

Autism and the Experience of Closeness

An Interpretative Phenomenological Study

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Abstract

The present study is the first qualitative investigation of the experiences of closeness in romantic relationships for individuals diagnosed with Autism Spectrum Disorder (ASD) and their partners. Eight participants in long term relationships, four of whom had been diagnosed with ASD, four of whom had partners with a diagnosis, were interviewed regarding their understandings and experiences of closeness in the context of their relationships. Interpretative Phenomenological Analysis was chosen as the method of analysis. Three dominant themes emerged: *closeness as authenticity*, *discovering the partner*, and *autism as an essential difference*. These themes were present in all participants' accounts. Subordinate themes revealed distinctions in the experiences of participants with and without a diagnosis, but, overall, commonalities were as significant as differences. The experience of closeness required that the partner felt able to express freely his or her "authentic" self through his or her actions, in the confidence that these would be understood, accepted, and responded to by the partner in a congruent fashion. Participants' understandings of ASD, as well as their partners', were integral to their experiences of closeness; within the diverse accounts gathered, autism presented both obstacles to, and opportunities for, the experience of closeness. The findings resonate with some aspects of dominant models of autism and closeness, but problematise others, and demonstrate the distinct contribution that qualitative research can make to the understanding of these constructs and their relationship to each other. Consideration is given to the implications of the findings for clinical work with people in relationships where one partner has a diagnosis of ASD, and to potential directions for future research.

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Dedication

The process of this research proved to be more emotive than I could have anticipated at the outset. I have been humbled by the generosity shown by each of the participants in the time and effort they have taken to provide such rich narratives, in response to questions that were searching and deeply personal. It is to yourselves that I owe the deepest gratitude, and so the dedication of this thesis belongs to you.

*“If you ever get close to a human being,
You’d better be ready to get confused.
There’s definitely, definitely, definitely no logic
To human beings.”*

- Björk, “Human Behaviour”

1. Introduction

Within this chapter, a review is given of existing literature relevant to the understanding of “closeness” in the context of autism, highlighting significant limitations of existing research on this topic. A rationale is provided for the adoption of a hermeneutic phenomenological investigation in the present study. Consideration is also given to pertinent conceptual issues.

1.1 On Autism

Autism: a label that suggests by its very etymological roots that the individuals to whom it is affixed are closed off from and to others, living within self-contained worlds in which other people, as conscious beings, are ignored, marginal, or altogether absent (Biklen, 2005). The world of the autistic individual is likewise given as indecipherable to the other. This putative intersubjective gulf has given rise to the representation of the autistic individual within much clinical literature, as well as in popular cultural representations, as a fascinating enigma, and autism as a phenomenon to be *observed*, in order that the difference of the autistic individual be *explained*. Since the inception of the diagnostic construct, an abundant body of empirical research has accumulated on the topic of the interpersonal features of autism, and a series of complex hypotheses advanced to account for the differences witnessed in the autistic individual (see Bowler, 2007). Comparatively little work has sought to understand the lived intersubjective experiences of people who have been given the diagnosis, or of others in dyadic relationships with them.

The construct of *closeness*, with its connotations of deep connection between individuals developed through the sharing of aspects of the self kept most private, stands as particularly problematic in juxtaposition to a condition of which the central intersubjective feature would appear to be *distance*. Yet, it is clear that, despite the interpersonal difficulties that must, by definition, exist for people designated as autistic, for many, the experience of others, of *the Other*, is a central focus of their engagement in the world. Moreover, autistic persons may also occupy the role of “significant other” in other individual’s lives, be they autistic or “neurotypical” (a recently developed term for an individual not affected by autism – see Sinclair, 1998). Intersubjectivity cannot, therefore, be reduced in

the context of autism to *absence*; research cannot rest at determining what is “missing” for autistic individuals and those in relation to them. Rather, the question is raised as to how intersubjectivity exists *substantively* in the context of autism – what significance does the Other hold for the autistic individual, and he for her?

1.2 Literature Review Strategy

A literature review was conducted in the planning of the present study. In August 2011, searches were conducted using the PsycInfo and PsycArticles academic databases. In reviewing current approaches to autism, searches were conducted using the keyword combinations “autism AND social”, “autism AND romantic AND relationships”, and “autism AND phenomenology”; due to the abundance of literature, the search was restricted to publications from 1991 onwards. Regarding intimacy and closeness research, searches were conducted using the keywords “intimacy” and “closeness”, and the keyword combination “intimacy AND phenomenology”; the search covered publications from 1981 onwards. Publication abstracts were read where the title suggested a paper to be of interest to the present study; where the abstract demonstrated the paper to be of direct relevance, the full publication was reviewed. Google Scholar was used selectively to identify publications citing papers gathered through the literature review. Finally, books pertaining to these subjects were reviewed at the UEL and Senate House libraries, as well as at the British Library.

1.3 Autism and Intersubjectivity

1.3.1 Autism

Autism is a diagnostic psychiatric construct signifying a set of deficits shown by individuals affected by a range of developmental conditions collectively designated as Autism Spectrum Disorders (ASD). The diagnostic category includes disorders familiar to most clinicians and many lay individuals, such as Autistic Disorder (henceforth “Autism”) and Asperger Syndrome (or “Asperger's Disorder”), as well as less common diagnoses such as Childhood Disintegrative Disorder. While within DSM-IV-TR (American Psychiatric Association, 2000), these conditions are classified as “Pervasive Developmental Disorders”, it has been proposed that in the forthcoming DSM-V, the more common nomenclature

of "Autism Spectrum Disorder" be formally adopted (American Psychiatric Association, 2011).

The core "autistic" features common to each of the separate diagnoses have, following Wing (1993), become widely termed the "triad of impairments". The triad includes significant difficulties in interpersonal relationships, impairment in communication, and a deficit in imagination. Individuals who have been formally diagnosed according to DSM-IV-TR criteria with Autistic Disorder or Asperger's Disorder must have shown at the time of assessment pervasive and enduring "qualitative impairment in social interaction" and "restricted, repetitive, and stereotyped patterns of behaviour, interest, and activities". Finally, a diagnosis of Autistic Disorder requires that the individual show a marked impairment in communication, including developmental delay of speech. Although a delay in language acquisition rules out a diagnosis of Asperger's Disorder, unusual verbal communication styles are often shown by people with this diagnosis (Attwood, 2006).

Of the features of autism, it is the marked qualitative differences in the ways in which autistic individuals relate to others which have received the most attention in research, and which lie at the core of the rationale for the present study.

1.3.2 Conceptualisations of Autistic Intersubjectivity

The predominant paradigms within contemporary research seeking to account for autistic difference are neuroscientific and cognitive. As the present research is focused on lived experience, the review of existing literature will be restricted to theories of the *psychological* differences in autism that are held to have a direct association with the intersubjective features of the diagnosis.

Neuroscience certainly has a contribution to make to the study of experience (Ratcliffe, 2006). However, neuroscientific research in relation to autism is intimately tied with cognitive modelling, such that any phenomenological consideration of neuroscientific findings will be mediated by cognitive accounts of autism. Therefore, due to restrictions of space, neuroscientific literature will not be reviewed here.

1.3.2.1 The Mindblindness Hypothesis

Of the cognitive accounts of the interpersonal features of autism, the most influential has been Simon Baron-Cohen's (1997) "mindblindness" hypothesis. The theory suggests that at the core of autism is a profound impairment in the understanding of human behaviour in terms of mental states, such as cognitions and emotions. Baron-Cohen's first substantive theory of autistic interpersonal impairments was based on a number of experimental findings, detailed below, made during the eighties and nineties which suggested that autistic children showed a specific impairment relative to other groups of similar intellectual ability in understanding epistemological states and emotional displays in others.

The most widely cited of the relevant studies concern the ability of autistic children to show an understanding of false beliefs in themselves and others. In Baron-Cohen, Leslie and Frith's (1985) ground-breaking study, autistic children and controls matched for mental age were presented with a vignette in which one doll, 'Sally' hid a marble under one of two cups before leaving the scene; during Sally's absence, another doll, 'Anne', moved the marble to the other cup. Participants were asked upon Sally's 'return' where she would look for the marble (the 'Sally-Anne Task'). Autistic children were significantly more likely than controls to indicate that Sally would proceed straight to the cup where the marble had been relocated. In an equally impressive study, Perner, Frith, Leslie and Leekam (1989) found that autistic children showed significant difficulties relative to controls in retrospectively recalling false beliefs they themselves had explicitly declared before being corrected.

Evidence is also presented to suggest that autistic individuals furthermore show impairments in recognising affective states in others. For example, Baron-Cohen, Wheelwright, and Joliffe (1997) found that, when presented with photographs of emotional facial expressions, adults with Autism or Asperger Syndrome were markedly impaired relative to controls in recognising complex emotions such as guilt or mistrust.

Baron-Cohen (1997) relates these apparent deficits in social cognition to Dennett's (1987) concept of the "intentional stance". Briefly put, Dennett (1987) argues that, when faced with the task of understanding and responding to human behaviour, the most effective stance for an organism to adopt is to view others' behaviour as *intentional*, in the sense of being guided by a person's goals or desires in relation to the person's *mental representation* of their environment. The intentional stance confers substantial advantages upon an individual seeking to anticipate others' actions, particularly in terms of accounting for human error and predicting others' responses to events. To adopt the intentional stance requires that the individual holds a concept of mentalistic structures – that is, that he possesses a "theory of mind." Within the literature, this "theory" is not a set of explicit declarative hypotheses. Rather, it is envisaged as the product of an automatic, preconscious hypothetico-deductive cognitive process (Gopnik, 1993). Dennett (1978) suggests that the best marker of a theory of mind is the ability to recognise false beliefs.

