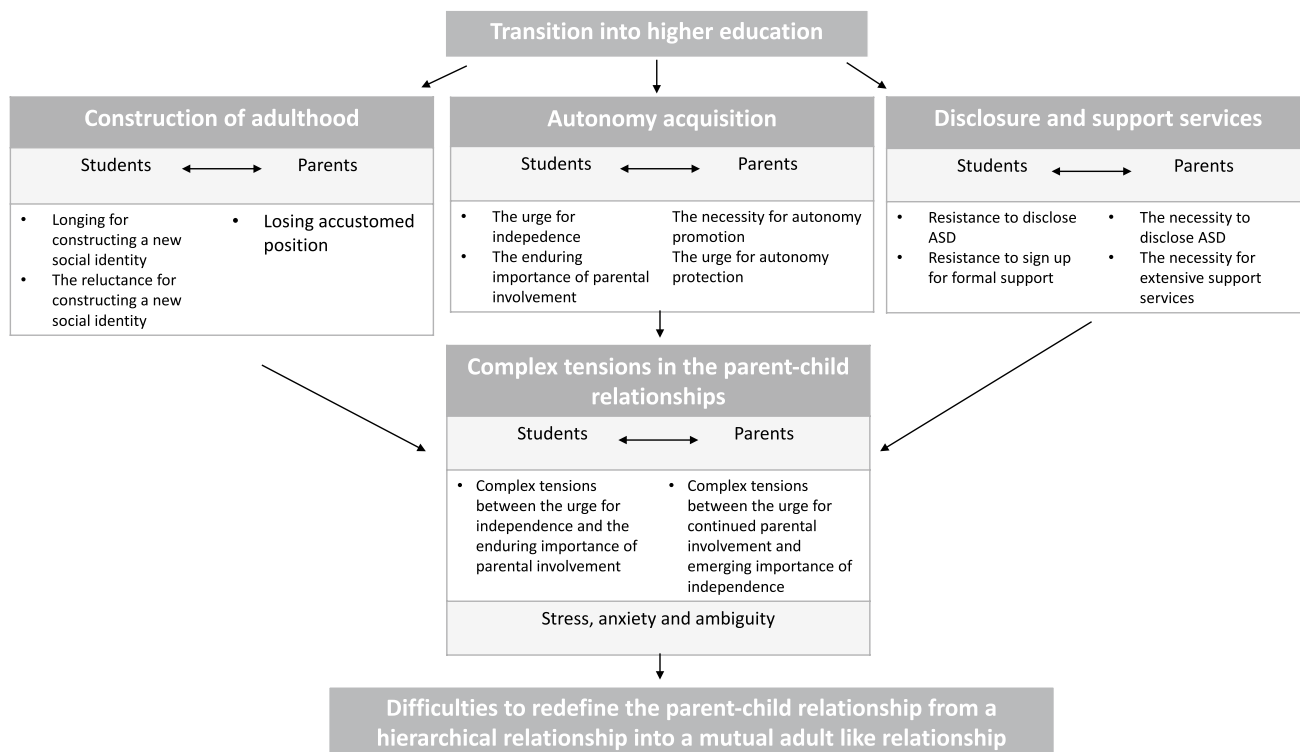

Fig. 1 Framework of how students with ASD and their parents navigate the higher education transition as a family

Table 1 Frequency and percentages of themes and categories identified by students and parents about the higher education transition

