Exploring the role of family in enhancing the well-being of patients with developmental disorders

Paula Lam, Constanza Bianchi
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Abstract

Purpose – The purpose of this paper is to investigate how family members co-create value and improve the well-being of patients with chronic developmental disorders, such as Asperger Syndrome (AS), that undertake permanent therapy services.

Design/methodology/approach – Qualitative methodology is used to identify family value co-creation activities and well-being outcomes. Extensive interviews with family members and professional therapists of AS patients were conducted as the main data collection method.

Findings – Drawing on previous conceptualizations of value co-creation activities in health contexts, the findings of this study identify specific value co-creation activities performed by family members that influence the different dimensions of well-being for AS patients and their families: co-learning, combining therapies, changing ways of doing things, connecting, co-operation and co-production, managing daily life, motivating, protecting, regulating and establishing roles. The findings also reveal improvements in the following dimensions of patient well-being: autonomy, self-acceptance, purpose in life, positive relationships with others, control of the environment and personal growth. In addition, value co-creation activities also improve family relationships at home and the well-being of patient family members.

Research limitations/implications – This research is among the few studies in the academic literature that considers value co-creation activities from other actors of a health service ecosystem, such as family members. Limitations derive from the qualitative nature of this study.

Practical implications – The findings of this study contribute to the existing literature on transforming services and aim to provide useful information for providers of therapy services in order to maximize the value of this service.

Originality/value - This study contributes to the services literature and addresses a gap in transformative service research by exploring the value co-creation activities of family members for improving well-being outcomes of patients with chronic developmental disorders. People with chronic developmental disorders engage in permanent therapy services and tend to have below average well-being scores, which also extends to their family members.

Keywords: value co-creation, patient well-being, Asperger Syndrome, developmental disorder, therapy services.
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1. INTRODUCTION

Increasing research on transformational services suggests that the result of health services on people’s well-being and quality of life not only depends on the service provider, but also on the positive involvement of patients in the service (Zainuddin et al., 2013). Previous studies have found that value co-creation activities complement main treatment regimens and improve the well-being of patients with illnesses such as cancer or diabetes (e.g., McColl-Kennedy et al., 2012, Sweeney et al., 2015, Engström and Elg, 2015). However, it is not clear if these findings can be extended to patients of therapy services that suffer from chronic developmental disorders, such as Asperger Syndrome (AS), due to the enduring nature of this disorder and the significant family support required for successful patient therapies.

AS is an autism spectrum disorder and a chronic developmental condition that people must endure for life and which has no cure. People with AS are usually characterized as lacking empathy, fearful of changes, having difficulty expressing themselves, clumsy, and they tend to communicate with obsessive traits and systematization (Baron-Cohen et al., 2001, Wing, 1981, Stoddart, 1999). They also tend to be depressive (Stewart et al., 2006), have lower levels of well-being compared to other people (Jennes-Coussens et al., 2006, Heiman and Berger, 2008), and this extends to their family members (Baron-Cohen et al., 2001, Cappe et al., 2011). Thus, family members need to develop coping strategies in order to deal with the various aspects of AS (Heiman and Berger, 2008).
The fact that AS is an “invisible disorder” at plain sight makes it difficult to understand the problems it generates for people and their families (Portway and Johnson, 2005). Individuals with this disorder are required to live their lives as any other person does, but are trapped within their social limitations, which lead them to attend permanent therapy services such as psychological, psychiatric and occupational therapy (Case-Smith and Arbesman, 2008). Therefore, support comes predominantly from professional therapy service providers and family members to improve the patient’s well-being (Khouzam et al., 2004, Stoddart, 1999). In addition to therapy services, the family is an important actor in the service ecosystem that helps improve patient well-being, due to the cognitive limitations of AS (Stoddart, 1999).

Although there has been an increase in research related to the impact of psychological or occupational therapies to treat developmental disorders (Anderson and Morris, 2006, Case-Smith and Arbesman, 2008, Woods et al., 2013, Cardaciotto and Herbert, 2004, Mishna and Muskat, 1998), these studies have been conducted mostly in the psychology, nursing sciences or medical disciplines and focus mostly on AS traits and therapy treatments. Less is known, from a services marketing perspective, about value co-creation and the well-being of patients with chronic disorders such as AS. In particular, the role of family, in relation to value co-creation in health services for chronic disorders, is still an understudied research area in the services marketing literature (Leino, 2017, Holman and Lorig, 2000).

Drawing on a Service-Dominant (S-D) Logic (Vargo and Lusch, 2004, 2008), this paper investigates value co-creation in a health service ecosystem. According to S-D Logic, value co-creation results from the integration of resources between consumers, service providers, and also between different actors of the service ecosystem to improve well-being outcomes (Edvardsson et al., 2011). A service ecosystem is a self-contained and self-adjusting system
of actors, connected by shared institutions and by the joint creation of value (Vargo and Lusch, 2016). Moreover, transformational service research has shown that value co-creation activities can have a positive effect on the quality of life of patients with severe illnesses, such as cancer (McColl-Kennedy et al., 2012, Sweeney et al., 2015).

Many diseases are transient and affect patients at a certain time in their lives. However, other health conditions are chronic in nature, such as AS, which require permanent and lifelong therapies and family support to help improve patient quality of life and well-being (Woods et al., 2013, Cardaciotto and Herbert, 2004). For patients with developmental disorders it may be difficult to participate in the co-creation of value since they have less initiative, proactivity and ability to regulate emotions (Jennes-Coussens et al., 2006, Khouzam et al., 2004), which are some of the value co-creation activities identified in previous health research (Sweeney et al., 2015). Thus, the family is a relevant actor in the ecosystem which can assist in value co-creation and contribute to the well-being of AS patients that undertake therapy (Pinho et al., 2014).

This topic is important in transformative services marketing because positive value co-creation outcomes are dependent on the capacity of customers to participate in the service through exerting effort, sharing information and providing suggestions (Black and Gallan, 2015). It is essential that patients are cognitively enabled to contribute to therapy services as value co-creation occurs through resource integration across entities in a network (McColl-Kennedy et al., 2017). However, healthcare customers cannot always engage optimally in value co-creation, as in the case of AS patients due to their cognitive limitations, and therefore, other actors of the ecosystem, such as family members, can become important and even essential actors for value co-creation to occur.
In summary, this study aims to address three existing gaps in the literature. First, it extends a dyadic perspective to an ecosystem view of value co-creation in health services by introducing family members as a third relevant actor, and it identifies specific value co-creation activities performed by family members which lead to patient well-being. Second, it analyzes value co-creation in health services for people with chronic developmental disorders, which they permanently endure. Third, this study identifies unexplored value co-creation outcomes in health services since their impact goes beyond patient well-being, and also benefits family members and their relationships at home. The general research question of this study is: How do value co-creation activities performed by family members of patients that engage in AS therapy contribute to the well-being of these patients and their families? The remainder of this study is organized as follows. First, the literature review is presented in order to conceptualize and define the theoretical framework. Then, the research methodology and data analysis process are explained and the results are described. Finally, the contributions, limitations and conclusions of this study are presented in the discussion.