Baron-Cohen (1997) argues that the aforementioned studies show that autism involves a basic impairment in the development of the individual's theory of mind, such that the person is left in a state of "mindblindness", largely unable to understand matters of desire, belief, expectation and error which make up the fabric of social interactions. Her ability to engage effectively with others through anticipating others' perspectives and adjusting her own behaviour accordingly will, therefore, be profoundly affected, and social interactions are likely to be riddled with confusion, both for herself and others. The difficulties experienced by autistic individuals in communication and reciprocal relationships are unsurprising consequences.

The mindblindness hypothesis has proven immensely influential both in theoretical models of autism and in clinical work. Ozonoff and Miller (1995), for example, detail an effective programme for "teaching theory of mind" for autistic children. The link made by Baron-Cohen and others between autism and the construct of a theory of mind has also been a boon to research on the latter, with autistic divergences from control groups' performances illuminating, by way of contrast, important aspects of typical social cognition.

1.3.2.2 Empathising and the Extreme Male Brain Hypothesis

Baron-Cohen (2002; 2003) expands on his account of autism by suggesting that the social deficits affecting autistic individuals are attributable to profound impairments in affective empathy. “Affective empathy” is defined as the adoption by an individual of an “appropriate” affective stance in response to another’s emotional state – for example, automatically showing concern when another is in pain, or showing caution when approaching someone who appears angry. It is, as such, a reciprocal interactive process, reliant upon, but reaching beyond, the more detached cognitive processes facilitated by the theory of mind; the interpersonal challenge faced by the autistic individual is thus not one simply of comprehension, but, moreover, of attunement. Baron-Cohen (2003) is not suggesting that people with autism are indifferent to others’ feelings – many, he notes, are very distressed if they discover they have upset someone – but rather that there is a lack of spontaneous affective reciprocity.

Baron-Cohen (2002) has suggested that individuals’ levels of affective empathy can be located along a continuum, with autism located at the lower extreme. Research has, accordingly, sought to quantify empathy in order to support this argument. Baron-Cohen’s research team have developed the “Empathy Quotient” (EQ) (Lawrence, Shaw, Baker, Baron-Cohen, & David, 2004), a self-report measure for assessing an individual’s level of empathy. The EQ was partially validated through showing that it reliably distinguished adults diagnosed with ASD from control groups.

Baron-Cohen has also suggested that “systemizing”, a drive to analyse or construct systems in order to predict or control their behaviour, may represent the process underlying repetitive and ritualistic behaviours as well as engrossing special interests engaged in by people with autism. Further to the EQ, his team have developed and validated a “Systemizing Quotient” (SQ) (Baron-Cohen, Richler, Bisarya, Guronathan, & Wheelwright, 2003) to measure individuals’ levels of systemizing; as with the EQ, the SQ has been found to reliably distinguish adults with ASD from controls.

An interesting feature of both measures is that they not only discriminate between autistic and control groups, but that they also reveal significant differences between the sexes – women tend to gain higher scores on the EQ, men on the SQ. Baron-Cohen (2003) suggests that these differences correspond to the generally greater orientation of women towards social affairs, and men towards practical tasks.¹ Considering these results, as well as developmental differences between the sexes in language and creative play, autism has been dubbed by Baron-Cohen (2003, p.133) as a form of the “extreme male brain”.

The hypothesis holds points of interest for the present study. First, it provides a framework within which the features of autism are placed on a continuum with “normal” functioning, which is in line with evidence suggesting that autism represents the extreme end of a distribution of traits that exist within the general population (e.g. Piven, Palmer, Jacobi, Childress, & Arndt, 1997). Second, the introduction of the construct of affective empathy appears to bring the account of autism somewhat closer to the experiential world, in which we not only comprehend others’ behaviour but also intuitively respond to and invest ourselves in social relationships.

The evaluation of Baron-Cohen’s (2002) interpretation of autism in terms of gender constructs is complex. Anticipating social constructionist arguments against his hypothesis, Baron-Cohen cites intriguing studies that show significant intersubjective behavioural differences between day old infants of either sex (e.g. Connellan, Baron-Cohen, Wheelwright, Ba’tki, & Ahluwalia, 2001). Nonetheless, the interpretation of such evidence in terms of predisposition towards differences in empathy and systemizing is contentious. It will most likely not surprise the reader that the “extreme male brain” hypothesis has proven controversial, and neuroscientist Cordelia Fine (2011) has offered a robust response offering a broader review of the pertinent literature than offered by Baron-Cohen, arguing that the evidence for essential differences in empathising ability is insufficient and contradictory.

¹ It should be noted that Baron-Cohen has been at pains to emphasise that the gender differences he attempts to demonstrate appear only at a cohort level, with large variations within gender groups.

Even if some differences in intersubjective behaviour between the sexes were to be accepted as influenced by biology, Baron-Cohen's (2002) account reductively constructs the intersubjective in purely intra-subjective terms, when, in fact, the research from which he makes his argument raises profound questions about the interface between biological sex and gender as a social construct. Autism is both a diagnosis which is overwhelmingly assigned to men, and is also a construct whose features resonate deeply with contemporary ideas of masculinity (Murray, 2008). While Baron-Cohen (2002) infers this as rooted in real biological underpinnings of cultural conceptions of gender, it has also been argued that the gendered construction of the diagnosis leads to an under recognition of autistic features in women, which in turn reinforces the image of autism as an essentially masculine condition (Ensum, 2012). Beyond the question of the origins of the gendered nature of the construct, the question is also posed as to how gender identity is constructed and performed in the context of the diagnosis. In the context of the current research, questions may be asked in particular as to how women who accrue an autistic identity navigate the matrix of cultural constructions of their gender in the context of romantic relationships.

In addition to the deep issues posed by Baron-Cohen's (2002) linking of autism to gender, the question is also posed as to whether affective empathy is a construct sufficiently broad to account for differences in autistic intersubjectivity. The image one gains from the clinical portrait of autism is not so much of one lacking in empathy, but, more fundamentally, of one removed from concern with others' experiences; it is this aspect of autistic relationality that has been addressed by Peter Hobson, whose account of autism will be covered next.

1.3.2.3 Hobson on "Being Moved"

Central to most approaches to autism is the notion that the interpersonal challenges faced by autistic individuals can be traced to the *opacity* of others' minds to them – a fundamental deficit in discerning, comprehending, and responding to mentalistic phenomena (Baron-Cohen, 1997). This focus on the autistic person's *comprehension* of mental states may be attributable in part to the dominance of the cognitive paradigm within psychological research in recent decades. Peter

Hobson (1993, 2002), in contrast, has approached autism from a psychoanalytic background, and has, accordingly, developed a very different conceptualisation of autistic intersubjectivity.

Hobson (2002) notes that, prior to showing delays in verbal communication and complex social cognition, children who are later diagnosed as autistic often show distinct differences from other children in more fundamental modes of interaction with others. Hobson argues for the significance in understanding autism of *primary and secondary intersubjectivity* (Trevarthen, 1979). The former signifies the way in which most infants engage from birth in smooth, immediate interpersonal interactions, the latter a developmental shift from around nine months in which infants will engage in triangulated interactions with others involving shared, affectively charged attention to objects in the surrounding world. He argues it is from these interactions, often strikingly absent in autistic children, in which the developing infant comes to discover through exploratory interactions with others that the world can be creatively represented from a range of affective perspectives, that the more sophisticated mentalising and empathic abilities, as implicated in Baron-Cohen's (1997) cognitive approach, emerge. Hobson (2006) suggests that the autistic individual approaches the interpersonal world from a very different position from those of other children, distinguished by the absence of a propensity to "be moved" to orient themselves in relation to others' subjectivity.

Hobson's account holds some appeal in so far as his portrayal of intersubjectivity appears to be closer to the lived interpersonal world as typically experienced, in which most people are motivated not only to understand or empathise with others, but, moreover, to share experiences with them. Nonetheless, Hobson's work has not exerted as wide an influence as has Baron-Cohen's, and even those sympathetic to his approach have suggested that he may, in rejecting cognitive modelling, inevitably oversimplify his account of relationality (e.g. Bowler, 2007).

1.3.2.4 Critical Notes on Autism Research

Autism has proven to be a captivating subject for researchers, clinicians, and, increasingly, the general public. Yet, it is important to consider the import of the overarching paradigms within which most of the literature on autism is situated.

Perhaps the most evident paradigm is that of the diagnosis itself. The validity of “autism” as a diagnostic construct has received widespread acceptance, even if the relation between different “spectrum disorders” has been the matter of some debate. However, this validity requires that there be a shared cause underlying both social-communication and non-social features of the diagnosis. A recent review of relevant research suggests that within the general population, these dimensions of autistic symptomatology are not significantly correlated and so are unlikely to share a common underlying cause (Mandy & Skuse, 2008). If a dimensional approach to autism is accepted, this finding calls into question the construct of an autistic syndrome. However, even if the concurrent presence of different “symptoms” does not indicate a unitary underlying “condition”, the constellation of features may yet signify a distinct mode of experiencing the world, and so inquiry into the experience of “autistic” adults remains a valid pursuit.

Another, more subtle, paradigm is that of *absence*. By this, I mean to suggest that autism has been constructed and portrayed in its intersubjective qualities in terms of what for or within the autistic person is *lacking* – a theory of mind, empathy, the disposition to “be moved” by the other. The conceptualisation of autism in terms of *negativity* may be “symptomatic” of wider psychiatric discourse, within which mental deviation is located as a site of absence in contrast to which common human rationality derives meaning (e.g. Foucault, 1967). However, the positioning of autism in particular as a site of absence has been important for researchers for its value in illuminating aspects of normal human development by comparison; Hobson (2002, p.46) has commented that, in researching autistic intersubjectivity, “it is the very unfamiliarity of the viewpoint that reveals what is otherwise too familiar to be found striking.”

Such an approach holds validity, and has indeed provided important insights for developmental psychology as well as leading to practical interventions to aid autistic individuals. However, even if the absence or impairment of certain “normal” psychological faculties in autism is accepted as valid, the question is nonetheless begged as to how autistic individuals come to *experience* others – an issue quite neglected in present research.