	Students (n = 34) % (n)	Mothers (n = 34) % (n)	Fathers (n = 26) % (n)
Students' perspectives			
The construction of adulthood as social identity	91.2% (31)		
Longing for constructing a new social identity	91.2% (31)		
The reluctance for constructing a new social identity	79.4% (27)		
Autonomy acquisition	91.2% (31)		
The urge for independence	91.2% (31)		
The enduring importance of parental involvement	85.3% (29)		
The reluctance for disclosure and formal support	97.1% (33)		
Resistance to sign up for formal support	97.1% (33)		
Resistance to disclose ASD	88.2% (30)		
Complex tensions in the parent–child relationship	91.2% (31)		
Complex tensions between the urge for independence and the enduring importance of parental involvement.	91.2% (31)		
Stress, anxiety and ambiguity	88.2% (30)		
Difficulties to redefine the parent–child relationship	82.4% (28)		
Parents' perspectives			
Construction of adulthood		100% (34)	96.2% (25)
Losing accustomed position		100% (34)	96.2% (25)
Difficulties to handle their child's whish for autonomy		100% (34)	96.2% (25)
The necessity for autonomy promotion		76.4% (26)	84.6% (22)
The urge for autonomy protection		100% (34)	96.2% (25)
The need for disclosure and extensive support services		100% (34)	92.3% (24)
The necessity for extensive support services		100% (34)	100% (26)
The necessity for disclosure		100% (34)	92.3% (24)
Complex tensions in the parent–child relationship		97.1% (33)	88.5% (23)
Complex tensions between the urge for continued parental involvement and emerging importance of independence		97.1% (33)	88.5% (23)
Stress, anxiety and ambiguity		88.2% (30)	83.3% (20)
Difficulties to redefine the parent–child relationship		97.1% (33)	88.5% (23)

ASD. Differences in perspectives regarding the construction of adulthood, the acquisition of autonomy, disclosure and subscribing to support services caused complex dialectic tensions in the parent–child relationship. In this section, both perspectives are described. To strengthen insight in the different perspectives we juxtapose the perspectives of children and their parents. Verbatim quotes—for which pseudonyms are used—are provided as examples. The families and the quotes illustrated were chosen according to data richness and are representative of the other families not illustrated here (Koren et al. 2016, p. 1559). Due to ethical considerations, all of the quotes from the children are from families different from those who provide quotes for the parent section.

The Construction of Adulthood

Students' perspectives. Longing for constructing a new social identity but reluctance to construct the new social identity. During this stage of life, students felt 'ripe' for leaving high school and looked forward to attend an *environment* of interest with a mature viewpoint and adult rules of engagement in which they could take on new roles and role-related identities. Students testified about difficult pathways of bullying in high school, and perceived the move to college as an opportunity to shed their disliked identities and to construct a new social identity, conforming to the expectations of adulthood.

> Actually, I'm fed up. I want to leave behind my secondary school. In high school, you're the young apprentice. Young children and adolescents surround you. Very noisy and immature. In postsecondary education, you go in for an adult study in which the point of view and rules of engagement are different. You are not treated as a child, but as an adult. (Billy, senior student)

When focusing on the characteristics of this new identity, students expressed their need for 'freedom', 'independence', 'autonomy', 'responsibility', 'fitting in', and tied these concepts to roles they had to master successfully in order to construct—as one student called—the identity of 'a legitimate college student'. Beyond making transition choices independently, attending classes, accomplishing academic tasks and achieving academic grades, being 'a legitimate college student' was primarily associated with 'integrating into collegiate life'. In order to integrate into collegiate life, students pointed to the importance of blending in with the larger student body. Due to shared interests and increased maturity among college students, students expressed their hope that forming meaningful friendships and relationships with college-aged peers and instructors would work out better in college.

> There is no normative path or gold standard to construct adulthood, and that is quite difficult with my ASD as I experience difficulties with change, uncertainty and communication. In a somewhat controlled and safe environment with 'kindred spirits', I will be taught independence, career skills, and social skills step by step. In that sense, college gives me time and guidelines to construct adulthood. (Linda, senior student)

Even though students expressed their need for constructing a new social identity, they experienced feelings of ambivalence hereabout. In some way, it seemed attractive and satisfying to attend college with its promises of increased freedom, friendships, career success etc. At the same time, however, it meant leaving behind familiar structures, patterns and persons, taking on new roles and 'deciphering' the expectations of the new environment. Given students' characteristic difficulties to manage change and their difficulties with reading social cues, they experienced fear, anxiety and reluctance to construct this new identity. Sometimes resulting in procrastination.

