

## Speaking Of Autism In Sessions Of Couple Therapy

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This article focuses on couples where one of the romantic partners was recently diagnosed with autism. This research explores how the diagnosis of autism functions in the conversation between romantic partners in distress. Therefore we conducted a thematic analysis on four transcripts of couple therapy sessions. Our research illustrates that seeking for a diagnosis is often a lengthy process. This process seems to be initiated by insecurities and questions about difficulties in the relationship. Our analysis suggests that obtaining a diagnosis, although bringing some relief, also gives rise to new questions and challenges for the couple.

**Keywords:** diagnosis, autism, couple therapy, thematic analysis, process.

Contemporary psychiatry considers autism to be a developmental disorder. According to the DSM-IV-TR (APA, 2000), autism is characterised by deficits in three core areas: a qualitative impairment in social interaction, communication, and restricted repetitive behaviours and/or interests. Autism functions as an umbrella term for a wide spectrum of disorders ranging from “classic” autism to high-functioning autism and Asperger Syndrome (Attwood, 2006). Books on partner relationships and autism seem to focus on this last end of the spectrum (Aston, 2003; Bentley, 2007; Edmonds & Worton, 2005; Stanford, 2003; Thompsom, 2008). In the literature there is an ongoing discussion about whether to use the diagnosis *Asperger Syndrome*, or high functioning autism in these cases (Freeman et al, 2002; Howlin, 2003). Still others support the use of the idea of a spectrum (Leekam et al., 2000). We will use the word ‘autism’ to encompass all.

It is often thought that, in line with the personal characteristics associated with the diagnosis of autism, having a long-term love relationship may be rather unusual for individuals diagnosed with autism (Bauminger & Kasari, 2000; Orsmond et al., 2004). However, recently several books have been published on the subject, suggesting that these individuals engage in romantic relationships more often than previously believed (Bentley, 2007; Edmonds & Worton, 2005; McCabe & Mc Cabe, 2003; Slater-Walker & Slater-Walker, 2002; Stanford, 2003). Furthermore, in the field of couple therapy, authors have addressed the topic of autism and its influence on the couple relationship (Aston, 2003, Smeltzer, 2007; Thompsom, 2008; Van Voorst, 2008). Most of the couples are confronted for the first time with autism through the process of the diagnosis of their child. Often only after the diagnosis of one of his/her children, a parent is diagnosed with autism. Autism diagnoses are possibly more given to adults nowadays because autism was not well known when they were children themselves (Punshow, 2009). As children, these adults may have been considered odd or special, but they were never diagnosed as autistic.

Although most couples have relational problems (Gottman, 1999), among couples in which one partner has autism, we might anticipate additional relational challenges and/or difficulties coping with them. For instance, solving difficulties together as a couple demands relational skills and competencies like communication, the ability to take the other's perspective and flexibility in the face of changing circumstances and contexts. According to the DSM, these are some of the relational skills that a person diagnosed with autism would be lacking. As Aston (2003) states, central characteristics of the diagnosis are also the ones needed to form love relationships. Punshon et al. (2009) state that autism is a peculiar diagnosis for adults as "autistic" features have always been there even before the diagnosis, but they were not recognized as such and not named. Furthermore, this diagnosis does not lead to a prognosis and has no cure. In this respect, the phenomenology of a diagnosis of autism is different than, for instance, the experience of being diagnosed with diabetes in adulthood (Peel, 2004). It should be noted that having a child with autism forms an additional stressor for these couples (Brobst et.al., 2009).

According to most authors in the field of couples therapy, accepting the diagnosis is a key factor in making the relationship work (Aston, 2003; Bentley, 2007; Edmonds & Worton, 2005; Smeltzer, 2007; Stanford, 2003; Thompsom, 2008). Stanford (2003) puts it this way: "...the most reliable solutions for now

*consist of wrapping our minds around the full extent of the diagnosis then brainstorming for solutions within that framework...*" (p.17). This means that in therapy sessions with these couples, talking about the diagnosis is very important. This also seems to indicate that these authors propose that the diagnosis should be central in organizing meaning. However, we do not know how these couples talk about their diagnoses before they enter therapy. We do not know how the diagnosis of autism functions in conversations between the partners. What does the diagnosis mean for these couples and how does the diagnosis take its place in couple interaction?