There is, therefore, a dire need for the recognition of what Stuart Murray (2008) has termed “autistic presence” – that way in which the autistic individual exists distinctively as himself in such a manner as resists definition in terms of that which he is *not*; that which is occluded by the clinical gaze, which withstands it. The lack of precision in the concept is itself cutting – for all the exactness which clinical literature demands of itself in renewing and refining its understanding of the structure of autism, the world of the autistic individual remains elusive and irreducible:

‘I view ‘autistic’ as a word for how part of my brain works, not for a narrow set of behaviours, and certainly not for a set of boundaries of stereotypes that I have to stay inside.’ - Activist Amanda Baggs (quoted in Murray, 2008, p. 44).

‘The autist is always himself.’ - Hans Asperger (1991, p.38)

‘He just is there.’ - Leo Kanner (1943, p.247)

I will argue below that phenomenological inquiry holds potential for bringing this presence forth. However, it will first be necessary to explore the rationale for placing the phenomenon of ‘closeness’ at the centre of the study.

1.4 Autism and Closeness

1.4.1 Closeness and Romantic Relationships

As with autism research, the literature on romantic closeness has been predominantly quantitative (see Mashek & Aron, 2004, for an overview); in contrast, however, an array of definitions of the term has been employed in

different strands of research. Closeness is a construct for which the psychological literature has not offered a unitary definition. The use of nomenclature within research is itself unclear; in reviewing the literature, I have included the keyword “intimacy” in electronic searches, as the term is more frequently employed than, but often used interchangeably with, “closeness”. For either construct, a difficulty in reaching an operational definition is present in that they are “natural types”, characterised by shifting sets of features in their ordinary use, such that it is difficult to formulate clear criteria for what would differentiate a relationship that is “close” or “intimate” from one that is not without either becoming overly inclusive or omitting significant dimensions of the terms’ generally accepted meanings (Prager, 1995). Divergent conceptualisations within the literature are thus not necessarily in competition, but rather may be addressing different aspects of the ordinary uses of the term.

Early social psychological research on closeness generally employed a rather restrictive focus on processes of verbal self-disclosure of private information (e.g. Patterson, 1976). While research has, over the past twenty-five years, adopted more comprehensive understandings of closeness and intimacy, a common thread has been maintained in the centrality of *mutual knowledge* within conceptualisations of the construct.

Most influential within research has been Reis and Shaver’s (1988) interpersonal process model. Reis and Shaver (1988) define intimacy as an interpersonal, transactional process, of which the principal components are self-disclosure and partner responsiveness. According to the model, intimacy emerges when one person communicates, verbally or otherwise, personally relevant and revealing information about their thoughts or feelings, and receives a response from the other which makes them feel understood, validated, and cared for. Laurenceau, Barrett, and Pietromonaco (1998) introduced a distinction between emotional and informational self-disclosure, the former of which appears a more powerful predictor of intimacy. A review of evaluation studies has supported the hypothesis that greater frequency of the processes implicated in the model is associated with greater reported levels of intimacy in relationships (Laurenceau, Rivera, Schafer, & Pietromonaco, 2004). The model holds particular utility in its

provision of a clear operationalisation of intimacy as a process, and, as such, has formed the basis for a multitude of studies on the variables influencing the process of intimacy (e.g. Cutrona, Shaffer, Wesner, & Gardner, 2007).

Reis and Shaver's approach has been significantly expanded upon by Karen J. Prager (Prager, 1995; Prager and Roberts, 2004). Prager and Roberts (2004) propose that intimate interactions can be distinguished from non-intimate interactions by the presence of three distinct conditions: self-revealing behaviour, positive involvement with the other, and shared understandings. In order for an interaction to create intimacy, a partner must be able and willing to reveal private, personal aspects of themselves, verbally or non-verbally, in the context of an experience of the other as fully, directly, and positively attentive towards the self. Furthermore, the interaction must establish shared understandings of one another's selves: "both partners experience a sense of knowing or understanding some aspect of the other's inner experience – from private thoughts, feelings, or beliefs, to characteristic rhythms, habits, or routines" (p.45). Intimate interactions will vary in aspects such as affective intensity or the degree of privacy of the aspects of self revealed, with repeated interactions of significant intimacy allowing the development of shared personal understandings and the growth of relational intimacy. Prager and Roberts' (2004) expansion on Reis and Shaver's (1988) model thus gives a clear rationale for seeing romantic relationships (when successful) as the platform *par excellence* for intimacy.

Prager and Roberts (2004) also argue for the significance within intimacy of the distinction between a partner's self-concept and their organismic, or experiential, self. A self-concept that conceals or omits aspects of an individual's experiential self precludes full intimacy. Prager and Roberts (2004) offer the example of a husband who conceives of himself as ambitious and emotionally invulnerable, who must thus conceal from himself and his partner inner experiences of vulnerability. Such incongruence between the self-concept and experiential self represents a profound barrier to intimacy, which requires the revelation and knowledge to both parties of the "true self".

Regarding the potential distinction between intimacy and closeness, Moss and Schwebel (1993), reviewing the definitions of intimacy used within research predating their paper, define closeness as a specific component of intimacy, characterised by either partner's knowledge of the other's "inner" cognitive and affective experiences; the other components are, according to the authors, mutual positive affect and commitment.

Finally, an intriguing and widely influential model of closeness (as distinguished more clearly from intimacy) defines the construct as the inclusion of the other in the self (Aron, Aron, Tudor, & Nelson, 1991). According to the "self-expansion model", 'closeness' signifies a state in which an individual's self has come to encompass elements that properly belong to another. As such, an individual may be prone to experiencing resources, perspectives, and identities as they are perceived to be held by the proximal other. For example, when viewing a film, a man may actually experience the movie in an immediate, unreflective fashion as he believes it would be experienced by his partner. A range of experimental findings have largely supported the central hypotheses of the model (see Aron, Mashek, & Aron, 2004). However, while the model provides an interesting perspective on the permeability of the boundary between self and other, the related literature has focused overwhelmingly on non-affective cognitive processes – notwithstanding an interesting recent fMRI study which found that the same neural networks were activated in participants when imagining painful situations occurring for themselves and for loved ones (poignantly entitled 'Love Hurts' - Cheng, Chen, Lin, Chou, & Decety, 2010).

1.4.2 Critical Notes on Closeness Research

The major difficulty with research in this field is not empirical but conceptual. Researchers on intimacy and closeness are generally well aware of the inherent difficulty in reaching a universally acceptable definition of the construct. A central problem is that a model will only be of utility in so far as the definition upon which it is based offers some precision, and yet it must also find validity in the ordinary, imprecise uses made of the terms (Prager, 1995). However, the issue is not only in imprecision. More profoundly, confusion remains as to the exact class or type of "thing" closeness, as a term, signifies. The conceptualisations given

encompass broad constellations of experiences, affective and cognitive processes, epistemic states, and behaviours. Clearly, a comprehensive understanding of the term must encompass each of these domains. Yet, each stands as a distinct form of object of inquiry, requiring a particular method of investigation and form of language to be adequately studied and described. A definition which seeks from the outset to be all-encompassing thus risks being of limited utility in illuminating the nature of the diverse classes of constructs which must be encompassed within.

The conceptual is also ethical. A significant critique of the prevailing definitions assigned to closeness is that they seem to favour stereotypically feminine aspects of relating. Wood and Inman (1993), reviewing the construction of the construct of intimacy in research from the 1960's, argue that the fairly robust finding that women, more than men, prioritized disclosive communication was conflated with a predetermined definition of intimacy in terms of such forms of communication. As such, women came to be seen on the whole as more expert on intimacy, and more traditionally masculine intersubjectivity came to be depreciated as "less intimate". While I do not wish here to endorse an essentialist view of gender and relationality, it is significant that studies specifically focused on men's perceptions of intimacy have provided alternative perspectives on 'closeness'. For example, Swain (1989) drew attention to what she called 'closeness in the doing' in the shared interests and activities that characterise many male friendships. Patrick and Beckenbach (2009), interviewing men regarding their views of intimacy, identified sharing, trust, genuineness and acceptance as central themes. It is also arguable that the very constructs of closeness and intimacy, as conceptualised in the research, are only intelligible within the specific cultures within which they are produced. The overriding emphasis on dyadic relationships within western culture have can, in fact, be argued to betray subtly a loneliness produced by contemporary individualism (Seepersad, Choi, & Shin, 2008).

1.4.3 Closeness and Autism

While it is not known how many people with autism enter into romantic relationships, it is clear from a number of sources (e.g. Aston, 2003; Henault,

2006; Hendrickx, 2008) that some do, posing the interesting question as to how closeness, universally agreed by researchers to represent a central dimension of romantic relationships, is established within these relationships, or what precisely might be the nature of obstacles encountered. However, there exists at present no research on the issue of closeness/intimacy and autism, so a consideration of the potential implications of intimacy research for relationships in which a partner has ASD must remain largely inferential, though reference may be made to empirical papers on related constructs, as well as to a number of popular publications on the issue of romantic relationships and autism.

The conditions for intimacy – understanding, validation, and care - outlined in Reis and Shaver's (1988) interpersonal process model may appear strikingly challenging for either partner to provide or receive in the presence of ASD within a relationship. If either the mindblindness or empathy deficit hypothesis is accepted as valid, it follows that an autistic individual may have extreme difficulty understanding the complex perspectives and emotions disclosed in intimate exchange, or, moreover, in responding affectively in the way expected within relationships. Equally, the autistic partner may be expected to have difficulty articulating his emotions in such a way as can be understood and validated by the other.

Research on a construct sharing significant overlap with autism offers some support for these hypotheses. "Alexithymia" is a term used in research to describe a putative condition in which individuals are chronically unable to understand, process, and communicate emotion (Sifneos, 1973), although it is not included in any widely used diagnostic manual. As well as finding common ground between the two constructs at a definitional level, Hill, Berthoz, and Frith (2004) found that 85% of a sample of autistic individuals (N=27) scored in the 'impaired' range on an alexithymia assessment inventory, suggesting that cautious inferences regarding autism may be made from research pertaining to alexithymia. Humphreys, Wood, and Parker (2009) found traits of alexithymia to be inversely correlated with the level of affection participants showed in their closest relationships, as well as the overall level of closeness achieved. In so far as autistic individuals show impairments in the understanding and

communication of emotion, this study supports the hypothesis that they may experience challenges in establishing closeness. This finding is also congruent with the importance attributed to emotional understanding by Reis and Shaver (1988) and Prager (1995; Prager and Roberts, 2004).