2. LITERATURE REVIEW

2.1 Value Co-creation in Health Service Ecosystems

Health services are complex systems that need to be analyzed considering the interactions among various actors of the ecosystem (Gummesson, 2008). McColl-Kennedy et al. (2017) argue that it is necessary to attain a better understating of value co-creation roles in health ecosystems, since all of the actors of an ecosystem may co-create value and affect
consumer well-being (Anderson et al., 2013). However, most value co-creation studies focus on the relationship between patients and health service providers (Arnould et al., 2006, McColl-Kennedy et al., 2012, Osei-Frimpong et al., 2015, Pera and Viglia, 2015, Plaud and Guillemot, 2015, Sharma et al., 2017, Sweeney et al., 2015, Thuy, 2016), and only a few consider the role of ecosystem actors on patient value co-creation outcomes (Pinho et al., 2014, Rosenbaum and Smallwood, 2013). In addition, chronic disorders affect every aspect of a patient’s life and places a burden on the entire family (Wodskou et al., 2014). For example, caring for a person with AS can substantially influence the functional ability and well-being of the family member who is often designated as the main caretaker.

Most transformational service studies consider health treatments for physical illnesses (e.g., McColl Kennedy et al., 2012), and very few examine chronic developmental conditions such as AS, where achieving the best possible patient well-being outcome is the main objective of therapy services (Holman and Lorig, 2000, Michie et al., 2003). In the context of chronic developmental disorders, the patient (customer of therapy) is likely to require support from family members which is beyond the support service providers can offer, and hence, value co-creation will take place within the customer’s service ecosystem and move beyond firm/customer service interactions (Sweeney et al., 2015).

Positive therapy outcomes depend largely on the active involvement of patients (Michie et al., 2003, Thorne, 1999). However, it is difficult for people with developmental disorders to get involved in value co-creation activities because it is a complex process that requires a high level of cognitive effort (Etgar, 2008, Sweeney et al., 2015). People with AS usually lack initiative, autonomy and the ability to regulate emotions (Stoddart, 1999), which are characteristics required for value co-creation activities (Sweeney et al., 2015). Similarly, communication is essential for value co-creation (Pinho et al., 2014), yet people with AS
also present difficulties in expressing themselves and communicating with others (Stoddart, 1999).

People with health problems usually integrate resources through actions and interactions with different sources in the ecosystem which may include people, technology, organizations and information (Pinho et al., 2014). Beirao et al. (2017) identify three levels of value co-creation in service ecosystems. The micro level includes dyadic interactions between individual actors such as medical personnel, patients and family. In health services, networks at the micro level emerge to achieve improvements in patient well-being (Black and Gallan, 2015). For example, Pinho et al. (2014) describe value co-creation among four relevant actors of the ecosystem (doctors, nurses, pharmacists and social workers), highlighting positive results for the patient, the organization and the ecosystem. The authors suggest that it’s important to examine the value co-creation of other members of the ecosystem, especially patient family members. Particular activities and interactions with people that are closer to the patient, such as family members, are more likely to have a greater impact on their well-being (McColl-Kennedy et al., 2017).

Family members are defined as two or more individuals related by blood, marriage or adoption that reside in the same household (Cherlin, 1981). People identify with their families, which play a fundamental role in consumer decision-making (Childers and Rao, 1992). Decision-making and joint problem solving with family members can help improve patient health outcomes (Heaney and Israel, 2008). For this reason, health organizations are increasingly involving family members in patient therapies and treatments (Black and Gallan, 2015).

In health contexts, doctors try to improve the well-being of patients as a main outcome of the care provided (Cohen et al., 1996). Despite these efforts, people with chronic
disorders and their families have lower levels of well-being (Cappe et al., 2011, Jennes-Coussens et al., 2006). Families that have a member with a chronic disorder condition experience enormous changes in their daily lives (Rowat and Knafl, 1985), and suffer emotionally and physically as they adapt to the disorder (Danielson et al., 1993). Families should use different resources when facing problems related to a chronic disorder, so they can function in an optimal way (Sanders, 1999). For example, Repetti et al. (2002) found that the social environment of a family can have positive consequences on the health of its members. This was also captured by Elgar et al. (2013), who discovered that good communication between family members helps improve the emotional well-being and life satisfaction of families that have relatives with chronic developmental conditions. Thus, understanding the influence that family members can have on patient well-being through involvement in the value co-creation process is crucial (Childers and Rao, 1992, Sheth and Parvatiyar, 1995).

In summary, this study aims to identify how family members of people with developmental disorders, such as AS, can contribute to patient well-being outcomes through value co-creation activities. Since families are relevant actors in health service ecosystems (Pinho et al., 2014), this study examines how family members contribute to the process of co-creating value for patients with AS within their ecosystem. The general research question of this study is: How do actors within patient ecosystems co-create value and contribute to patient well-being? More specifically: How do value co-creation activities performed by family members of patients with chronic disorders contribute to the well-being of these patients and their families?

A few authors have identified value co-creation activities that are carried out by patients in health services: co-learning, combining therapies, changing ways of doing things,
connecting, co-operation and co-production (McColl-Kennedy et al., 2017, McColl-Kennedy et al., 2012, Sweeney et al., 2015). Furthermore, the concept of well-being has been studied from an eudaimonic perspective which identifies six dimensions of individual well-being: autonomy, self-acceptance, purpose in life, positive relationships with others, control of the environment and personal growth (Ryff, 1989, Ryff and Keyes, 1995). These proposed value co-creation activities and well-being dimensions serve as a conceptual framework to investigate family value co-creation activities and well-being outcomes for AS patients in therapy (see Tables 1 & 2).

Insert Tables 1 and 2 here

3. RESEARCH METHODOLOGY

3.1 Research design

Qualitative methodology was used to investigate the value co-creation activities performed by family members of patients that undertake AS therapy services, as well as the corresponding well-being outcomes for patients and their families. Qualitative methodology is appropriate for this study because it provides valuable descriptions of complex and less studied phenomena (Sofaer, 1999). Specifically, data was collected through in-depth semi-structured interviews with 12 family members of AS patients who undertake some type of therapy, and 4 therapy service providers. The sample size is consistent with previous studies in services marketing journals which consider vulnerable or disabled consumers that might be reluctant to participate (e.g., Abney et al., 2017, Engström and Elg, 2015). Detailed respondent characteristics are described in Tables 3 and 4.
Due to the nature of developmental disorders, most of the family member interviewed were mothers of AS patients because they usually have a closer relationship with the patient (Cappe et al., 2011). Additionally, mothers are the most affected person when there is a family member with a chronic condition in the household (Elgar et al., 2013). Although the interviews were conducted with one family member (mostly mothers), the questions asked in the interview were designed to understand the role of each family member in dealing with the various aspects related to the patient in AS therapy. Interviews with professional service providers of therapy for AS patients were also conducted.