> Actually, I have a difficult time dealing with the transition. I am completing high school and becoming self-supportive. So, I am finishing some chapters of my life. Now I have to open new ones, but I don't know what to expect, so I don't know how to open these chapters. That frightens me. So instead of opening them, I am lingering and postponing the decisions about my transition. (André, senior student)

Parents' perspectives. Losing accustomed position. Although parents acknowledged that college attendance was important for opening professional doors and the development of personal life skills toward independence, parents felt powerless concerning the loss of their own accustomed position in higher education. Both mothers and fathers emphasized that they had become accustomed to handling all communication with teachers and counselors in their children's school lives so far, and admitted that losing this familiar position in the higher education transition, associated with privacy laws, was difficult to accept and handle.

> From the moment, you get into contact with the institution of higher education, you're a parent only by name. I understand that my son has reached an adult age and he has to run his own life, but I have a child with ASD. You feel that it is important that you are kept well informed—more than other parents. (Linda, mother of a first-year college student)

Autonomy Acquisition

Students' perspectives. The urge for independence but the enduring importance of parental involvement. In their focus on constructing a new identity, students expressed the importance to get the recognition of their parents as full agent by letting them make their own transition decisions.

> It is important that I learn to stand on my one. I have come to an age where this becomes important. My parents must also along with that. They should not make choices in my place. (Rebecca, senior student)

Notwithstanding their need for independence from their parents, students underscored the importance that their parents supported them and were involved in their transition process. Students actively asked their parents for support in a multitude of situations, including guiding their curriculum choices by collecting information about career options, coordinating the administration for the transfer from high school, liaising with the school in order to provide documentation for applying for reasonable adjustments, etc.

> My mother helped me with gathering information and making phone calls, because I usually encounter difficulties with communication with unfamiliar people. These are things I cannot take on me. (John, first-year college student)

Additionally, students stressed the critical importance of the emotional support their parents provided to keep them on track during the uncertainties and challenges they faced by listening to their uncertainties and giving appropriate advice concerning their questions about transition decisions.

> I become more independent, but when something goes wrong, I need my parents very hard. I need their advice, and also a big hug (laughs). (Robin, first-year university student)

Parents' perspective. The necessity to promote independence but the urge to protect autonomy. Parents acknowledged

that their transition is a crossroad key period in the lives of young adults, and that it is a critical moment to promote the independence of their children.

> I have to let him go. I am conscious of the fact that it is a critical time to promote independence. (Jeanne, mother first year college student)

Hence, parents were highly worried about their children's capability to manage the elevated demands of postsecondary education. Due to the emotional vulnerability of their children, their ASD-symptoms and difficulties to take the lead, parents experienced difficulties to handle their child's wish for independence. Fueled by their own experiences, parents felt inner resistance to promote and stimulate the autonomy of their child. Differences emerged between mothers and fathers in the way they dealt with the acquisition of autonomy of their child. In contrast to mothers, fathers were more inclined to let go and stressed the importance to let their child make his or her own decisions and mistakes. Mothers experienced more difficulties in this respect, and admitted they frequently felt the tendency to step in their child's activities and take the lead. As a consequence, mothers were more involved in the transition process in a multitude of ways.