A second theme in the closeness literature which is of particular interest in relation to autism is the significance of *shared experience*. By this I mean the suggestion that an intimate partner is one who is able to not only demonstrate a declarative understanding of her partner's feelings, but is, moreover, driven to experience the world as if from the vantage point of her significant other, and to desire the same in reciprocation. Again, the supposed mentalising deficit in autism prospectively poses profound challenges. To what extent can an autistic individual not only *comprehend* her partner's thoughts and feelings, but also step into his shoes through construing the world in a meta-representational fashion? To what extent is she likely to 'be moved', in Hobson's (2006) phrase, towards this pursuit? The challenge is not restricted to the autistic partner, however. The neurotypical individual may struggle to understand the meaning of his autistic partner's behaviour in terms of her underlying experiences, particularly if she is neither able nor inclined to communicate these to him. Confronted with behaviour that may appear aloof or distant, he may construe his partner as uncaring or unresponsive to the world or even to him. Anecdotal evidence suggests that this inability to discern the world of the autistic individual may lead neurotypical partners to value the insight into their partner's behaviour they may feel is provided by the diagnosis. For example, Katrin Bentley's (2007) autobiographical account of her marriage to a man with Asperger's Syndrome details the retrospective understandings she reached of hitherto bewildering or hurtful communications from her partner through employing theories of ASD.

It might be even argued from an overview of the prevailing approaches to autism and closeness that the very possibility of closeness might be largely precluded by the conditions of autistic intersubjectivity. The recognition of private and deeply personal thoughts and feelings in the other; the drive to share and validate sensitive experiences: if these are the core conditions of closeness, then the very notion of closeness/intimacy may be unintelligible: "Intimacy can be a

vague concept for many individuals with AS,” writes Isabelle Henault (2006, p.90).

Indeed, there exists within the popular literature on romantic relationships and autism, largely written directly for the partners of autistic individuals, a prevailing sense that the establishment of closeness and intimacy will pose specific and profound challenges. Sarah Hendrickx (2008) writes of the frustration and resentment that may be caused for both partners by the normative expectation that the autistic partner will be readily able to understand her partner’s experiences, and suggests that for someone with ASD, emotional closeness may be experienced as intrusive and overwhelming. Louise Weston (2010) emphasises the need for the neurotypical individual to listen attentively to her Asperger’s partner, as otherwise she too may be prone to misunderstanding, and recommends that she actively seek out alternative avenues for meeting certain intimate needs, such as finding support groups in which to be understood and validated. The potential concerns raised by the effects of autism within a relationship appear to some authors as so significant that Maxine Aston has gone so far as to propose a new diagnostic label for severely afflicted neurotypical partners, ‘Cassandra Affect Deprivation Disorder’ (Aston, 2003).

1.4.4 Issues in Considering Closeness in the Context of Autism

The first issue to be noted when considering the implications of autism for the establishment of closeness within relationships is that, at present, there is a lack of an empirical basis for the evaluation of any hypotheses. While there exist a number of popular publications on romance and ASD that may be found useful by their target audiences, they largely reflect the individual experiences of the authors. Alternatively, where the perspectives of wider samples have been sought, recruitment and analysis have not utilised a formal methodology.

The second issue is that it is unclear what understanding of “closeness” is most useful and valid in this area. And yet, although there is a lack of a clear definition of the construct, “closeness” is generally given within the literature as the remit of the (invariably *female*) neurotypical partner. It is suggested numerous times that the ASD partner requires assistance not only to provide some measure of

intimacy for his partner, but even to recognise his own “need” for closeness. The essentialist split on which the popular literature is founded, and which it in turn reinforces, is such that the Asperger and neurotypical partners can become within the texts ‘different species’ (Weston, 2010). While at least one writer has recognised the multiplicity of meanings which might be assigned to closeness or intimacy (Henault, 2006), the language of intersubjectivity is generally made the property of the “neurotypical species”.

A need is thus present for an approach which examines “closeness” as a signifier with potentially diverse meanings within different individuals’ lived experiences. The terms of such an endeavour resonate with the need, described above, to comprehend autism in substantive terms, seeking out *presence* in autistic subjectivity and refraining from imposing normative understandings. This is not to deny suffering: autism as a label by definition denotes an interpersonal stance or positioning which may, indeed, pose significant challenges for the establishment of closeness. Nonetheless, the requirement is for an approach which seeks out substance in “autism” and “closeness” as terms widely employed, already sometimes directly juxtaposed, but not yet fully explored in all their signifiatory potential.

1.5 Autism, Intersubjectivity, and Phenomenology

1.5.1 Phenomenological Inquiry

Phenomenology is a mode of inquiry into experience, in which the elucidation of the core dimensions of phenomena *as phenomena* is pursued. While the vast range of ideas which fall under the banner of phenomenology mean that it cannot be reduced to a single method, at the core of the mode of inquiry is the suspension (*epoché* - Husserl, 1988) or “bracketing” of everyday assumptions regarding the reality of the experienced world, with the nature of experience itself made the object of inquiry. The originator of phenomenology proper, Edmund Husserl (1988), aimed through his investigations to reach an understanding of a transcendental subjectivity. Phenomenology as a movement was radically transformed by Heidegger’s (1996) profound argument that the phenomena must be understood in terms of a perceived world to which we relate in an engaged

fashion, and to which we assign meaning as worldly beings (the 'hermeneutic turn' – Hoy, 1993).

There is a history of fruitful dialogue between phenomenological inquiry and 'realist' science. Within philosophy, Merleau-Ponty (2002), for example, made use of accounts of the experiences of individuals with neurological damage to illuminate his study of 'typical' phenomenology by way of contrast (in a fashion similar to the use of autism research in developmental psychology). More recently, Ratcliffe (2006) has argued for dialogue between phenomenology and cognitive neuroscience, arguing that phenomenology can give meaning to scientific findings, while science can in turn indicate how the experience of different phenomena becomes possible. In more recent years, phenomenologically oriented methods have become more widely employed in psychological research (see Langdrige, 2007, for an overview).

1.5.2 Phenomenology and Autism: Conceptual Problems

An immediate objection may be posed to the proposal that phenomenology may offer insight into the experiences of those affected by autism. Several leading researchers and theorists of autism have made arguments that the condition involves either impairment in or an absence of self-consciousness. Gopnik (1993) argues that the development of a theory of mind is essential to understanding intentional states not only in others, but also in the self. While autistic individuals are, she argues, able to experience "simple sensations", to the extent that they have impaired "theory of mind", they are unable to possess proper intentional states. In support of this argument, she invokes the finding, detailed above, that autistic children are not only impaired in identifying false beliefs in others, but are also challenged by tasks requiring them to identify previously held but disproven false beliefs. She writes:

We first have psychological states, then we observe the behaviours and the experiences that they lead to in ourselves and others, then we construct a theory about the causes of those behaviours and experiences that postulate intentionality, and *only* then do we have an experience of the intentionality of those states. (Gopnik, 1993, p.12)

The implication of the argument would be that, if phenomenological inquiry involves an interrogation regarding phenomena as experienced intentionally, then autism precludes any meaningful phenomenological inquiry into the experience of autistic individuals.

However, it can be argued in response that a distinction must be made between the intentional *stance*, in which a complex understanding of the relationship between self and object as mediated by perceptual and mentalistic processes is reached, and an intentional *experience*, in which an object is perceived in relation to an observing self. Indeed, phenomenological analysis would suggest that the notion of a “non-intentional experience” is a contradiction in terms, for the perception of any object includes within it a self to which it is given, however unelaborated this ‘self’ may be (Sartre, 1956). Moreover, Gopnik’s approach poses unanswered questions about whether infants should also be judged as not self-aware, a suggestion Hobson’s (2002) portrayal of early intersubjectivity would appear to contradict (Zahavi & Parnas, 2003).

A similar argument to Gopnik’s (1993) is made by Frith and Happe (1999), who propose that autistic individuals are in possession of experiential mental states, but that they are unable to reflect upon them. From this, they make something of a logical leap as they proceed to suggest that autistic individuals are not self-conscious. The nature of the proposed qualitative difference involved in reflective self-awareness is never precisely explained by the authors, however. The crucial issue is, perhaps, to note that self-awareness, even of a declarative sort, needs to be distinguished from complex self-knowledge – to have an experience of what might be mentalistically termed a thought or a belief which one can report verbally does not require that one understands these experiences as thoughts or beliefs (Zahavi and Parnas, 2003).

1.5.3 Towards a Phenomenological Approach to Autistic (Inter)subjectivity

What value, then, might phenomenological inquiry hold for “autism research”?

I return first to the ideal of *autistic presence*, that substantive aspect of the autistic individual which has been excluded from most research. If the prevailing approach to autism has sought to construct the condition in terms of absence, a phenomenological approach to the experience of the autistic individual offers a framework within which presence cannot but emerge; phenomenology represents a call to understand the phenomenon of the Other as it *presents* itself for the autistic individual, and likewise to understand how she *is present for others*. This is not to say that what emerges is positive in valence; it is not to deny the phenomenal existence of challenges or suffering. Nor is it to deny that absence may present itself substantively as a phenomenon, or dimension thereof; as Sartre (1956) demonstrated, absences can be a salient dimension of phenomena.