The interviews were done to obtain different opinions about the phenomena under study, and provided detailed contextual information (Gwinner et al., 1998). The interviewees were chosen to represent family members of patients with different demographic characteristics. Furthermore, the interviews were conducted following Francis et al.’s (2010) data saturation principles for theory-based interview studies (Lincoln and Guba, 1985). According to Saunders et al. (2018), data saturation refers to the extent to which predetermined themes are adequately represented in the data. These authors argue that decisions regarding the necessity of collecting further data are commonly based on the researcher’s sense of what they are hearing in each interview, and the non-emergence of new themes from the data obtained. Due to the sensitive context of AS patients and their families, it is very challenging for researchers to recruit a larger sample of people willing to be interviewed (Wady, 1996). Thus, the data collection process continued through interview 16, which did not elicit any new information, and therefore, data saturation was reached and the data collection process was terminated at this point.
The main objective of the interviews was to understand the role of family members, mostly mothers, in the value co-creation process for patients in AS therapy, and to explore the outcomes of these value co-creation activities on patient well-being. In order to triangulate this information, four professionals were interviewed in addition to the family members. All of the professionals had experience working with AS patients. These interviews were useful in better understanding AS and in identifying how family members co-create value and contribute to patient well-being.

Interview protocols were developed and pre-tested to ensure accuracy. In addition, interviews were conducted in a place that was convenient for participants. Thus, family members were interviewed in their homes and professionals in their workplace. The interviews lasted approximately sixty minutes and were audio-recorded, and later transcribed by the main author of this study. Each interview began with an explanation of the study objective and demographic information was collected. First, a warm-up question was asked regarding the interviewees’ relationship with the family member diagnosed with AS. This was further developed to better understand the characteristics of AS and therapy. Subsequent questions were designed to identify value co-creation activities in AS therapy, and participants were asked to provide concrete examples. Final questions focused on identifying AS therapy outcomes.

3.2 Analysis and Interpretation

Once all of the interviews were completed and transcribed, the authors of this study analyzed each sentence of the transcriptions as suggested by Spiggle (1994). The data was analyzed and interpreted using the following validated steps: categorization, abstraction,
comparison and integration. At first, both authors carefully read each phrase and coded them according to content, searching for all of the phrases that included any activity carried out by family members or resulting outcomes. Then, similar codes identified in the process of abstraction and generalization were grouped together into categories. After the categories were clear and integrated, the data was interpreted. In the interpretation stage, the authors made sense of the data by drawing on the conceptual models of value co-creation activities and well-being, presented in Tables 1 and 2, and expanded these models using the data. This same process was carried out to identify dimensions of well-being outcomes.

4. RESULTS

4.1 Value co-creation activities

The data reveals that family members of people with AS perform different value co-creation activities that contribute to patient therapy. First, the data identifies value co-creation activities carried out by patients found in previous studies of value co-creation in health services, such as co-learning, combining therapies, changing ways of doing things, connecting, co-operation and co-production (McColl-Kennedy et al., 2012, Sweeney et al., 2015). Second, the data identifies value-co-creation activities performed by family members, which are specific to patients with developmental disorders: managing daily life, motivating, regulating, establishing roles and protecting (see Table 5).

Insert Table 5 here
4.1.1 Co-learning

Co-learning in health services means seeking and collating information related to illnesses, treatments and others, as well as collecting the information and sharing it with others (McColl-Kennedy et al., 2012, Sweeney et al., 2015). Multiple sources are used to obtain information, the Internet and testimonials from people with similar experiences are the most common. People know very little about AS, therefore, most parents don’t know how to deal with a person with this condition, or know about the appropriate therapies or possibilities for future development (Portway and Johnson, 2005). Consistent with previous studies (McColl-Kennedy et al., 2012, Sweeney et al., 2015), co-learning is a crucial activity for most families because it gives siblings and other members of the service ecosystem a better understanding of the disorder, as shown in the following quote:

*I went to different workshops and I downloaded information from the Internet. This helped me understand the condition.* - (R11, mother of an 8 y/o patient).

Also, co-learning considers activities performed by parents to educate other people about the disorder, such as the patient, other children, and other members in the ecosystem who have the same disorder. This is illustrated with the example below:

*Since he was little, he felt different from others. I used to tell him that we are all different. Then we watched "The Big Bang Theory", where every character has a personality disorder. I said, "who do you look like, Sheldon or Leonard?" Then I said, "you have Asperger Syndrome." He replied, "now I understand everything."* - (R12, mother of a 19 y/o patient).

4.1.2 Combining therapies

Previous studies in health services show that another value co-creation activity performed by patients is combining different types of therapies (McColl-Kennedy et al., 2012, Sweeney et al., 2015). Similarly, family members encourage their children with AS to try
and utilize different complementary therapies that involve themselves and other family members, such as pharmacological medication, exercise, alternative therapies, family therapies, school support and camouflage therapy to improve their quality of life, as shown below:

On Monday he visits the specialist teacher, on Wednesday, the speech therapist, on Thursday, the occupational therapist and psychologist. He has an entire multidisciplinary team. - (R6, mother of a 9 y/o patient).

The interviews also show that family members of people with AS carry a very high burden, usually accompanied by a certain level of guilt or negation. This leads many parents to attend family therapy sessions, as stated in the following quote:

This situation is hard for families. We are worried about our family matters. We are receiving family therapy with an expert. - (R7, mother of an 11 y/o patient).

4.1.3 Changing ways of doing things

This activity corresponds to activities targeted at managing long-term adaptive changes (McColl-Kennedy et al., 2012). People with AS are usually very inflexible and it is very hard for them to adjust to unknown contexts. They are frequently disturbed by noise, crowds and textures in food and clothes. They also have few social skills and interests, and tend to stay in a solitary comfort zone with no risks. Parents are constantly looking for ways to help their children face the contingencies of life. They believe that it is not beneficial to "hide" their children, so they choose to expose them to complex situations, motivating them to try new things. This is exemplified below:

We never locked him up at home. I used to see parents who did not take them out because it was noisy or there were a lot of people. I took him everywhere. We always faced what bothered him and now he can stand it. - (R1, mother of a 20 y/o patient).
Parents also look for activities that can distract their children, so they can stop thinking about their problems as illustrated below:

*We are trying to help him to loosen up. We have gone to concerts, to Kidzapalooza. We also invite over a friend and leave them alone.* - (R5, mother of a 14 y/o patient).