> It is more difficult for us to let him go. On the contrary, I am indulging him. He expects that from me in little things. For example, I take him to the railway station by car. His sister always takes her bike. But he says: Mum, I am going to be late. And I do not want him to be late. So, I drive him myself. (Elisa, mother of a senior student)

Disclosure and Support Services

Students' perspectives. The reluctance to disclose ASD and to sign up for formal support services. Even though students expressed the wish to be independent, difficulties with managing change and uncertainty, communication, and interaction regularly hindered them to take the lead and to self-advocate when managing subjects related to transition planning. Specifically, students reported difficulties with managing the large amount of transition decisions (e.g., career decision, disclosure, the administration to coordinate the transfer from high school), and felt intimidated by the lack of structure and predictability in higher education. Additionally, students worried about academic issues and social challenges in the domains of education, student life and daily living (e.g., group projects, text comprehension, participation in activities organized by students' unions), and highlighted sensory issues, primarily due to the large scale of education institutions. Although the lack of structure and predictability, and having to handle new situations is

typical for higher education settings and challenges nearly every freshman student, students with ASD underscored that this context caused intense feelings of ambivalence and anxiety to them. On the one hand, they realized their persistent need for structure and predictability in order to function, but on the other hand, they felt the need to push themselves not to give in to that need for structure and predictability in order to prevent themselves from getting stuck intellectually. Although students had a clear understanding of their ASD and recognized that support services might be designated to cope with the transition challenges, in their focus to develop independence and a 'new social identity', they remained reluctant to disclose their ASD to instructors, staff and peers, as well as to request support services. Thus, students focused on acting just like other students and were reluctant to disclose their ASD.

> People are accustomed to grade people. If you have no label, you are treated as normal, but from the moment they know that something is not normal, there is risk of a downside and that is what I want to avoid. So, I will not disclose my label. Instead, I will accomplish tasks and participate in activities like the rest of the student body, even though it is more difficult for me. But that is one thing that is crucial toward my development at college in order to feel a sense of belonging on campus. (Robert, senior student)

Despite their reluctance to accept support, students generally intended to request minimal support services in order to enhance success rate or to satisfy their parents, but immediately pointed out the importance of limiting support to a minimum. Students were generally not interested in proposals of summer transition programs and were hesitating about participating in peer mentoring programs. They preferred to take a 'fresh start'. In that regard, they advocated for a demand-driven support approach. Next to reasonable academic accommodations, students pointed out the importance of a contact person in the higher education setting who they could turn to if they were confused or when they had questions. Students stressed the importance of being familiarized well in advance with the expectations of the new environment by this contact person (e.g., by providing detailed information of the activities, codes on how to behave, etc.).

> It is important that guidance is scaled down in higher education. You reach a point where you have to become independent. Today's society expects that, but of course support in the transition is significant. So guidance should be available in postsecondary education, but not as extensive as in high school. (Robert, senior student)

Parents' perspectives. The necessity for extensive support services and disclosure. Parents were highly worried

about their children's capability to manage the elevated demands of postsecondary education. Due to their children's difficulties with social interaction and communication, and their difficulties handling change and uncertainty, parents reported on current and future sensory, social and academic challenges in the three domains education, student life and daily living (e.g., text comprehension, group work, study planning, acceptance, social network, self-care).

> The most difficult thing will be working in group with other students. He is going to close down and will not have contact with anyone. On the one hand, he does not really need contact, but on the other hand he wants to be accepted. (Cecile, mother of a senior student)
> He wants to live on campus during the week, and I am worried about that. It is difficult for him to organize himself. My concerns are healthy eating, sleeping, studying, going to classes, and making friends. He is not self-sufficient and does not ask for help (Simon, father of a university student)

They seemed most occupied with their children's capacity to function socially and whether or not course instructors, staff and peers would accept them.

> I especially hope that instructors, staff and peers will accept her. That's the most important thing in this transition. (Sarah, mother of a senior student)

To overcome the transition challenges, parents underscored the necessity for extensive support services in the transition into college, including the implementation of reasonable adjustments, study coaching, peer mentoring, and psychological support. Parents were also convinced about the necessity for open communication about the disability in order to gain understanding and appropriate support. In that regard, parents were in favor of disclosing the disability to staff and course instructors before the start of the study career. Quite often parents mentioned unrequested the disability to staff and course instructors in the presence of their children, while visiting information days and campuses. Mothers and fathers stressed their expertise in the needs of their children and advocated to be involved in transition planning and enrolment.