These are some of the questions we address in the present research. We choose to do an explorative qualitative research in which we analysed transcripts of couple sessions focussing on the partners' utterances that referred to the diagnosis of autism.

Before we go on to present our research in more detail, it may be important to be explicit that we use a social-constructionist lens and we consider a diagnosis as a social construct (Brown, 1995; Gergen et.al., 1997; Gergen & Mc Namee, 2000; Jutel, 2009). In our opinion a diagnosis is an attempt of a community to grasp experience in a concept (Migerode, 2010). Once accepted the diagnosis starts to function in social relationships as if it really exists. Although the diagnosis of autism is constructed in a social-cultural context (society in general, a scientific community, ...) couples refer to this diagnosis in their own way: they make use of the constructed meaning and add their own meaning to it, in that way co-constructing the diagnosis. The local use the couple makes of the diagnosis, (e.g. the way it makes sense within the context of the couple interactions ,the meaning added to it by the couple, ...) is what we will focus on in this study.

## Method Section

The present study uses a qualitative design, which features a thematic analysis (Braun & Clarke, 2006) of the data.

### *Data body*

In the context of a broader research project on autism and couples therapy, we videotaped several sessions of marital therapy with couples in which one of the partners was diagnosed or suspected with autism. Randomly, we

selected four of these sessions to conduct a micro-analysis for an eventual study on the inner dialogue of the therapist (Rober, unpublished). The second author (LvE) transcribed these four sessions. These sessions were used in this research. All sessions lasted one hour. The first author was therapist in all of the sessions. In session four An Hooghe was co-therapist. In accordance with our university's ethical regulations, all participants signed informed consent forms in which they gave permission to use the videotapes of the session for research purposes.

### *Participants*

The 4 participating heterosexual couples were all referred to our centre for couples therapy after it became known to the referring persons in our region that we were setting up a research project on marital therapy and autism. In all four cases the husband was the partner diagnosed with autism (n=3) or suspected of fitting an autism diagnosis (n=1)<sup>1</sup>. All four couples learned about autism through their worries about one of their children who was diagnosed with autism. In the course of the diagnostic process of the children, the partners, mostly on instigation of the wife, began contemplating the possibility of an autism diagnosis for the husband.

### *Analysis*

All three authors are clinical psychologists. The research was initially started by the second author (LvE) as part of her MA dissertation. The first author (LM) is a couples and family therapist for 30 years, mainly working from a dialogical/narrative/systemic perspective. He was therapist in the four sessions we analysed and is supervisor of the research project on autism and couples therapy. The third author (PR) is a child psychologist and a family therapist for 25 years. He works from a dialogical/narrative/systemic perspective. He contributed to this research his expertise in qualitative research. He also acted as co-writer of this report.

### *Data analysis*

The analysis involved three stages.

1. First the videos of the session were transcribed by the second author.
2. Secondly, we examined the transcript, and tried to identify all words in some way referring to autism. Only utterances of one of the partners about his/her partner were selected. Some of these utterances literally referred

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1. This person was on a waiting list for formal diagnosing. After the couple therapy was finished we heard that he was officially diagnosed with autism.

to autism (e.g. when they used words like “*autism*”, “*the diagnosis*”, etc.), but also more implicit references to autism were selected (e.g. “*there must be something wrong*”, “*disability*”, “*the problem*”). All these references were marked in the transcripts. We used a consensus process (Hill et al., 1997) in order to come up with a final list of utterances referring to the diagnosis of autism. This process started with the second author and another psychology master student separately reading through the transcripts and selecting all words implicitly or explicitly referring to autism. Then they compared notes and worked towards a consensus. As a validity check, the first author also read the transcripts and then the first and second author talked about the differences in their selection until consensus was reached. In the end 71 conversational sequences implicitly or explicitly referring to the autism diagnoses were selected.