### 4.1.4 Connecting

Another value co-creation activity found in health studies is connecting, which includes building and maintaining relationships with others and participating in support groups (McColl-Kennedy et al., 2012, Sweeney et al., 2015). People with AS tend to have difficulty socializing, and therefore, parents decide to help them build and maintain positive relationships, as shown in the following example:

*At school, he has his little football group that I formed for him. Unbelievably, the four children in that group have AS.* - (R11, mother of an 8 y/o patient).

It is difficult for people with AS to understand other people's feelings, and thus, are labeled as having no empathy. However, data shows that people with AS connect well with animals; therefore, parents recognize that animal pets can help their children interpret emotions and develop empathy, as shown in the following quote:

*She has a dog and it has been really helpful for her. She realizes that the animal is happy, and she puts herself in the animal’s place and understands its emotion.* - (R2, mother of a 13 y/o patient).

### 4.1.5 Co-operation

Co-operation includes compliance with basics, responsible behavior, accepting information and following the advice or tips given by service providers. Families worry about patient behavior and ensure that they demonstrate responsible behavior regarding the requirements of therapy. Families usually accept the information and advice provided by therapists. The
following example shows how parents co-create by accepting information from the therapist:

*She was depressed; so, we had to be careful, control everything. The psychologist told me "any false step and she can do something we do not want."* (R2, mother of a 13 y/o patient).

4.1.6 Co-production

Consumers co-produce when they become involved in firm activities (Vargo and Lusch, 2004). Co-production in health includes redesigning therapy, assisting in the delivery of service, reconfiguring the composition of provider staff and assisting with the administration of therapy (McColl-Kennedy et al., 2012). Data shows that parents play an important role in the design of therapy treatments, and most of them attempt to replicate some elements of the therapy at home. Thus, parents can be identified as therapy co-producers, who are also a part of the therapy goals. In addition, given the difficulties experienced with AS patients, some parents propose modifications to the evaluation tools, as illustrated in the following quote:

*I told his teacher "if you want to measure his knowledge and comprehension, do not ask him to draw but ask him oral questions. He still does not write or read well. He will do better narrating." His first mark was a 4.8 and from then on, he has straight 7s. - (R11, mother of an 8 y/o patient).*

Parents recognize that work at home must complement any therapy treatment. They believe this is the only way to improve the behavior of their children. Parents fulfill multiple roles since there are different needs involved in managing their child’s condition, as explained in the following quote:

*When you have a child with Asperger’s you become a nurse, a teacher, a therapist, everything. With that, we have learned to do the therapies, because the therapist gives us tips and we have learned to do everything else. - (R3, mother of a 5 y/o patient).*
4.1.7 Managing daily life

This activity encompasses everything that family members do to facilitate the resolution of everyday life problems. People with AS are characterized by their naivety, innocence, and extreme literalness. This can be demonstrated with their use of inappropriate comments, the excessive importance they give to little things and in their propensity to aggravate minimal problems. Family members try to solve these problems by teaching them social codes, providing advice on making decisions and explaining the consequences of their actions. Interviewees agree that solving everyday issues is more difficult for people with AS. For this reason, parents try to help their children better manage their life by teaching them social codes, and by providing advice on appropriate decision making. This is exemplified by the following quote:

There are things that they do not understand that are socially incorrect. For example, if you feel itching somewhere in your body, you are not going to scratch an intimate part, but they do it. Then you have to explain to them literally "you do not have to do this because of this reason." If you just say, “do not do it”, it’s ambiguous for them. - (R4, mother of a 33 y/o patient).

4.1.8 Motivating

Motivating means helping a person find a sense of purpose in life. Most of the parents interviewed mention that their children have no sense of future goals in life. Also, people with AS usually have a very low tolerance for frustration. When faced with mistakes, failures or unexpected results, unexplained tantrums can be triggered. Learning to manage frustrations is one of the main objectives of therapists and parents. Therefore, family members focus on motivating them and constantly provide positive feedback. Parents encourage their children to engage in various activities and facilitate access to the resources necessary to successfully perform these activities, as in the following case:
He loves to swim, go to the pool, do water things. We focus on what is good for him, so we accompany him. - (R7, mother of an 11 y/o patient).

Experiences of other people with AS inspire parents to help their children look at the future in a more optimistic way. Therefore, based on testimonies or motivation, parents illustrate a more positive future to their children, as shown in the example below:

When he is disheartened, I usually tell him: "You are not the only one. I have suffered too. You have to think that you are an intelligent man; you are autistic, but you are not ignorant. And it's not an impediment, there are a lot of autistic married people." - (R4, mother of a 33 y/o patient).

4.1.9 Protecting

Protecting refers to all the activities that family members perform so that a patient feels supported by family and protected from potential negative circumstances. Most interviewees report that their children are highly sensitive and have very low self-esteem and self-confidence. Therefore, parent support is crucial in making their children feel that their family nucleus is warm, pleasant and protected. Parents look for different ways to provide support and protect their children in the context of their home and family by containing, protecting, maintaining positive relationships at home, being more patient, encouraging and accompanying them to therapies and helping, as represented in this quote:

Fighting or arguing stresses her out a lot. So, we have been trying to make home a place where she feels at peace and at ease. When we argue, we do it in a place she cannot listen, so we avoid conflicts in front of her. - (R2, mother of a 13 y/o patient).

4.1.10 Regulating

This activity refers to establishing rules for the behavior of therapy patients. While many parents help their children perform certain tasks, they believe that it is essential for them to take care of some things on their own, so they set limits. Data shows that parents assign
responsibilities to their children and also set limits. The following quote illustrates how parents assign responsibilities to their children:

He failed two years in his first experience at the university, but he never told us. He had always been an excellent student beforehand. After failing, he wanted to work, so I told him “no, you have to study and get your college degree.” So, we forced him to start again at another university. - (R9, mother of a 21 y/o patient).

Parents reveal that children do not usually comply with the rules, but they believe that there are certain characteristics of AS that can be used to make regulations more effective. By taking advantage of their literalness, parents establish rules through clear step-by-step sequences and use incentives to achieve commitments, as shown in the following example:

He could be on the computer all day long. We have a contract: if he does not study half an hour and starts using the computer early, the next day he cannot use it. He signed that agreement, because he wanted a prize, so he doesn’t resist waiting. - (R7, mother of an 11 y/o patient).