Over recent years, a number of studies have used phenomenological methods fruitfully to explore the experiences of autistic individuals. Biklen (2005) has edited a compilation of phenomenologically-oriented autobiographical accounts of people diagnosed with autism. Huws and Jones (2008) carried out an interpretative phenomenological analysis using interviews with a group of diagnosed children to explore the experiences of diagnosis, disclosure, and 'having autism'. It is striking, however, that only two papers appear to have considered the phenomenology of the intersubjective encounter in the context of autism. Williams (2004) has analysed published autobiographical accounts of individuals with autism, from which she argues that the notion of 'theory of mind', in its connotations of abstracted theory-based engagement with the other, is in fact an apt description of the authors' engagement with others. Cashin (2004) explores existential aspects of parenting a child with autism. He argues that the experience involves fundamental changes in their subjectivity through the permeation of their children's difficulties into their parents' own selves. Moments of 'connection', of sharing an experience, are nonetheless manifest in parents' narratives.

Phenomenological accounts of intersubjectivity have also challenged the frameworks within which theories of social cognitive deficits in autism have been developed. Dan Zahavi (2005), a phenomenological philosopher, questions the

notion that the mind of the other exists as an inferred, 'theoretical' entity in the intersubjective encounter. He notes that a phenomenological investigation suggests that the mind of the other is encountered in all its affective significance directly in expressive phenomena: we see a face as friendly or angry, rather than the emotion being experienced as an inferred mental construct. The question is whether a 'theory of mind' adequately captures the lived experience of the face-to-face encounter. While the sort of automatic, pre-reflective processes postulated in models of theory of mind are still by this picture feasible, it is striking for Zahavi (2003; 2005) that infants normally show clear affective reactions towards others well before the development of complex understandings of mentalistic phenomena, suggesting that intersubjectivity should be understood first as an embodied emotional/perceptual 'skill', rather than the product of theoretical postulates. However, while Hobson (2002) and even, to a certain extent, Baron-Cohen (1997) acknowledge the importance of developmentally early intersubjectivity, Zahavi (2003; 2005) argues strongly that pre-'theoretical' intersubjectivity remains primary not only in chronological development, but, moreover, in all face-to-face human encounters.

An important implication of this is that the question of the experience of 'the Other' for autistic individuals becomes intelligible in a way that might be precluded within a framework which denies the very notion that an experience of the Other is possible in the absence of a theory of mind. Moreover, a phenomenological approach to intersubjectivity steps beyond an exploration of the dynamic effects of cognitive and behavioural differences to ask what precisely might define the experience of a relationship with an autistic individual.

A phenomenological approach may furthermore be of particular value in freeing 'closeness' in its status as a signifier from the conceptual problems besetting contemporary research. As noted above, research on 'closeness' (or 'intimacy') is beset with a conceptual problem in so far as the nature of the object of research has not been clearly defined. A phenomenological approach would conceptualise 'closeness' strictly as a signifier denoting an aspect, or perhaps several aspects, of an individual's lived experience, and, from these conditions, allow the various experiential dimensions of intimacy to emerge in a 'bottom-up'

fashion from an investigation of qualitative data – circumventing the need to advance a hypothetical, researcher-defined model requiring post-hoc validation. Moreover, an approach which seeks out the hermeneutic position of ‘closeness’ for individuals *vis a vis* their lived experiences offers an opportunity to evade the procrustean process of setting forth researcher-defined constructs according to which levels of closeness may be universally measured and individuals and couples ranked. Rather, the potential exists for the signifier to perform multiple significations, varying according to the broader phenomenological dimensions of an individual’s lived experience.

1.6 Aims and Research Questions for the Present Study

The aims for the present study are:

1. To explore the experiences and understandings of closeness for people with a diagnosis of Autism Spectrum Disorder in long-term romantic relationships, as well as of non-diagnosed partners in relationships with them.
2. To work towards an understanding of the experience of autistic individuals and those close to them constituted in substantive terms.
3. To consider the potential implications of the findings for understandings of romantic relationships in the context of autism; for conceptualisations of the constructs of autism and closeness; for clinical practice with individuals from the populations included in the study; and for future research on this and related topics.

The research questions for the present study are:

1. In what ways is closeness understood and experienced by either partner in romantic relationships in which one has been given a diagnosis of an Autism Spectrum Disorder?
2. In what ways is the experience of closeness facilitated or hindered for either partner?
3. In what ways, if any, is autism experienced as a phenomenal object affecting closeness within the relationship?

2. Methodology

In this chapter, the procedures employed in the recruitment of participants, obtainment of data, and analysis are outlined, and a rationale for each given. In line with the hermeneutic orientation of the present study, the chapter closes with a consideration of reflexive issues pertinent to the analysis.

2.1 Design

As the research question concerned the nature of an experience – ‘closeness’ – as well as the significance of the phenomenon for individuals in a specific context – romantic relationships in which one partner has a diagnosis of an Autistic Spectrum Disorder (ASD) – the study required a hermeneutic phenomenological approach. Thus, Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) was selected as the most appropriate method. Data was collected through semi-structured interviews with individuals in long-term romantic relationships whose partners had been given formal diagnoses of ASD, or who had been diagnosed themselves. The analysis focused on the meanings ‘closeness’ held for individuals. The data was analysed collectively, without grouping individuals according to the presence or absence of a diagnosis.

2.2 Ethics

Full ethical approval was obtained from the University of East London School of Psychology Ethics Committee prior to commencing with recruitment. An image of the application for ethical approval signed by the Chair of the Committee is given in Appendix A.

2.3 Participants

2.3.1 Sampling

For the present study, individuals both with and without a diagnosis of ASD were recruited as participants. This use of a “mixed” sample is unconventional within IPA research, in which homogenous samples are usually sought (Smith *et al.*, 2009). However, as romantic relationships are by definition intersubjective, the study sought to include the experiences of individuals on ‘both sides’ of the diagnosis. Furthermore, the present research sought to illuminate the core dimensions of specific phenomena, and phenomenological research with this

objective can benefit from using diverse samples, as emergent thematic commonalities can differentiate essential from incidental aspects of the phenomenon (Langdrige, 2007).

It was planned that eight to ten participants would be recruited for the study, with at least four participants with a diagnosis and four without. The use of a small sample reflects the idiographic orientation of IPA, in which a thorough disclosure of participants' experiences is sought, allowing a degree of exploration and acknowledgement of diversity that is often excluded by the demands of nomothetic, large-scale studies (Smith *et al.*, 2009).

The inclusion criteria were as follows:

1. *Either the participants or their partners should have received a formal diagnosis of an Autism Spectrum Disorder (including Autism and Asperger's Syndrome) from a mental health professional.*
2. *One partner in the relationship should not have received a diagnosis of ASD. This was to ensure that the relationships included in the study would be comparable.*
3. *The diagnosis should have occurred at least one year before participation in the study. This requirement was included both for ethical and hermeneutic reasons. The receipt of a diagnosis for one's self or one's partner can hold profound significance, and so it was felt that ample time should be left before inviting affected individuals to participate in an interview in which related emotive material would be discussed. Furthermore, a diagnosis of ASD may lead both partners to re-evaluate previous understandings of themselves, their partners, and their relationships. Data gathered from individuals in the wake of diagnosis would, therefore, be of questionable comparability to data gathered from individuals who have had a greater length of time to adjust to the diagnosis.*
4. *Participants should have been in a romantic relationship with their partner for at least one year prior to taking part in the study. This criterion was necessary to allow the assumption that sufficient time had passed for the*

participants to have acquired an understanding of how they experience closeness in relation to their partners.

The time specifications in criteria three and four are, admittedly, somewhat arbitrary. However, due to the dearth of prior research in this area, there is a lack of evidence to suggest alternative criteria. Moreover, it was anticipated at the outset that recruitment might be challenging, and so a minimally restrictive set of inclusion criteria was required.

There were two exclusion criteria. First, for ethical reasons, it was required that participants would not be considering leaving their relationship at the time of the study, in order that participation should not, as far as possible, be to the detriment of participants' relationships, nor of their own or their partners' well-being. Second, participants were not included when either or both partners had a diagnosis of learning disability. While more research into romantic relationships for people with learning disabilities is very much needed, the inclusion of this additional diagnostic construct risked creating a degree of complexity in the data requiring an analysis beyond the scope of the present project.

2.3.2 Recruitment

The recruitment of participants proved arduous. It was initially planned that all interviews would be conducted face-to-face. The first stage of recruitment involved performing internet searches to identify networks within commuting distance from London either including or supporting individuals with the diagnosis or their partners. These included internet forums, support agencies, research groups, and counselling services; in total, information about the project was sent via e-mail and post to over thirty groups (an example is given in Appendix B). With the administrators' permission, information about the project was also posted on several internet forums specifically designed for people with the diagnosis and their families.

This first stage of recruitment gained the participation of two individuals over three months (from June to September, 2011). Following this disappointing

outcome, both the recruitment and interview procedures were amended, with permission from the Chair of the Ethics Board at UEL (see Appendices C and D). The data collection procedure was broadened to include the possibility of telephone and electronic interviews, allowing the participation of individuals living some distance from London. Updated recruitment information was sent to several groups who had expressed interest in the research, and existing posts on internet forums were updated. The recruitment process was also expanded to allow information about the research to be distributed directly to individuals eligible for participation who had placed information about themselves in the public domain (e.g. through weblogs). Finally, the National Autistic Society kindly agreed to include information about the research in their members' magazine. Following these changes, a further six participants were recruited by January 2012.

2.4 Data Collection

2.4.1 Materials

Four interviews were conducted face-to-face, for which a digital audio recorder was utilised. Three interviews were conducted telephonically, two with diagnosed participants and one with an undiagnosed partner. For these interviews, I spoke with participants via Skype™ on a personal laptop using a USB headset; the interviews were recorded using 'MP3 Skype Recorder', a free software package available online. Finally, one participant was interviewed at her request over the internet using MSN Messenger. For all interviews, I used a copy of the interview schedule (given in Appendix E), as well as a notepad. All electronically recorded data was stored on a password-protected laptop; the data were also transcribed on this laptop, with the recordings played back using the 'Express Scribe' software package (also available online).