3. In the third stage a thematic analysis (Braun & Clarke, 2006) was conducted on this selection of conversational sequences. A constant comparison method was used, comparing data with data, data with categories and categories with categories, (Charmaz, 2006) resulting in a categorisation of possible meanings of these conversational sequences.

### *Findings*

Five main categories emerged out of our analysis:

1. the process of searching for a diagnosis,
2. diagnosis as an answer to questions and insecurities,
3. diagnosis as identity,
4. couple conflict concerning the diagnosis, and
5. how to make autism a topic of conversation in the couple.

We will give a condensed overview of the 5 main categories, illustrating each of these categories with some examples of sequences of conversation of the partners.

#### *Category 1: The process of searching for a diagnosis.*

Couples tell the story of how they came to suspect that autism might be involved in the difficulties they were experiencing in their relationship. It seems that searching for a diagnosis is a process: it takes time to go from the idea “*something is wrong*”, to deciding that autism might be the answer. Our data gave us the possibility to gain a deeper understanding of this process. In our sample, it seemed that the partner without the autism diagnosis was first alarmed by her partner’s behaviour. She uttered her suspicion that something was wrong a long time before the diagnoses was made. In the beginning it

was a vague suspicion. For instance the wife of couple 2 said: “For years I have been saying ...’there’s something wrong’...’it doesn’t add up’...” (couple 2, 14-37). Later they tried to find ways to ground this suspicion in more systematic observations and comparisons. The wife of couple 4, for instance, explained how she compared the relational rapport she had with her husband with the rapport she had with her son. This comparison reinforced her suspicions: “I had this suspicion [that the husband was autistic] for some time...I have a son ...and you feel a different rapport with him... You know that you understand each other...and that you can sense each other... [she addresses her husband] but that is something I miss in you...” (couple 4, 249-254). Some partners looked for answers in the self-help literature (e.g. couple 4, 275-276; couple 3, 490-497) or in self help groups (couple 2,45-47). Another partner started a diary, in which she wrote down what she observed and what she suspected was wrong (wife of couple 2) with her husband.

### *Category 2: Diagnosis as an answer to questions and insecurities*

This searching process of the partners who were worried and suspected that there might be something wrong, often resulted in seeking professional help. A clear, professional diagnosis, seemed to promise an answer to their questions and a relief of their worries.

W: “It is years now that I am saying: “something is not right”. No as much in our relationship, I refer to him personally, there are things that...that especially last years, because,...our financial situation is very precarious and meanwhile I thought...I thought and thought and well the last two years I thought: “no this is impossible. There must be something”. And furthering my thought from there, his way of behaving, in fact from day one I met him, but yes, then you are in love aren’t you, en yes one loves one another he.”(couple 2, 19-25)

This promise of answers seemed to initiate and motivate the search for a diagnosis. Again, these worries are more felt by the partner. The wife in couple 4 explained: “his homecoming was often difficult, I couldn’t reach him, then there was the suspicion that there could be found a piece of autism in my husband...” For her, a diagnosis would provide the relief of being handed a name for difficult and scary experiences as well as for problems experienced in the relationship. What seemed incomprehensible became more understandable through a diagnosis. But, turning to an expert for a diagnosis was only possible if the male partners accepted that it made sense to consult a professional. The husband, although initially reluctant, finally conceded. In the session he said:

*“Well, those problems in our couple must have a reason. And I think eventually there can be a little piece of that autism of me that can explain something of the trouble” (husband in couple 4 384-385).*

### **Category 3: Diagnosis as identity**

The diagnosed partners expressed doubts with regard to their identity: Who am I then if they call me autistic? What is autism exactly? Is it a disability? The husband in couple 3, for instance, wondered: *“I have difficulties with the diagnosis. I am still me aren’t I? I don’t change because of the diagnosis, I still feel the same... But the diagnosis doesn’t make this easier because one thinks: Am I really different or not, do I really think differently than other people, do I really feel different than other people”* The partner without a diagnosis asked similar questions: *If my husband has autism, what and who is he then? Does the diagnosis mean that he is disabled?* Also the husband in couple 3 referred to the meaning of the diagnosis in terms of his own identity. At a certain moment, for instance, he said to his wife: *“...when you talk like that I feel like...disabled...”*. These husbands also wondered if their value as a person had changed now they were officially diagnosed. They asked themselves questions like: *Am I not normal anymore?* Some feel blamed or accused through their diagnosis. This sequence between wife and husband of couple 2 illustrates this:

Wife: *“When I see you with your brother I notice you have the same problem”*

Husband: *“Yes, but is that a crime maybe?”*

Of course, some of these husbands also have doubts about the diagnosis: *if I don’t recognise myself in some features of autism, am I really autistic then?* The husband in couple 3, for instance, stated: *“I read that men are more autistic than women. So all is connected. When does it become too much? What is the line to cross? And how far am I over that line then?”*... For some of these men it is hard to understand the diagnosis, for instance, because autism seems to them to be too broad a concept. The husband in couple 4 stated: *“That psychiatrist stated, ‘you also have it’, but that autistic spectrum is so wide, he said, he had difficulty delineating what exactly it is...”*

### **Category 4: Couple conflict concerning the diagnosis.**

This category refers to sequences in the conversation where the couple seemed to be having discussions about the diagnosis. Mostly it was the wife insisting that the diagnosis fitted her husband, while the husband, himself, refuted this idea: One wife complained: *“Well, I have the impression that he doesn’t want to accept his diagnosis”* (Couple 3, 445). The wife in couple 2 (220-229) said *“..."*

and that he accepts it, instead of stating that he is a normal person every time I want to show there is something wrong". These conflicts in the relationship seem to be closely connected with issues of identity (category 3). The husband of couple 3 (610-625), for instance, said: "I don't want to call myself disabled, but you do." The wife replied: "No, I don't consider you as being disabled, I would rather see it as a limitation you have". Furthermore, conflicts around intentionality seemed to emerge. The wife from couple 3 said (448-451): "It is hard to make my mind up. Is it autism that makes him rigid or is it plain stubbornness?". For the partner it can be confusing that the autism sometimes is not apparent: "...sometimes you seem to be able to refrain from thinking autistically, ... , that is difficult for me..." (the wife from couple 3, 573-577).

#### **Category 5: How to make autism a topic of conversation in the couple**

The couples in our sample told us that talking about autism was not easy for them. Depending on the context, sometimes just mentioning the word autism in their conversations with each other, could be hard to do. If it is true, as our data seem to suggest, that an autism diagnosis is intimately connected to the identity of the partner diagnosed (category 3), and may lead to conflicts about acceptance and identity (category 4), it is understandable that autism is a delicate subject in couple communication. Our couples told us that at times, they deal with this delicacy by using their own idiosyncratic words to refer to autism. They use words or phrases that euphemistically refer to the diagnosis. One of the women (couple 4, 124-128) for instance said "...dat er bij mijn man een stuk autisme zit..." (literally "...that there is an autistic part in my husband"). A man said "...ondanks die dingetjes van autisme bij mezelf..." (literally: "...notwithstanding the sort of autism in me..." (couple 1, 125-132). Another couple (couple 4, 188-197) used their own code word to refer to autism: they called it "au" or "miauw" (literal translation: "meow", referring to the sound a cat makes). They explained that they preferred to use these words, because autism is such a loaded word, and mentioning autism could lead to tensions in the couple. On another level the different categorical words ("problem", "disability", "limitation", "diagnosis", "aspergie") used to make reference to autism can be understood as the couple trying to make conversation on this sensitive topic, without burdening the partner or the relationship too much.

## **Discussion**

The present qualitative research explored the meanings of the diagnosis related conversations in couples seeking couples therapy. Four first sessions of marital

therapy were transcribed, analysed, and categorized following a thematic analytic approach. Five categories could be constructed and were presented here. These categories seem to describe a process in a couple preliminary to therapy: the process starting from *sensing something is wrong, over moving towards a professional diagnosis* (category 1), and ending in *dealing with the consequences of that diagnosis for the couple* (category 3,4,5). The motor of this process seems to be the desire to reduce insecurities and the search for answers (category 2).