4.1.11 Establishing roles

All interviewees mention that family roles are established, either explicitly or tacitly. They explain that there is one family member in charge of setting the rules and calling attention to issues if necessary. Other roles observed among family members are containment, helping and accompaniment. Parents prefer to avoid any misunderstanding about the roles within a household; therefore, they clearly explain the roles to other family members. If these roles are not adequate, then family members change them to attain a better outcome. This activity is described below:

She fought a lot with her father; she did not let him reprimand her. Then we made an agreement, I am in charge of setting limits and rules, so my husband tells me when it is necessary to call her attention to something and I do it. She does not get angry with me, so that works. - (R2, mother of a 13 y/o patient).
4.2 Well-being Outcomes

Previous studies in health show that there is a positive relationship between value co-creation and patient well-being (McColl-Kennedy et al., 2017, McColl-Kennedy et al., 2012, Sharma et al., 2017, Sweeney et al., 2015). Consistent with previous studies, and in the context of this study, value co-creation activities are carried out by family members which leads to improvements in the different dimensions of eudaimonic well-being: autonomy, self-acceptance, purpose in life, positive relationships, environmental mastery and personal growth. Nevertheless, the data reveals two additional well-being outcomes from family value co-creation activities: improving relationships at home and the well-being of third parties (see Figure 1).

Insert Figure 1 here

4.2.1 Autonomy

This dimension describes a person’s capacity for self-determination and independence, and their ability to resist social pressure demands (Ryff and Keyes, 1995). People with AS are characterized as being highly dependent on others in their day-to-day activities. Family members are responsible for guiding and helping them with daily matters. Parents reveal that one of their main objectives is for their child to establish autonomy and develop an independent life. The results of this study show that various value co-creation activities result in improving the autonomy of people with AS, as shown in the following quote:

*He has achieved autonomy, goes out alone. Now he knows that it is his responsibility to regulate his frustration outside. It is still difficult for him, but today he can go out, take a bus, shop online and go downtown. Ten years ago, this was unthinkable for me. - (R4, mother of a 33 y/o patient).*
4.2.2 Self-acceptance

Self-acceptance refers to having a positive attitude about oneself and being satisfied with oneself. Moreover, people with self-acceptance are comfortable with their past (Ryff and Keyes, 1995). One of the characteristics of people with AS is that they are constantly questioning the reason they are different. Several parents note that society’s lack of empathy, bullying, or bad relationships at home have led their children to experience a significant decrease in self-esteem, and in many cases, depression. Most parents acknowledge that the process of accepting AS is very complex for patients and their families. Despite this, the data suggests that value co-creation helps in this dimension, as observed in the following quote:

*He has interacted with other children with the condition and they get along very well. They have met by chance and it’s as if they speak the same language, they all have a very similar history. That helps his self-acceptance.* - (R12, mother of a 19 y/o patient).

4.2.3 Purpose in life

Motivation or purpose in life is one of the dimensions of well-being. A person who has a purpose in life has a sense of direction and has principles that provide purpose in their life. On the other hand, if patients do not have a sense of meaning in life, it is probable that they also lack purpose in life (Ryff and Keyes, 1995). The data shows that value co-creation activities can result in motivating patients, which helps them create a purpose in life. For example, parents sense that their children are doing better when they comment on future expectations, intentions, goals or plans, as seen in the following quote:

*Maturing and thinking positively has helped her a lot. Now she thinks she can improve and be better. Last year she was very depressed. She constantly said: “why am I this way? It would be better to not have been born.” It was awful. But now she is motivated and wants to improve herself.* - (R2, mother of a 13 y/o patient).
4.2.4 Positive relationships with others

Lower levels of well-being are related to difficulties in being warm and open, worrying about others, isolation and frustration in personal relationships and avoidance in making commitments to others (Ryff and Keyes, 1995). Having warm, satisfying and rewarding relationships in which both parties give and receive affection and intimacy, and also caring about the welfare of others, positively influences well-being. The greatest problem faced by people with AS is their difficulty in relating to others. Also, it is hard for them to understand the emotions of other people, which is frequently perceived as a lack of empathy. Due to the attitudes of people with AS, many parents believe that their children are selfish, unconcerned with the interests of others and have a lack of empathy. However, some value co-creation activities carried out by family members help them improve in this dimension, as shown below:

When his younger brother was born, my son was still not diagnosed, and he used to hurt his brother. He threw him out of bed, bit him, and hit him. As he has gotten better, he has also improved the relationship with his brother. Now they love each other, take care of each other; and, he is his little bother’s protector (R3, mother of a 5 y/o patient).

4.2.5 Environmental mastery

This dimension reflects the sense of mastery and competence people have in managing their environment, controlling complex external situations, effectively using opportunities and finding appropriate contexts for their personal needs and values (Ryff and Keyes, 1995). People with AS usually have difficulty solving everyday problems, and often feel overwhelmed or stressed by external stimuli such as noise, masses of people or lights, which can lead to a tantrum. This means that their environmental mastery is not optimal. Therefore, parents seek to help their children solve everyday scenarios through different
activities. This is reflected in their child’s ability to better handle different situations and achieve greater control of the environment. This is seen in the following quote:

*Going to the supermarket led to tantrums and crying. But we keep on taking him. I believe that I cannot lock him up in the house if the world is full of disturbances. This helped him get used to noise and tumults. There are now less tantrums.* - (R1, mother of a 20 y/o patient).

### 4.2.6 Personal Growth

The feeling of continuous development is one of the dimensions that denotes personal growth. This means that the person is growing and is open to new experiences, and shows greater self-awareness and effectiveness. When people lack personal growth, there is a sense of personal stagnation, there is no improvement over time and they are often bored or disinterested in life. In this case, well-being is highly affected (Ryff and Keyes, 1995). People with AS are usually very pessimistic, have a low tolerance to frustration and take little initiative. Parents try to improve these aspects by engaging their children in various activities to help them develop a more positive view of their own performance. This is illustrated below:

*He is more tempted to try new things. For example, with us he does not want to eat anything, only certain things, and friends tell him to try something and then he tries it. He makes plans, being able to make plans is really good. He has changed a lot.* - (R5, mother of a 14 y/o patient).

### 4.2.7 Relationships at home

This dimension is defined by the dynamics of the relationships and interactions of the people in a household. Interviewees report that people with AS usually generate problems at home, either with their parents, siblings or others who live in the home. In addition, interviewees feel that they live in an uneasy environment with a high frequency of conflicts
and discussions. Data shows that value co-creation activities carried out by family members lead to feelings of serenity at home, greater empathy towards other family members, better relationships and more valuable interactions. This results in better relationships at home, as seen in the following example:

*We do many more things together. Before he did not want to go anywhere, so someone always had to stay home. Also, there are fewer problems. Before, I fought every day with him and it was exasperating, because I did not have patience. Now I understand the situation better and our home is much more peaceful.* - (R8, sister of a 17 y/o patient).