2.4.2 Interview Schedule

The interviews conducted for the study were semi-structured, as is standard within IPA (Smith *et al.*, 2009). The central aim of the interview was to address two questions. First, what is the meaning of 'closeness' for this participant? Second, in what ways does he/she experience 'closeness' in the context of his/her present relationship? The interview schedule developed was, therefore,

used as a tool for setting a framework within which these questions could be explored, and, as such, was intended to be used flexibly, with the elicited narrative and reflections, rather than the schedule, driving the interview, in so far as the aforementioned questions continued to be addressed.

Nonetheless, the schedule formed an important guide for the interview. The opening question and prompts concerned the background to the participant's relationship (including its duration and development, marital and living arrangements) as well as the diagnosis (when and how it was obtained, and its significance for either partner). While these 'scene setting' (Smith *et al.*, 2009, p. 61) questions were not directly related to the research questions, such contextual information can be hermeneutically invaluable, and, as they are relatively easy for participants to answer, can facilitate the development of rapport. Subsequent items aimed to explore directly the participant's experience of closeness, funnelling down from the general ("What does 'closeness' mean to you?") to the specific ("Can you describe an experience in which you have felt close to your partner?"). These items made up the bulk of the interview. As "closeness" is by definition an intersubjective process, an item was also included querying the participant's understanding of his or her partner's experiences of closeness. While the diagnosis of ASD was queried in the initial item, no questions or prompts were planned for the main body of the interview regarding the diagnosis, unless it emerged as a significant experiential theme within the participants' narratives. Only in the last item was the participant queried on how, if at all, he or she experienced the impact of ASD on closeness in their relationship. The interview schedule was, as far as possible, not guided by any preconceptions as to the meaning of "closeness", nor by a priori hypotheses regarding the nature of participants' experiences.

The schedule was discussed with my research supervisor, which led to minor amendments in the wording of items. While it would have been ideal to have piloted the interview with individuals meeting the inclusion criteria, due to the difficulties encountered in recruitment, this was not possible.

As the first contact made with each participant was via the internet, arrangements for the interviews were made through e-mail, and participants were invited to ask any questions they might have prior to the interview. Copies of the research information sheet and consent form (given in Appendices F and G, respectively) were e-mailed to participants ahead of the interviews, and participants were asked to confirm that they met the inclusion criteria. Signed consent sheets were obtained prior to commencing with the interview.

2.4.3 Interview Procedure

At the start of each interview, time was spent explaining the format and purpose of the interview. Participants were reminded that they would be free to pause or stop the interview at any point, without giving a reason. Participants were again invited to ask any questions they might have, prior to commencing with the interview.

The progression of the interviews followed the schedule in moving from general to specific experiences. During the discussion of the “scene setting” interview items, a comfortable interview pace and rhythm was sought; as the interview unfolded, in most instances fewer and more open prompts were used. As the research questions concerned the significance of experiences ‘as lived’, participants were encouraged through prompting to remain focused on their own experiences rather than abstract understandings (van Manen, 1990). Following Smith et al.’s (2009) guidelines for interviewing, participants were encouraged to pursue narratives or reflections, assisted, when appropriate, by prompts and probes, until these reached what seemed a natural conclusion. When a potentially significant topic emerged which could not be immediately pursued, I made a note of it and returned to it later in the interview.

The participant’s contribution to the dialogue already represents an interpretation of the phenomenon being investigated, developed through the medium of the interview conversation – as van Manen (1990) argues, the interview is a process of “interpretation through conversation” (p.97) and interviewees are, in fact, “co-investigators” (p.98). The interviewer must, therefore, act cautiously to selectively elicit further and more in-depth reflection by the interviewee while

refraining from introducing themes that may not naturally emerge from the interviewee's interpretations. Hence, I took it as my task when probing for further details to be minimally guiding, making an effort to restrict prompts to simple, open requests for more details on what experiences were 'like' (Roulston, 2010). Although it was not possible to maintain this line at all times, the use of more directive questions regarding, for example, participants' 'thoughts' or 'feelings', risked disrupting participants' interpretative reflections, in which 'thoughts' and 'feelings', in their typical meanings, might not feature as prominent thematic dimensions. Alternatively, probes were frequently given regarding specific key terms emerging within the participants' accounts, seeking further elucidation as to their significance. Following Smith *et al.* (2009), I avoided making interpretations, reflections, or connections in response to interviewee's accounts.

After the interview was finished, time was allocated to de-briefing. This involved asking participants about their experience of the interview (including determining whether any distress had been caused) and sharing further information about the project, including, if participants were curious, the reasons for my personal interest in the topic. Most participants indicated that they had found the interview challenging but interesting, and all indicated an interest in receiving a copy of the completed thesis. Follow-up contact was made with one participant who appeared to find the interview emotionally difficult. On follow-up, the participant stated that she did not feel that her response to the interview had been 'an issue', and that she felt that continuing reflection on the interview was providing her with some personal understandings of her experiences.

2.5 Data Analysis

2.5.1 Rationale for Interpretative Phenomenological Analysis

The present research focused on an exploration of participants' experiences, and, thus, necessitated a phenomenological approach. The researcher's ontological position is influenced by Heidegger's (1996) hermeneutic approach, according to which the objects of experience are always already constituted as interpreted. Moreover, following Gadamer (cited in Moran, 2000), the interpretation of discourse always implicates and requires assumptions held by the researcher – research involves a 'double hermeneutic' (Smith & Osborn,

2003). An openly reflexive hermeneutic phenomenological method was, therefore, necessitated.

Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate method. As a phenomenological approach, IPA focuses on the disclosure of the central dimensions of participants' experiences of specific phenomena through thorough thematic analysis of interview transcripts (Smith *et al.*, 2009). As a hermeneutic method, IPA conceptualises research as a process of contextualised interpretation, rather than a pursuit of 'objective' knowledge. Findings implicate the researcher as well as the data itself, and so IPA requires a reflexive account of the research process.

Certain aspects of the present study are, nonetheless, unconventional within IPA research. First, as noted above, the sample included individuals both with and without an ASD diagnosis, and the data has been analysed collectively as a single body. This contrasts with the convention within IPA of using maximally homogenous samples, in accordance with the method's focus on meaning as always contextual (Smith *et al.*, 2009). Second, no assumptions were possible about the definition of the phenomenon under investigation, "closeness". While IPA involves the bracketing of assumptions regarding the specific meanings of experiences for participants, the vast majority of IPA research has been carried out on phenomena for which some definition can be assumed, such as physical pain (Osborn & Smith, 1998), relationship endings (Larkin, Watts, & Clifton, 2006), or sexual experiences (e.g. Lavie & Willig, 2005). The research has, therefore, necessitated an interrogation of the very phenomenological essence of "closeness" for the participants.

As suggested above, the use of a mixed sample is particularly valid where the research question concerns the very nature of an experience, as commonalities across different participants' accounts come to differentiate the essential from the incidental. Equally, the use of a diverse sample may help to illuminate essential *differences* between the experiences of different groups; in the terms of the present project, the possibility is left open that the term 'closeness' may emerge as signifying different phenomena across an eclectic body of individuals. Such

an approach is not without precedent within IPA. Larkin and Griffiths' (2004) investigation of "risk" using IPA involved a mixed sample of bungee jumpers and ecstasy users, highlighting both commonalities across all individuals, as well as differences emerging between and within groups. Smith *et al.* (2009) also argue that research using two different groups of participants may lend weight to the analysis of a phenomenon through triangulation.

It had been originally planned that the data would be analysed as two separate sets, with a secondary analysis of commonality and difference between the groups. However, prioritising the interpretation of each participant's data as part of an "autistic" or "neurotypical" set risked obscuring common threads uniting participants between these groups, as well as diminishing diversity within groups. Furthermore, the analysis of data from individuals with an ASD diagnosis alongside data from non-diagnosed individuals is in line with the commitment of this research to disclose *presence* within the experiences of people labelled as autistic. To analyse a narrative as already in some sense "autistic" would be to participate in discursive practices which, I have argued in the Introduction, risk negating the subjectivity of the individuals diagnosed – and would, furthermore, not be properly phenomenological. Conversely, a collective analysis can allow individual narratives to speak in their own right, and for thematic links and distinctions to emerge fully in a "bottom up" fashion. The open nature of the analysis, in which the identification of both commonality and difference was pursued, also accommodated the recruitment of a non-homogenous sample.

One unexpected aspect of the final sample was its gender makeup: all but one of the final sample were women. Given the significance of gender issues in the current understandings of autism, this called for a supplementary analysis, included at the end of the next chapter.

The analysis was also influenced by the existential phenomenology of Heidegger (1996) and Sartre (1956). Van Manen (1990) argues that the exploration of data in terms of existential dimensions of experience, including intersubjectivity, embodiment, and temporality, is a powerful means of revealing the core essence of phenomena, as well as identifying essential differences between phenomena.

For example, a recent unpublished doctoral thesis exploring the experience of “spirituality” for dying individuals used an existentially-informed phenomenological methodology to identify two distinct modes of being within which “spirituality” held essentially different meanings (Taylor, 2009). Similarly, within the present research, a uniform understanding of “closeness” could not be assumed for all participants, and so an existentially informed approach was utilised to add depth to the analysis. While existential thought is not integral to IPA, it is at its core phenomenological, and the employment of robust theoretical frameworks in the analysis is in accord with the “interpretative” aims of IPA, which seeks not only to “give voice” to experience but, moreover, to “make sense” of it (Larkin et al, 2006).

As will hopefully have become clear in the Introduction, the nature of language formed a central consideration in the development of the research. The research question concerned the essence of “closeness” as a signifier. A central focus on language is perhaps more often associated with qualitative methods other than IPA. Foucauldian Discourse Analysis as a method is highly concerned with the linguistic discourses from which qualitative data emerges or is constructed (Willig, 2008). Conversation Analysis represents another method involving an intensive exploration of linguistic practice between individuals (Sidnell, 2010). However, the concerns regarding language that drove the development of the research were primarily phenomenological: the concern was to understand what participants’ language reveals about their *lived experience*. An epistemological assumption is held that participants’ language was eminently revelatory of lived experience. The critical orientation towards language was thus intended to enhance, rather than problematise, the phenomenological analysis. It is nonetheless the case that the exploration of language poses questions concerning its social origins and relation to power and discursive practice, and some consideration to these issues is given in the Discussion.