> I am convinced that you need to disclose your disability and tell (the institution) about ASD. Why? People are accustomed to grade people. That means that if we do not specify that our daughter has ASD, people will automatically categorize her, but perhaps not places her in the right box. Maybe they will think my daughter is rude. I would find that very regrettable. I think we keep more perspectives open by disclosing her disability. (Denis, father of a senior student)

Complex Tensions in the Parent–Child Relationship

As represented in Fig. 1, complex dialectic tensions in the parent–child relationship arose as a cumulating effect of the differences in perspectives regarding the construction of adulthood, the acquisition of autonomy, disclosure and subscribing to support services.

Students' perspectives. Complex tensions between the urge for independence and the enduring importance of parental involvement. Although students acknowledged parents' concerns about their ASD in the higher education setting, they were focused to be recognized as a full agent by their parents. Students found their parents overprotective and regretted parental reactions to take over the lead and step in into their activities unrequested.

> Even now with my paper, because they are too scared that I will lose myself totally, they do not really let me do. To put it bluntly: they hold me under commando. I receive too little freedom. I'm struggling with how to react on their behaviors. (Lisa, first-year college student)

However, out of respect for the efforts of their parents to keep them on track in this transition, students were prudent to share their frustrations with their parents. They struggled between the wish to talk about their feelings and frustrations with their parents and to advocate their 'rights', and the wish to keep these feelings silent. Although parental reactions strengthened students' urge to prove themselves against their parents and environment, they carried the burden of their frustrations themselves and didn't react. When they did share some of their frustrations with their parents, this mostly made them feel guilty.

> I don't tolerate that they are so protective. I want to figure out things by myself, also in order to prevent some situations. But the fact is that they do not let me sort things out. I'm not being offered the chance to do so, which is enormously frustrating. But they helped me so much in the past, and also at university. So, it is inappropriate to bring up my opinions. (Sam, first-year university student)

Parents' perspectives. Complex tensions between the urge for continued parental involvement and emerging importance of independence. Parents regretted their child's resistance to formal support services and to disclose their ASD. Due to these choices and the difficulties to outgrow their own accustomed position, parents often felt urged to intervene and to step in their child's activities in order to keep their child on track in this transition period. Hence, parents were also aware of the emerging importance of their child's independency. They reported on this ambiguity and their search to distinguish the differences between ASD, puberty

and laziness. Some parents experienced difficulties to fathom the needs and thoughts of their children.

> I know that she has to become independent, but she is not self-sufficient... Understanding what is happening, that is a big challenge for me. I cannot look inside of her head, no matter how much I would like to, and she cannot explain it to me. Yes, in fact, after 18 years I still do not know what is on her mind. That is quite difficult… It acts as a brake for growth to independency. (Dennis, father of a senior student)

Parents acknowledged that raising their child with ASD in this life stage occurred quite differently and less strictly than how they coped with other siblings in the household.

> I am somewhat stricter, more severe for my other children. For them, I set the bar slight higher. With them, I tend to tell them the unvarnished truth. For him, I am a little bit softer. I weigh my words more carefully. I am more massaging, because otherwise he chokes. So, I have to take more time. (Roger, father of a senior student)

Out of respect for the difficulties of their children and out of the respect for the qualities and the persistence of their children, parents were also prudent to share their issues with their child. Moreover, they were proud of the progress achieved so far, and stressed that the exit from high school also seemed to slowly catalyze positive changes in the quality of the parent–child relationship: they pointed to increasing levels of mutuality, asking advice and having more appreciation and respect for one's opinion.

> You're gradually evolving in an advisory role, and I feel we are becoming closer now. (Jessica, mother of a first-year college student)

Stress, Anxiety and Ambiguity

The challenges, opposing needs and thoughts, and the complex tensions in the parent–child relationship had important consequences for the inner experiences of both parents and students with ASD. They experienced strong feelings of ambivalence, stress and anxiety during this transition period.