4.2.8 Family member well-being

Family members recognize that value co-creation activities also lead to improvements in the family’s well-being. They recognize that not understanding certain reactions or unexpected behaviors causes them guilt, pain and even, in some cases, depression. Family members of people with AS, mainly mothers, have below-average well-being rates (Cappe et al., 2011). Parents believe that value co-creation activities are valuable for the entire family since these activities allow them to improve their own well-being, as described below:

*I had to do therapy too. It has helped us a lot, for me more than anyone. They suggested a therapist for the parents to help us handle it better. It is hard for parents because you do not understand where you are going or what you are going to face.* - (R6, mother of a 9 y/o patient).

5. DISCUSSION

Previous research studies in transformational health services have considered value co-creation between patients and service providers (Alves et al., 2016); however, these studies mostly examined transient diseases and suggest that value co-creation activities
complement main treatment regimens and improve the well-being of patients with illnesses such as cancer (e.g., McColl-Kennedy et al., 2012, Sweeney et al., 2015, Engström and Elg, 2015). Little is known about patients with chronic developmental disorders, such as AS, which require significant family support for successful patient therapy outcomes. Most research has focused on the impact of therapy treatments in psychology and medical disciplines (e.g., Anderson and Morris, 2006, Case-Smith and Arbesman, 2008, Woods et al., 2013); and less is known, from a services marketing perspective, about the role of family in relation to value co-creation in health services (Leino, 2017, Holman and Lorig, 2000).

This study expands previous research by providing a better understanding of how family members co-create value and impact well-being outcomes for patients with chronic developmental disorders. In particular, AS patients require permanent therapy services and their support comes mainly from professional service providers and family members to improve well-being (Khouzam et al., 2004, Stoddart, 1999).

Consistent with previous research regarding health patients (McColl-Kennedy et al., 2012, Sweeney et al., 2015), the results of this study show that family members perform various value co-creation activities, such as co-learning, combining therapies, changing ways of doing things, connecting, co-operation and co-production, that contribute to patient well-being and therapy services. Nonetheless, additional value co-creation activities, such as managing daily life, motivating, protecting, regulating and establishing roles, emerged from this study which are specific to family members of patients with chronic developmental disorders. Value co-creation activities carried out by other actors of the ecosystem can also complement these additional value co-creation activities.
The results of this study present both similarities and differences in respect to previous studies. First, six of the existing value co-creation activities identified in the previous literature emerge from the data (co-learning, combining therapies, changing ways of doing things, connecting, co-operation and co-production). Second, there are five new value co-creation activities performed by family members (managing daily life, motivating, protecting, regulating and establishing roles), which are specific to the context of this study. This supports the contention that unlike other health conditions, chronic disorders require constant and permanent work over time by family members, which probably makes them perform different co-creating value activities in order to live their lives in the best way possible and learn how to cope with the difficulties of the disorder.

Due to the scant amount of mainstream information available for some disorders, parents integrate their resources to increase the visibility of the condition within the family nucleus, as well as in the ecosystem and in the world, so that people know more about the disorder and develop a more empathetic attitude towards people with such disorders. Parents integrate resources to help manage the daily activities of patients with AS and establish norms for their behavior in order to help them manage a normal and independent life. This way, people with AS can better understand social codes and perform better in everyday life. In order to provide a more optimistic future outlook, parents integrate resources to motivate patients to do things in their lives, enhancing their virtues and ability to manage frustrations. In order to avoid unexpected reactions or tantrums, parents also integrate resources to contain, protect patients and establish roles for different family actors. In this way, the parents are responsible for maintaining the relationships at home, giving affection and avoiding non-beneficial exposures in order to help their child with AS feel welcomed and remain calm within the family ecosystem. These co-creation of value activities
generate greater value for the services delivered to patients, which is complemented by the co-creation of value other actors of the ecosystem perform.

In line with previous research (McColl-Kennedy et al., 2012, Sharma et al., 2017, Sweeney et al., 2015), the data of this study reveals that value co-creation in the ecosystem leads to improvements in patient well-being through its different dimensions (autonomy, self-acceptance, purpose in life, positive relationships with others, control of the environment, personal growth). In addition, value co-creation also improves relationships at home and the well-being of patient family members. This result is relevant because people with chronic disorders have lower well-being indexes than the average person (Jennes-Coussens et al., 2006), and the well-being of their family members is also affected (Cappe et al., 2011).

5.1 Theoretical contribution

Some studies have considered the role of ecosystem actors in the value co-creation of health services (McColl-Kennedy et al., 2012); however, there is scant research analyzing the role of the family as an actor of the ecosystem (Pinho et al., 2014). Therefore, the first theoretical contribution of this study is examining the role of family as a relevant ecosystem actor, which has been less studied in transformational service research. The role of family is fundamental in value co-creation for therapy patients with chronic developmental disorders since they have less autonomy and initiative, which hinders their ability to co-create value. The data reveals that family members are key co-creators of value for therapy, and that they are very influential in improving patient well-being dimensions. This finding contributes to the existing value co-creation literature by highlighting the importance of considering value
co-creation beyond a dyadic relationship between providers and customers, as most studies do.

The second contribution of this study is that it extends the research on value co-creation of health services to consider chronic disorders with psychosocial and cognitive aspects. Although several studies on value co-creation in the health context have been conducted (e.g., McColl-Kennedy et al., 2012, Sweeney et al., 2015), these studies only considered transient diseases. However, there has been no research on chronic disorders without a cure, especially on those disorders without physical ailments but involving psychosocial and cognitive components and patients with low levels of autonomy and independence. This is a contribution to the area of transformative services marketing because it acknowledges that healthcare customers cannot always engage optimally in value co-creation activities due to cognitive or physical limitations, and therefore, require the participation of other ecosystem actors, such as family members, for positive outcomes such as well-being.

The third contribution of this study is that it expands the research on value co-creation activities by proposing seven new activities that are carried out by the various actors within the ecosystem. Until now, research on value co-creation has been broadly related to patient well-being (e.g., McColl-Kennedy et al., 2017). This study identifies specific value co-creation activities for family members of AS patients, including new activities that could also exist in other contexts. This study also reveals that value co-creation activities performed by family members can improve patient well-being, as previously demonstrated in other studies. Furthermore, this study contributes to the literature by identifying well-being outcomes for the entire family, such as improving relationships at home and the overall well-being of family members. This finding shows that value co-creation is not only
beneficial for the main customer of a health service, but also for other actors in the service ecosystem that have a tangential relationship with the service.