2.5.2 Analytic Procedure

The transcripts were printed out with wide margins, read and re-read, with my own observations, reflections and queries being noted in a research diary (see next section). IPA is an iterative process, in which interpretation of individual

elements of the text influences and is influenced by the interpretation of the whole of the text – a process common to all understanding that has been called the “hermeneutic circle” (Smith *et al.*, 2009). Therefore, it was only when I felt confident that I could bear the whole of a transcript in mind that I began an intensive, line-by-line reading, making exploratory comments and noting emergent themes in the margins. Using a colour-coded system, I also noted remarks on the potential impact of the interview process on the data, points at which I was struck by a clear resonance or dissonance between a section of the transcript and another participant’s transcript, potential superordinate thematic interpretations, and existential dimensions of the texts. My understanding of what constituted a “theme” was guided by van Manen’s (1990) description of themes as “the experience of focus, of meaning, of point... the form of capturing the phenomenon one tries to understand.” (p. 87)

Upon finishing the annotation of an individual transcript, I moved directly to the following case, sequentially in accordance with the order in which I had interviewed the participants. Each transcript was read as far as possible in its own terms, and I sought to find labels for themes that were in accord with the terms of each individual case. While Smith *et al.* (2009) suggest collating and organising emergent themes before proceeding to subsequent transcripts, I felt in my own case that this could lead me towards prematurely formulating hypotheses regarding common thematic structures and reading subsequent texts in a confirmatory fashion.

After all transcripts had been read, I worked individually through each transcript in the reverse sequence to the order in which they had been annotated, compiling a list for each transcript of emergent themes and noting each point at which they were manifest within the transcript. As I found myself thinking about the themes spatially, for each participant, I printed out the lists of themes and cut out each theme label, placing these on a floorspace and arranging them according to apparent connections. The juxtapositions reached included subsumption and merging of themes within dominant categories, the establishment of groups of distinct but related themes, and the polarization of dichotomous themes. Thus, thematic “maps” were formed reflecting the

relationships between themes; I took digital photographs of these before typing up the organised lists of themes for each participant.

When analysis was completed for all transcripts, the theme lists were reviewed alongside each other, laid out collectively on a large space, along with the separate body of notes made during the analysis. In comparing themes across transcripts, I sought first to identify dominant and “master” themes disclosing phenomenological dimensions common to all cases. However, I also was led by the data to identify themes common to some but not all participants which, although not generalised, were nonetheless essential to the understanding of the experiences of these sub-groups of participants. In this latter process of identifying thematic distinctions, an understanding of the existential dimensions of differing themes proved highly useful. The final set of themes was then juxtaposed in a table (given on page 42, below) outlining their respective relationships.

2.5.3 Research Journal

A journal was kept throughout the research process. The entries document much of the process through which my reflections and thoughts regarding the data and the research process were worked out. Notes were also made prior to and following interviews both to document and expand on my own reflections on the data, as well as to facilitate reflections on how my interviewing style may have affected the data, and to consider ways in which my approach could be improved upon. A sample from the diary is given in Appendix H, below.

2.6 Validation

2.6.1 Data Quality Check

As interviews were conducted in several formats, the resulting data were compared during the analysis. The number and depth of the emergent themes was comparable for data derived from telephone, face-to-face, and online interviews.

2.6.2 Participant Feedback

The issue of participant validation within phenomenological research is complicated. Phenomenology assumes the primordial first-person givenness of experience (Zahavi, 2005), and phenomenological research relies upon introspection mediated through language. As such, an argument can be given that the researcher should establish a dialogue with participants regarding the interpretation of their accounts, in order to establish the validity of the findings; van Manen (1990), in particular, advocates a dialogical approach in phenomenological research. However, participant validation is not widely used in IPA. As argued by Langdrige (2007), the pursuit of participant feedback on analysis is problematic even within a phenomenological framework. Most significantly, Langdrige (2007) argues that, due to the nature of phenomenological analysis and writing, it is possible that participants may not recognise the interpretation as being reflective of their lived experience. However, this does not necessarily indicate error on the part of the researcher. Equally, it may reflect that interpretative phenomenology seeks to disclose a level of meaning apart from that which is explicitly present in participants' original accounts. Due to these concerns, as well as the limited scope and time availability for the project, participant feedback was not sought for the analysis.

However, as detailed in section 2.4.3, the collection of participants' accounts was seen as a dialogical process, and the validity of the original accounts was a prominent concern. All participants were therefore invited to be in contact with any further comments or queries following the interview. Only one participant, who had been interviewed by MSN Messenger, sent further comments a month after the interview via e-mail. As the participant indicated that she felt the comments were necessary to provide a complete account, these were included in the analysis of the data from her interview.

Furthermore, all participants were offered copies of their interview transcripts, which five accepted; comments were invited on the transcripts. Two participants provided minor corrective comments on transcript errors; these did not affect the analysis.

2.6.3 Independent Audit

Smith *et al.* (2009) argue that the research process must be transparent to demonstrate validity. Accordingly, the findings of the analysis were reviewed with my research supervisor to verify that a coherent argument was being developed that constituted a valid interpretation of the data. For the examiners' review, Appendices I to L give an extract from an annotated transcript, compiled list of instances of emergent themes, a fragment of the physical thematic map, and final thematic analysis for one participant, to demonstrate the way in which the analysis was performed. Analytic material of the data from first participant, "Emma", was chosen, as the analysis both began and concluded with her data. All annotated transcripts, theme lists and maps are available to the examiner upon request.

2.7 Reflexivity

2.7.1 IPA as a Reflexive Method

As a hermeneutic method, IPA is inherently reflexive, in so far as the process of interpretation relies upon the researcher's own understandings pertaining to the object of inquiry (Biggerstaff & Thompson, 2008). The double-hermeneutic cannot and should not be regarded only with suspicion as an obstacle to "objectivity", as it forms the very vehicle of communicative disclosure of the phenomenon. However, interpretation is also a process of "conversation" in which the researcher must continue to pose questions regarding the data and his understanding of it. In turn, the process of discovery through research may be transformative for the researcher (van Manen, 1990). I therefore felt that an explication of my own pre-conceptions regarding certain central phenomena prior to the analysis was necessary to monitor for overly biased readings of the texts. In this section, therefore, I will give a personal account of my preconceptions of "closeness" and "autism" as held at the start of this study; I will return to these in the final chapter to consider their relationship to the findings.

2.7.2 Reflexive Notes on "Closeness"

I suspect that the vast majority of individuals – with notable exceptions - would consider closeness to a loved other to be vital to a happy, fulfilled life, but that the precise meaning of closeness might vary considerably across individuals. A

personal fascination with close dyadic relationships (parental, romantic, and friendly) has deeply influenced my approach to psychology; indeed, it played a determining role in my decision to pursue clinical psychology as a career path. I am, as such, highly invested in the meanings I assign to “closeness”. My assumption at the start of the study was that, essentially, a close relationship is constituted through the experience of the other having an intimate sense of the quality of one’s own being – that the other has a sense of “what it is like to be you” – and, naturally, that this is reciprocal. This meaning is carried over into my understanding and evaluation of closeness in my own personal relationships.

2.7.3 Reflexive Notes on “Autism”

That I have a longstanding interest in autism will be unsurprising in light of the fact that I have a younger brother who has been diagnosed with ASD. I have not, to my knowledge, often consciously used theories of autism to understand him, and, moreover, his own development has been remarkable in that, as an adult, he no longer meets the diagnostic criteria. Nonetheless, it has become a topic of great personal interest to me. While I am not a great advocate of psychiatric discourse, autism has often struck me as a construct with considerable power to illuminate experiences affecting diagnosed persons which they may have difficulty articulating in the absence of a diagnosis. I believe firmly that autism should be understood as an issue of difference, rather than purely of disability. I have often found the “mindblindness” hypothesis (Baron-Cohen, 1997) a useful tool for understanding autistic individuals. Accordingly, I anticipated initially that autism would pose profound challenges for the establishment of closeness (in the highly mentalistic meaning to which I had assigned it). I remained open to the possibility that “closeness” might hold essentially different meanings for autistic individuals relative to those not diagnosed.

However, in the process of developing the project, my consideration of the dominant discourses surrounding autism called into question many of these assumptions, as will hopefully have become apparent in the previous chapter. This led me to adopt a position of greater curiosity, and a wish to avoid prematurely foreclosing my understandings of the experiences of people

diagnosed autistic by allowing assumptions regarding the differences signified by autism to run ahead of my interpretation.

3. Findings

This chapter opens with an overview of the participants' relationship and demographic backgrounds, and a brief summary of the dominant themes emerging from the analysis. Detailed explication of the dominant and subordinate themes is then given, with illustrative extracts from the data and explicatory commentary.

3.1 Introduction to the Participants

Emma

Emma is a white British woman, aged 49, who has been in a relationship with her partner, Michael, for 22 years, although they have been separated at points during this period. They live together with their two children. Michael was diagnosed with Asperger Syndrome in 2009. Emma was interviewed in person.

Anthony

Anthony is a white British man, aged 69. He married his wife, Lina, who is from East Asia, twenty years ago, and they share a home in her country. They have no children together, but Lina has a family from a previous marriage. Anthony was diagnosed with Asperger Syndrome in 2009. Anthony was interviewed in person.

Margot

Margot is a 59 year old white British woman who has been in a relationship with her partner, Adrian, for 13 years; they have lived together for the past 12 years. Neither have any children. Adrian was diagnosed with Asperger Syndrome in 2003. Margot was interviewed over the telephone.