> There are many new things. New people, another way of teaching, bit also at home habits and relations become different. That's is quite difficult because I prefer structure and stability. That brings a lot of stress and frustrations. (Lisa, first-year college student)
> Pushing her every step of the way is my main burden. I always have to stimulate her. I always have to encourage her. That is the hardest in daily life. (Marlene, mother of senior high school student)

Difficulties to Redefine the Parent–Child Relationship

The mutual desire for student independence, the perceived need for parental involvement, and attention of navigating the transition in which both of those issues are played out amid stress, anxiety, and ambiguity during the postsecondary transition, contributed to an underlying tension that seemed to hinder the change of the relationship from a hierarchical one to a mutual adult one. Both parents and students were struggling to find a balance between connectedness and individuality.

> You want him to build up his independence and you want him to learn to take over these things… So sometimes I let him fall a little bit because that is a learning process, but it feels not right and a bit unnatural. (Patrick, father of first-year college student)
> Sometimes I have the impression that they want to help too much... They want to manage too much for me… But I admit that becoming independent in my case is difficult… The help of my parents is important to hold everything under control… So I also realize that the close connectedness is critical. (Leila, first-year college student)

Discussion

The main goal of this study was to investigate how youngsters with ASD and their parents cope with the higher education transition and how this context impacts on the dynamic in the parent–child relationship. Just like fellow students, students with ASD perceive this transition as an opportunity to redefine themselves and to construct a new social identity, confirming the expectations of adulthood (Arnet 1997; Chickering and Reisser 1993; Erikson 1974). Therefore, acquiring new relationships and rebuilding a supportive social network are key areas of focus (Leary and Kowalski 1990). To achieve these goals, effective self-presentation—the process through which individuals communicate an image of themselves to others—is of great importance (Baumeister 1982). Our study clearly indicates that students with ASD are very occupied and hesitant about how to present themselves in a new context. In order to present themselves as legitimate college students, many of them do efforts on a daily basis to suppress autism-related behaviors and try to display 'normal' behavior. Therefore, they hardly communicate about their disability and are reluctant to subscribe to support services. In line with previous research (e.g., Cox et al. 2017; Van Hees et al. 2015) students with ASD take a pragmatic approach to disclosing their autism diagnosis.

In the academic context, they typically reveal their diagnoses only as needed to acquire some formal accommodations from the postsecondary institution. With fellow students and staff, they wait until circumstances or another person's actions brings the issue to the surface. Students with ASD, however, experience inner tensions between their public efforts to pass themselves off as normal and their private efforts to embrace autism as part of their identities. In that respect, the transition places them in a clear straddle regarding identity development.

Parents have an influence in the identity formation of their child, even in adolescence. By providing a warm, secure, and autonomy-supportive environment at home, they can support processes like exploration (e.g., by encouraging the adolescent to look up new information on a possible study or career) and commitment (e.g., by explaining the child why it is important to make clear and sound choices concerning relationships), which in turns may promote the individual developmental process of their child (Beyers and Goossens 2008). In contrast to parents of fellow college students who seem to hold higher expectations for autonomy than their emerging-adult children themselves (Kenyon and Koerner 2009), parents of students with ASD in this stage of life, seem to have low expectations for autonomy behavior and struggle to promote independent actions and autonomous behavior of their child. They describe themselves as uncertain, vigilant and overprotective, and persist in efforts to maintain a certain level of control about the activities of their children as well as about their accustomed position. Mothers experience more difficulties in this respect, and frequently step in to take over the lead in order to avoid failure and problems. By not allowing failure experiences and continually solving their child's problems, however, they deprive the child of the opportunity to develop an independent self-esteem and effective coping skills (Segrin et al. 2013).