The final contribution of this study is the extension of the existing literature on AS, and its examination of therapy services from a services marketing perspective. Several specialists have demonstrated that AS is an underdiagnosed condition that requires considerable support from society (Begeer et al., 2009; Nylander et al., 2013). People with AS disorder are often trapped within their social limitations and require permanent psychological, psychiatric and occupational therapy services to live their lives as anybody else does (Case-Smith and Arbesman, 2008). Therefore, professional therapy service providers and family members are key actors in helping AS patients improve their lives, as well as the lives of their families (Khouzam et al., 2004, Stoddart, 1999).

5.2 Managerial Contribution

The results of this study identify eleven specific value co-creation activities through which family members of AS patients co-create value and contribute to improvements in patient and family well-being. In practice, this study aims to provide useful information for service providers of therapy and family members of people with developmental disorders such as AS. This study also aims to reach government entities in order to broaden their knowledge about developmental disorders with the purpose of designing public policies that allow for greater access to therapy and create complementary activities.

Service providers can use these value co-creation activities to better advise family members on how to deal with a patient with a chronic developmental disorder. Furthermore, family members can adopt the value co-creation activities identified and
anticipate positive outcomes for both patients and themselves. The following are several suggestions that AS therapy providers may utilize to optimize the quality and efficiency of the service provided: 1) associate with other AS specialists in order to create a multidisciplinary team that offers the different therapies an AS patient may need, 2) offer family members relevant literature and equipment related to AS. This may be useful for families to better understand the challenges they will encounter in caring for a relative with AS, 3) provide suggestions of the adaptive changes family members may implement, with clear examples that have had positive results in other patients, 4) generate opportunities for patients and families to get to know other people and parents that share a similar diagnosis through organized support groups, 5) maintain a diary with each family so they can stay up to date on the evolution and results of therapy, 6) remain open to suggestions made by family members regarding therapy, and adapt to specific conditions when necessary, 7) help parents learn how to set limits with their children by providing advice and tips that have been useful with other patients, and 8) create a list of the different role profiles needed to effectively support a relative with AS, and suggest which family members should take on each one of those roles.

The findings of this study support previous research that finds that family members of AS patients should be seen as “secondary customers” supporting “primary customers” (Leino, 2017, Pavia and Mason, 2014), and therefore, cannot be viewed as being outside the service ecosystem. Thus, family members should also receive support from health professionals and support groups to help them cope with feelings of distress and loneliness (Wodskou et al., 2014). In addition, therapy providers should involve the family in order to facilitate better communication and continuity of care (Bekelman et al., 2011).
Finally, this study aims to acknowledge and highlight chronic developmental disorders that are less known and understood in mainstream society. Ambitiously, government agencies may be able to better recognize the invisibility of these disorders in society and respond to the urgent need for appropriate therapies in the public sector.

5.3 Limitations and Future Research

Despite its theoretical contributions, this study has several limitations. First, the co-creation of value from a specific actor of the ecosystem, the family, was studied; therefore, the value obtained from other actors is not observed. Second, the data was collected by interviewing family members of people with AS, and therefore some of the results may be related to the specific characteristics of this disorder which limits generalizing the results. Third, the co-creation of value activities and well-being dimensions were observed independently, so there is no clarity as to which specific activities are related to each dimension of well-being, which makes this an interesting topic for future research. In conclusion, this study provides an opportunity for conducting future research related to the co-creation of value in the ecosystem considering other actors of the ecosystem and other contexts.
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**Figure 1: Family Value Co-Creation Activities and Well-being Outcomes for Patients with Developmental Disorders**

| Family Value Co-Creation Activities | Well-being Outcomes |
|-------------------------------------|---------------------|
| Previous studies in health services | Patient well-being  |
| 1. Co-learning                       | • Autonomy          |
| 2. Combining therapies               | • Self-acceptance   |
| 3. Changing ways of doing things    | • Purpose in life   |
| 4. Connecting                       | • Positive relationships with others |
| 5. Co-operation                     | • Environmental mastery |
| 6. Co-production                    | • Personal growth   |
|                                    |                     |
| Value co-creation activities specific to AS | Family well-being  |
| 7. Managing daily life              | • Relationships at home |
| 8. Motivating                       | • Family well-being |
| 9. Regulating                       |                     |
| 10. Protecting                      |                     |
| 11. Establishing roles              |                     |
**Table 1: Customer value co-creation activities** *(McColl-Kennedy et al., 2012; Sweeney et al., 2015)*

| Value Co-Creation Activities | Description |
|------------------------------|-------------|
| Co-operation                 | Customers accept information delivered by the service provider and comply with basic requirements. |
| Information seeking          | Customers seek and sort information from their environment and also share it with others. |
| Combining therapies          | Customers combine complementary therapies such as supplementary medicine, exercise, diet, yoga and meditation. |
| Co-learning                  | Customers actively seek and share information from other sources, such as the Internet and from other professionals. |
| Changing ways of doing things| Customers manage long-term adaptive changes and get involved in activities deliberately designed to take their mind off the situation. |
| Connecting                   | Customers build and maintain relationships, engage in support groups and connect with others with similar experiences. |
| Co-production                | Customers assist with redesigning treatment programs and reconfiguring the composition of medical staff. |
| Cerebral activities          | Customers have a positive attitude, engage in emotional labor, talk to themselves and accept their situation |
**Table 2: Eudaimonic well-being dimensions** (Ryff, 1989, Ryff and Keyes, 1995).

| Dimensions                  | Characteristics                                                                 |
|-----------------------------|---------------------------------------------------------------------------------|
| Autonomy                    | People with autonomy are self-determined and independent. They can resist social pressure and regulate their behavior. They follow personal standards and do not make decisions based on the judgments of others nor consider their evaluations and expectations. |
| Self-acceptance             | Self-acceptance refers to the capacity for people to appreciate and accept the multiple aspects of themselves, including strengths and weaknesses. They do not want to change who they are. |
| Purpose in life             | This dimension includes having goals in life and a sense of direction. People with purpose in life are able to distinguish between their past and present and have beliefs that give purpose to their life. |
| Positive relationships with others | Having positive relationships with others implies maintaining warm, satisfactory and rewarding relationships with others. It also means caring about the well-being of others, and feeling empathy, affection and intimacy, as well as being able to give and take in human relationships. |
| Environmental mastery       | People with environmental mastery have a sense of competence in managing their environments. They can control a complex number of external situations and effectively use opportunities. |
| Personal growth             | This dimension refers to having a feeling of continuous development, believing in one’s ability to grow and expand, being open to new experiences and observing one's own improvements. |
Table 3: Respondent Characteristics (family members of AS patients)