***Talking of autism is a process for couples.***

As we understood it, the process often started with one partner - in all our couples it was the wife - being alarmed and worried. She sensed that something was wrong with her husband. Although the partner (husband) tried to reassure her, these suspicions lead her to search for answers. It seems that after a while the wife started to hope that a professional diagnosis would give answers to her worries and doubts. For her the diagnoses might be a moment of relief: finally there was an answer that explained everything. Furthermore, the professional diagnosis reassured her that she was not paranoid or over sensitive. The wife at last receives an acknowledgement that something was indeed wrong with her husband. This is captured in the second category: 'diagnosis as an answer to questions and insecurities'. However, the hope that diagnosis is an answer to everything seemed to vanish quickly as the diagnosis made room for new challenges: questions of identity (category 3) and insecurities what the diagnosis might mean in the couple's interaction (category 4). The third category is about the connection between diagnosis and identity. This category highlights the diagnosed partner's struggles with his new identity. At the same time it also speaks about the meaning of this changed identity for the wife and for the couple. The connection of the subject of autism with identity, in combination with identity being a sensitive topic for couples, offers some explanation for conflicts between partners on this topic (category 4). Category 5 illustrates that the couples tried to find ways to deal with this sensitivity. They do this for instance by talking cautiously about the topic of autism. The partners seem to be searching for words that can help to address the topic of autism, without harm for one of the partners or for the relationship.

***The phenomenology of the diagnosis: the role of the partner.***

As we wrote in our literature review, Punshon et al. (2009) state that autism is a peculiar diagnosis, very different from other diagnoses like, for instance, a diagnosis of diabetes or arthritis. Indeed, features of autism have always been

present in the partner being diagnosed as autistic, even before the official diagnosis. Also, for the partner, this diagnosis doesn't describe a change in functioning nor announces one. The partner in a sense struggles with autism long before the diagnosis was set.

Our data also allow us a glance at what may be another peculiarity of the phenomenology of receiving a diagnosis of autism in adulthood: it seems to be the partner who guides the search for a diagnosis. This is reflected in the meaning units of the first category where the excerpts show that in couple 2 and 4 it was the wife searching for a diagnosis because she wants some answers. The husband of couple 3 recounts that he went to a professional for a diagnosis primarily for his wife's sake. We can understand this motivation for an official diagnosis coming from the partner, referring to what is called the *Cassandra syndrome* (Aston, 2001, 2003; Thompson, 2008). This term is used to describe the problems the spouse of someone with Asperger's Syndrome suffers, especially the disbelief she encounters in her social environment. In this way, the prospect of having an official expert diagnosis about the husband seems to help to make the wife's sorrow and loneliness bearable and acceptable (Aston, 2001). Moreover, it seems that the partners often have a history of being alone with their worries and suspicions, often not being believed by friends and family (Aston, 2001). In this way the process of seeking a diagnosis not only enters the couple dynamics, but also the relation of the couple with the outside world. An official diagnosis legitimates the wife's worries, her sorrow and her suspicions. It also shows friends and family that it is not necessarily her fault that their relationship is difficult, and that her task as a partner is more difficult than in an ordinary couple.

*Diagnosis a mixed experience for couples.*

In contrast to some of the literature on couples and autism (Aston, 2003; Bentley, 2007; Edmonds & Worton, 2005; Smeltzer, 2007; Stanford, 2003) our data seem to suggest that obtaining a diagnosis is not solely a positive event. While the process towards a diagnosis has positive aspects (e.g. relief, reassurance), some experiences are more difficult (e.g. dealing with the new identity – category 3). This is in line with some of the results of the Punshon et al.'s (2009) study where all the participants were able to identify both positive and negative aspects of being diagnosed. Their study, being the first peer reviewed study on the psychological impact of receiving an Asperger diagnosis in adulthood, doesn't mention partners. Our study adds to Punshon et al.'s in the sense that our data highlight the positive and negative implications for the

couple. For instance, category 4, reflects some of the difficulties receiving the diagnosis can generate in couples, not only for the autistic husband, but also for his wife. This mixed effect of being diagnosed with autism resembles the results of the Robinson et. al. (2004) study exploring the way couples make sense of a diagnosis of dementia. Also these couples report both positive and negative effects of being diagnosed. As in our study, one of the positive reactions of couples in the Robinson study is the confirmation that something is wrong.