Next to different viewpoints on the construction of adulthood and the acquisition of autonomy, parents and students with ASD and their parents have different points of views on disclosure and subscribing for support services. While students show resistance to disclose and to sign up for support services, both fathers and mothers are convinced that communicating openly about ASD and subscribing for support services is required to deal with the transition challenges successfully. Therefore, they do lots of efforts to convince their child to disclose their ASD and to sign up for support services.

The opposing needs and thoughts of students with ASD and their parents entail uncertainty and create a state of affective tension. While students feel frustrated about the complexity to be recognized as a full person by their parents, parents feel inner and outer tensions in allowing children to discover a new situation on their own and guarding them against all sorts of dangers. Students and parents also experience inner tensions between their urge to take distance and the needs to stay closely connected. Just like other families without a child with ASD, families with a youngster with ASD in the transition to higher education are confronted with the challenges of separation–individuation, finding a correct balance between connectedness and individuality (Grotevant and Cooper 1986). Moreover, these tensions seem more pronounced as parents reported that raising their child with ASD occurred quite differently and less strictly than how they coped with other siblings in the household.

Although dialectical tensions are inherent in parent–child relationships, an important point is what agents *do* with dialectical tensions (Kuczynski and De Mol 2015). When people experience opposing needs of meanings that contravene their self-constructed understanding and autonomy, they attempt to restore their autonomy through overt and covert resistance. Parkin and Kuczynski (2012), for example, found that adolescents expressed overt resistance assertively and engage in an array of covert forms of resistance when they wish to avoid confrontation. In our study, however, out of an enormous respect for the past support efforts of their parents and the fact that parents are concerned about their child's psychological capacity, both students and parents do not dare to react with resistance. In fact, they weaken their resistance significantly by holding their comments and frustrations rather for themselves to reassure they not will damage their relationship. These findings indicate that both students and parents value their parent–child relationship highly (Kuczynski and De Mol 2015).

In conversations on this issue both parents and students took care of each other and of their family relationships and avoided to talk about their frustrations. This can also be allied to the issue of 'systemic emotion management' (Rober and Rosenblatt 2013). Especially in case of sensitive issues in family conversations, family members typically try to monitor the emotional state of all family members, including their own emotional state. More specifically, they regulate the emotionality within the family to a certain degree by deciding what to disclose in a given context (Van Parys et al. 2016). In our study, not only parents decided not to communicate openly about the tensions, children also seemed to sense this uncertainty and tried to act responsively. These dialectical tensions between openness and closedness in communication and relationships can be related to broader communication and relational theories (e.g., Baxter and Montgomery 1996; Parkin and Kuczynski 2012; Petronio 2002). Caughlin and Afifi (2004), also situated the reluctance to talk about certain issues in people's 'risk assessment'. Discussing the topic can hold risks for themselves (while they aim for self-protection) as well as for their relationships (while they aim for relationship protection) (Van Parys et al. 2016, p. 2005). Maintaining stability

and positive emotional feelings within the relationship, seemed to be motives why both parents and students in our study decided not to communicate openly about their frustrations. They clearly preferred to maintain the strength of the current parent–child relationship. As such, the oppressed openness contributes to the maintenance of an underlying tension in families with a youngster with ASD that complicates efforts to change the relationship from a hierarchical one to a mutual adult one.

The privileging of efforts to maintain stability and positive emotional feelings within the relationship, seem also to have a flipside as both parents and students reported on strong feelings of stress, anxiety and ambivalence, confirming previous research that the transition period is a vulnerable period for both students and parents and that guidance may be needed (Friedman et al. 2013; Pinder-Amaker 2014). In that sense, the lack of openness seems actually detrimental to the interests of both the student and the parent. Because the relationship is involuntary and individuals are investing in the relationship, the tensions must be managed in some way (Kuczynski and De Mol 2015). As in a context of ASD clear roles and rules are designated, it is important that families with a youngster with ASD who feel the need, are assisted in redefining the parent–child relationship.