| Resp. | Relationship with patient | Patient Age | Patient Activity | Family Members                                      | Therapy Services                                                                 |
|-------|---------------------------|-------------|-----------------|-----------------------------------------------------|----------------------------------------------------------------------------------|
| R1    | Mother                    | 20          | School          | Mother, father, 2 younger brothers, grandfather     | Psychiatrist, psychologist, speech therapist, occupational therapy, family therapy |
| R2    | Mother                    | 13          | School          | Mother, father, older sister                        | Psychiatrist, psychologist, speech therapist                                     |
| R3    | Mother                    | 5           | School          | Mother, father, older brother                       | Occupational therapy, Break Dance                                                |
| R4    | Mother                    | 33          | Community groups| Mother, uncle, grandmother                         | Psychiatrist, psychologist, speech therapist, occupational therapy, art therapy, aqua therapy |
| R5    | Mother                    | 14          | School          | Mother, stepfather, stepbrothers                    | Psychologist, school support                                                     |
| R6    | Mother                    | 9           | School          | Mother, father, younger brother                     | Workshop on social abilities, multidisciplinary school                           |
| R7    | Mother                    | 11          | School          | Mother, father, 3 younger brothers                  | Psychiatrist, psychologist, speech therapist, occupational therapy              |
| R8    | Sister                     | 17          | School          | Mother, father, older sister                        | Psychiatrist, psychologist, speech therapist, occupational therapy and workshop on social abilities |
| R9    | Mother                    | 21          | University      | Mother, father, 2 younger brothers                  | Psychologist                                                                      |
| R10   | Mother                    | 18          | Community groups| Mother, stepfather, 1 brother, 1 step brother       | Psychiatrist, psychologist, occupational therapy                                |
| R11   | Mother                    | 8           | School          | Mother, father, younger sister                      | Workshop on social abilities, speech therapist, occupational therapy             |
| R12   | Mother                    | 19          | University      | Mother, younger brother                             | Psychiatrist, occupational therapy, alternative therapies                        |
Table 4: Respondent Characteristics (service providers)

| Resp. | City      | Occupation           | Therapy Service                                                                 |
|-------|-----------|----------------------|---------------------------------------------------------------------------------|
| R13   | Santiago  | Actress              | Theater workshop for children and teenagers with disabilities                   |
| R14   | Santiago  | Psychologist         | Neuropsychology therapy for children and teenagers                               |
| R15   | Santiago  | Physical Education Teacher | Head teacher in a private school that allows integration                          |
| R16   | Viña el Mar | Psychologist    | Therapy for caretakers of children with AS, especially mothers                   |
Table 5: Family Value Co-Creation Activities for AS Therapy Services

| Family Value Co-creation Activities | Examples |
|-------------------------------------|----------|
| **1. Co-learning:**                 | - Gathering information  
| Family members look for information and different treatments for AS in multiples sources, such as the Internet and from the experience of others in similar situations. People do not know much about AS, so this activity is essential for most parents to help their children and identify proper therapy. | - Sharing information  
| - Teaching others  
| - Explaining the disorder to the patient, their other children and others in the ecosystem |
| **2. Combining therapies:**         | - Complementing different types of therapy  
| Family members encourage patients to combine different traditional and alternative therapies along with exercise. There is no unique treatment for AS that works for every patient. Thus, families choose to complement therapies and include therapeutic activities that are not directly related to the disorder. Because of the impact of AS on the family nucleus, some families also consider integral family therapies. | - Pharmacologic medication  
| - Exercise  
| - Alternative therapies  
| - Family therapies  
| - Seeking support at schools  
| - Camouflage therapy |
| **3. Changing ways of doing things:** | - Exposing them to complex situations  
| Patients are constantly facing adaptive changes, so family members choose to expose them to different situations and teach them how to deal with these changes. Family members of people with AS want patients to live their life as normal as possible, and follow recommended therapies. This is why they face adaptive changes, challenging their social and sensory weaknesses. | - Challenging them in social situations  
| - Motivating them to try new things or experiences  
| - Distraction activities |
| **4. Connecting:**                 | - Support groups  
| Family members of people with AS encourage patients to connect with others in order to improve their, generally deficient, social skills and help them relate to others and become more empathetic. With this clear objective, family encourages them to build and maintain relationships, participate in support groups and connect with other people in the same situation. | - Connecting with others in the same situation  
| - Help build and maintain positive relationships  
| - Pets |
| **5. Co-operation:**               | - Responsible behavior  
| Family members of people with AS co-operate according to the indications of therapy providers. In general, family members demonstrate responsible behavior, follow therapy advice and keep up with what happens in therapy in order to replicate it at home. | - Accepting the information delivered by the therapist  
| - Following tips given in therapy  
| - Being up to date with therapy |
| **6. Co-production:**              | - Proposing changes to evaluation tools  
| Family members of people with AS co-produce by being involved in the design of therapy treatments. They propose changes to different aspects of therapy or in the patient’s environment and perform work at home that forces them to fulfill multiple roles. | - Fulfilling multiple roles |
| **7. Managing daily life:**        | - Teaching daily things and social codes  
| Family members of people with AS help solve everyday issues so the patient better evolves on a day-to-day basis. Due to a lack of common sense and social norms on the part of patients, as well as difficulty in solving everyday problems, family members provide patients with advice, examples and explain things related to everyday issues. | - Explaining that there are differences between people  
| - Advising  
| - Explaining the consequences of certain acts |
**8. Motivating:** Family members of people with AS motivate patients to have goals in life. They are responsible for helping patients create a vision for the future and help manage their tolerance to frustrations, so that they can motivate themselves and persevere. In this way, family members provide patients with the necessary tools to boost their positive abilities and provide feedback on their performance.

- Motivating to keep on trying
- Enhancing virtues
- Promoting positive interests
- Giving feedback
- Incite goal setting
- Illustrate the future

**9. Protecting:** Family members of people with AS provide containment and affection to patients so that they perceive their support and feel contained in the family nucleus. They provide affection to patients through companionship, a safe environment and by working on their level of patience. Family members also protect patients since they know that certain situations can generate distress, altering their behavior. Due to this, they avoid many types of exposures that are not beneficial for the patient.

- Providing containment
- Positive relationships at home
- Accompanying to therapies
- Being more patient
- Avoiding non-beneficial exposures, events that may generate frustration and negative environments

**10. Regulating:** Family members of people with AS establish standards for patients so they can regulate their behavior according to limits. Patients do not have clarity regarding social limits and do not have a high level of initiative to fulfill responsibilities, so they prefer to establish clear rules and responsibilities, be firm in them and, in some cases, rely on didactic elements for more effective understanding.

- Giving responsibilities and demanding them
- Setting limits
- Staying steady
- Doing routines based on rules
- Making commitments based on trade-offs

**11. Establishing roles:** Family members of people with AS set roles for the different relevant members in the patient's ecosystem. They distribute the tasks related to the patient according to the different abilities of each family members and their relationship with the patient. This is why roles are established, which can change over time.

- Defining roles
- Changing roles
- Clarifying roles