Furthermore, our analysis suggests that the couples' search for a diagnosis, in a sense, seems to mirror the function diagnoses have in the medical world; that of ordering the "deviant", the "dysfunctional" (Gergen et.al., 1997; Jutel, 2009; Migerode, 2010). For the people concerned, making the step from being "strange", "weird", "unusual" (Gergen & Mc Namee, 2000), "eccentric" (Nadesan, 2005), to "sick" is a step into getting accepted into society, be it at the edge. Attwood (2006) states that being diagnosed as autistic can be a very important positive experience in this sense. Our data suggest that couples can find relief in the diagnosis, and that the diagnosis offers a possibility to give meaning to differences (category 2). Simultaneously being diagnosed can be difficult, as it may activate questions about one's identity (e.g. category 3) (Attwood, 2006; Punshon et al., 2009; Thompson, 2008) and as it may lead to tensions and conflict in the couple (category 4) (Thompson, 2008). Furthermore, Smeltzer (2007) warns that when someone is diagnosed as "sick", this can also be understood as being "responsible for". In this sense diagnosis could blind couples and therapists for reciprocal influences (Smeltzer, 2007). Thompson (2008, p 42) proposes that the mixed experience of obtaining a diagnosis of autism would lead therapist and partners to considering each couple as unique.

### *Limitations*

Since this is a very small scale study we should be humble in our claims. For one thing, only using data from 4 sessions seriously limits the generalizability of our findings. Furthermore, we choose to only study first sessions because we were interested in the way couples deal with autism of one of the partners prior to therapy. Focussing on first sessions implies that our data do not allow us to observe evolutions in the way the diagnosis functions in a couple's dynamics during therapy. Moreover, the fact that in these couples all partners with the diagnosis were male, and that the introduction of words relating to the diagnosis were preponderantly made by the wife, forms another limitation.

Furthermore, following our aim to study the local meaning of diagnoses in couple conversations, we chose to only analyse those instances in therapy when the partners mention the 'autism'. This forms a limitation in the sense that the therapists' influence on the meanings is neglected.

*Future research.*

Given the small scale of our study, it might be interesting that future research would replicate our study with a bigger sample of couples. Such a bigger sample would probably allow for more differentiation in the sample. For instance, we wonder if our findings would have been different within couples where instead of the husband, the wife or both partners would have a diagnosis of autism (Aston, 2003). Future research could investigate this further.

Future research could also study the conversational meaning of the diagnosis in consecutive sessions of the same couple. In this way, the evolution of the meaning of "diagnosis" in therapeutic conversations could be studied. In the session of couple 3 for instance there seems to be an evolution in the words used to refer to the diagnosis: first partners speak of 'autism' and 'diagnosis', further in the session there is an evolution towards 'autistic' and 'autistic thinking'. At the end of the session this couple refers to 'disability' and 'limitation'. One could wonder what this means for the couple and for the therapeutic encounter. Obviously, taking more sessions into account could further our understanding of the phenomenology of autism diagnoses in couples, as it would deepen and widen the set of meaning categories found.

Finally, if the acceptance of the diagnosis with both partners is as central as is claimed in the literature on the topic (Aston, 2003, Stanford, 2003; Edmonds & Worton, 2005; Bentley, 2007, Smeltzer, 2007), it seems important to research the effects of this acceptance of the diagnosis on the couple relationship. This research should also take into account the possible negative experiences (Attwood, 2006; Punshon, 2009, Thompson, 2008) and the ethical implications (Crews & Hill, 2005) for the persons involved and for the conversations between them.

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