Clinical Implications

Therefore, several recommendations can be formulated for clinicians and postsecondary educational setting. Firstly, in line with current approaches in family therapy, families with ASD should not be seen as a 'problem' but as a system that is 'attacked' by transition challenges out of family context. After all, contradictions in relationships are always contextually dependent (Kuczynski and De Mol 2015). Clinicians could help students with ASD and their parents to communicate about the different perspectives and to find more adaptive ways to relate to one another by teaching them how to be there for each other while at the same time allowing the other the independence they want and need. For instance, students with ASD could be stimulated to inform their parents about support agreements and progress in their programs. This information could substantially reassure parents and might in this regard stimulate positive changes in the redefinition and quality of the parent–child relationship. Secondly, it is designated that parents, but also clinicians and colleges, encourage the students' urge for independence and agency. The acknowledgment and acceptance of the emerging adult status surely forms a critical step in the maturation process of young adults (Aquilino 2006). Granting this recognition to students with ASD assists them in forming a stronger sense of identity and identity exploration at a time when it is most crucial. Thirdly, it is beneficial

that clinicians and postsecondary settings acknowledge that parental involvement is an ongoing and critical component of growth and development for students with ASD, even after leaving secondary school. Given that students with ASD actively ask their parents to assist them in the transition process in a multitude of ways, and given that parents frequently feel unacknowledged by colleges and universities, it is beneficial that institutions nurture an atmosphere where the parents of students with ASD are welcomed, informed and acknowledged in their expertise, without delaying the shift in responsibility from family to the student.

Limitations and Future Research

Some limitations should be acknowledged when interpreting the results of this study. Firstly, a participation bias may have affected the results of our study. The fact that roughly all families in this study described their family relationships as mostly warm and reciprocal, and the fact that all students applied for academic accommodations, might have been a consequence of the participant recruitment process. Indeed, one may argue that families with positive experiences and families who were more actively participating in transition planning may be more willing to share their experiences in a scheduled meeting. Although students with ASD had a good understanding of ASD and no obvious problems occurred in the interviews, difficulties with perspective-taking, may have affected their answers on certain questions. Secondly, the lack of a comparison sample must be noted as a limitation, as only families with youngsters with ASD participated in the study. Future research should clarify to what extent these perceptions are unique to the disorder or are more representative of general transition-aged dynamics. Thirdly, the use of a qualitative analysis only allows an examination of the perceptions of participants. It does not allow for more direct measures of parent–child relationships and interpersonal influences. Future studies with a comparison group could also include standardized measures (e.g., interpersonal influences and partner responsiveness, anxiety, and stress) to get a wider view on the impact of ASD on family life during this transition stage. Thereby, it is also important to examine the effect of demographics variables like being a first-generation student, the birth order in the family or the severity of ASD. Future quantitative research should clear out the impact of such variables. Finally, we limited our study to interviewing students and their parents. Apart from parents, siblings are part of the family system. In fact, students and their siblings might share similar developmental tasks, which allows them to share information and emotions, and by doing so providing each other with specific support and aid. Therefore, it is important to further study the role and quality of relationships with siblings in this stage of life.

Conclusion

In spite of these limitations, this study was the first to examine the first-person accounts of students with ASD, their fathers and their mothers on a systemic within-family level. The dyadic interview analysis made it possible to carefully compare, reflect on and integrate the perspectives of the participating family members and in this way lifted our systemic understanding of the complexity of the transition process for families with a youngster with ASD. Differences in perspectives occurred regarding the construction of adulthood, the acquisition of autonomy, disclosure and subscribing to support services. These opposing needs and thoughts caused complex dialectic tensions in the parent–child relationship, hindering the transformation of the parent–child relationship into a more adult-like mutual relationship. If the school setting, clinicians, and the wider network around the family, approach this complexity with mutual respect and understanding to both parents and the students with ASD, a strong partnership can be created which contributes to a more successful transition experience for these families. We emphasize the need for further clinical and educational reflection and research to forward our understanding on family functioning in families with a youngster with ASD.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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