Stephanie

Stephanie is a Jewish-Scottish woman, aged 34, who has been in a relationship with her partner, Kevin, for just under three years. They live separately but see each other at regular times during the week. Stephanie received a diagnosis of Asperger Syndrome in 2008, a few months prior to starting her relationship. Stephanie was interviewed over the telephone.

Sarah

Sarah is a white English woman, aged 31, who has been in a relationship with her partner, John, for 12 years, and has lived with him throughout their relationship. Her partner has two adult sons, one of whom lives with them. Sarah was diagnosed with Asperger Syndrome in 2010. Sarah was interviewed over MSN Messenger.

Gemma

Gemma is a 26 year old white British woman who has been in a relationship with her partner, Karen, for three years; they have lived together since 2010. Gemma was diagnosed with Asperger Syndrome at the age of 21. Gemma was interviewed over the telephone.

Caroline

Caroline is a 38 year old white British woman who has been in a relationship with her husband, Will, for nine years. They have a six year old son together. Will also has two sons from a previous marriage, who live some distance from Caroline and Will. Will was diagnosed with Asperger Syndrome in 2006. Caroline was interviewed in person.

Jane

Jane is a 53 year old white English woman who has been with her partner, Stephen, for twenty years. They live together, but neither partner has children. Stephen was diagnosed with Asperger Syndrome in 2011. Jane was interviewed in person.

Table 1, overleaf, gives a summary of the demographic information for each participant.

Name	Age / Age Group	Ethnicity	Diagnosis
Emma	49	White British	None.
Anthony	69	White British	Asperger Syndrome
Margot	59	White British	None.
Stephanie	34	Jewish-Scottish	Asperger Syndrome
Sarah	31	White English	Asperger Syndrome
Gemma	26	White British	Asperger Syndrome
Caroline	38	White/Caucasian British	None.
Jane	53	White British	None.

Table 1. Participant demographics.

3.2 Presentation of Transcript Material

The data was transcribed according to the guidelines suggested by Banister *et al.* (1994), with some additions. IPA is a method concerned chiefly with the semantic content of data (Smith *et al.*, 2009), and so detailed information regarding the duration of pauses, intonation, and stutters has not been included in the transcription. In order to present interviewees' comments accessibly, brief validating interjections by myself (e.g. "mhm", "yeah", "okay", etc.) have been omitted in the excerpts given. However, pauses during interviewee's speech, clear emphases placed on particular words, and repetitions of words have been preserved, where significant for the interpretation. Bracketed full stops and ellipses signify brief and extended pauses, respectively. Un-bracketed and square bracketed ellipses indicate where, respectively, a brief or substantial section of the quotation has been omitted as not directly relevant to the thematic analysis in which it has been included.

3.3 Overview of Findings

The analysis uncovered three "master" themes: "closeness as authenticity" (Theme I), "discovering the partner" (Theme II), and "autism and difference" (Theme III). These themes pervaded the data set, and were central to the interpretation of all participants' experiences. The themes are explored below in order of their hermeneutic priority, as the interpretation of each latter theme requires an understanding of previous themes. Each master theme gave rise, in turn, to sub-themes, vital to the interpretation of groups of participants' data, but not necessarily present for all interviewees. It was at the level of these sub-

themes that some distinctions emerged between the diagnosed and undiagnosed participants. An overview of the full thematic findings is given in Table 2, overleaf.

Master Themes	Subordinate Themes
I. Closeness as authenticity	I.a Validation of the self
	I.b Sharing experience
II. Discovering the partner	II.a Discovery and diagnosis
	II.b Action as revelation
	II.c Exclusivity
III. Autism and difference	III.a Autism, adjustment and authenticity
	III.b Autism facilitating closeness

Table 2. Overview of master and subordinate interpreted themes.

3.4 Analysis

3.4.1 Theme I: Closeness as Authenticity

The central dimension of closeness, common to all participants, is the experience of being able to express freely one's needs and desires within the context of the relationship; closeness represents essentially an *authentic* mode of being.² The participant's experience of her partner gives rise to the possibility for the self's deepest needs to be expressed freely and with security in the understanding that these will be understood and responded to in an attuned manner by the other.

The expression of the self consists in part in a sharing of knowledge, but an

² Although my interpretative approach has, as noted, been influenced by existential theory, the meaning of the term "authenticity" here is quite distinct from its use in Heidegger (1996).

active dimension of closeness is also revealed - the authentic self is expressed through activity:

Jane: We can assert our needs, opinions, preferences, et cetera, and the other person will hear them...I can live more freely, more authentically...

Anthony: I think closeness involves...doing what you feel you want to, rather than what you feel you should do.

In describing this authenticity, each participant contrasted closeness directly with forms of self-consciousness and self-adjustment characterising other, less close relationships. Closeness thus provides a release from the constraints of ordinary relating. The reliance on the use of contrasts shown by each participant appears not to be solely descriptive in purpose, but rather reveals that an essential element of the experience of closeness is its *difference* from other modes of intersubjectivity. Already within the quotation given above from Jane, we see the use of comparative language as integral to her description of closeness. Stephanie's account of closeness resonates in its portrayal of closeness as a respite providing a "little bit of normality":

Stephanie: ...it's something that I've aspired to have...just this little bit of normality where...I don't have to think about it in a conscious way...so that things happen in a certain way. I just want it to happen naturally.

The breadth and lack of exact detail in the comments that have been given is demonstrative of how closeness is not, at core, constituted in specific acts, but as a mode of being. Ordinary relationality emerges as a state of effort in which the self must be controlled and adjusted in line with external demands; closeness, by way of contrast, is characterised by a lack of self-adjustment, wherein what is expressed is in harmony with one's own constitution, or, in Stephanie's terms, "nature". While the detailed accounts given of specific experiences of closeness varies markedly between participants, the understanding of closeness as a state of authenticity thus reveals this diversity to be nothing less than a reflection of the individuality of each participant.

Relationality is, within all participants' accounts, intimately tied to a self-concept – identity is experienced with what is expressed within a relationship, such that the self-adjustment within ordinary, distant relationships constitutes the playing of a role of someone else. Anthony, for example, spoke of his efforts to make himself acceptable to others as “*wearing the mask*.” By contrast, within closeness, the open expression of “inner” experiences and needs gives rise to an experience of “being” one’s “true self”³ within the context of the relationship. In Gemma’s account, we again see closeness as a state in congruence with one’s “nature”:

Gemma: When I say “being yourself”, nobody – it’s a very private thing, nobody else gets to see that...that’s how I get to be my real self, with her – that’s me in my purest form...That’s a natural thing that goes with loving somebody.

Again, for all participants, closeness, as authenticity and freedom, is a state of potential for activity. The self is expressed in so far as the self’s way of acting within the context of the relationship is felt to be in accord with one’s needs and desires. The self is not, however, static, but subject to change and open, potentially, to discovery and growth. Security in the acceptance of the self by the partner gives rise to freedom to explore new modes of being; where these come to be experienced as in line with the self’s developing constitution, and are expressed before the partner as witness, the experience of authenticity is also one of personal growth:

Margot: The closeness [is] really the understanding...of who we are, and we shouldn’t... change that, and falsify that... We allow each other to be poles apart. And that’s never happened to me before, so I’ve been able to develop more as a person - be able to go and do different things, and come back and tell him about them.

³ I should stress that “true self” is meant here in a phenomenological sense; it is the individual’s experience of authenticity that is being indicated. No statement is made here regarding “true self” as a psychological construct.

The quotation again reveals the essentialist dimension of closeness – each partner has a certain mode of being which *is* who he or she is; the self cannot be “changed” without being falsified. Yet, through novel action witnessed by the other, the self can be transformed.

The self is, then, for both the diagnosed and the undiagnosed participants, intrinsically intersubjective, existing for and through the other. However, in more detailed considerations of the ways in which the experience of the other gives rise to authentic being, subtle distinctions emerge between participants with and without a diagnosis.

3.4.1.1 - Theme 1.a: Validation of the Self

Within the accounts of participants with a diagnosis of ASD, a central aspect of closeness is the *validation* of the self. Although, as already noted, an experience of acceptance by the other is a universal condition of closeness, within the accounts of the diagnosed participants, priority is given to evaluative aspects of closeness. The experience of the self being fully revealed and, in turn, positively valued and desired by the other, allows an experience of the self as valuable and valid:

Stephanie: It makes me feel...more valid that there is somebody who actually cares enough about me to give up their weekend every weekend.

In the revelation of the authentic self before a partner, the self is made profoundly vulnerable to the other’s response. The way in which a partner responds to the self becomes experienced as an authoritative evaluation of the self. Closeness, thus, involves an objectification of the self – in the revelation of one’s authentic being, the participants identify with the self as observed and responded to by the other. As illustrated by Stephanie’s quotation, validation often centres upon the other responding to the self with *desire*. For Anthony, central to the significance of a failure to maintain closeness with his wife is her lack of desire for his “presence”, which, in turn, constitutes a categorical statement upon himself as “a disappointment”:

Anthony: I think most people want to feel wanted...that the other partner appreciates their presence... and that they're pleasing the other partner... a general feeling that (.) your presence is doing some good for the partner... And I feel selfish... It's a failure to please the other partner... I am a disappointment...

The revelation of the self to the other is entwined with complex preconceptions about the nature and acceptability of the self. Each of the diagnosed participants describes a history of rejection by others which has, at times, led them to question the acceptability of their selves to others. Accordingly, the validation provided in closeness may represent a *reconciliation* to the self. Gemma describes the significance to her of an occasion on which Karen invited her brother and his partner along on a holiday, a situation which potentially left her vulnerable and exposed to their reactions to her atypical behaviour. The confidence shown in her by Karen represents a transformative statement on the value of the self:

Gemma: It made me feel...that I wasn't a bad person. That I wasn't a malicious person and that they realised that any behaviour that I presented wasn't out of malice or out of me being a bad person, it was just part of my condition.

Gemma's account resonates with a description given by Stephanie of a struggle with periodic "meltdowns" in which she loses a sense of control over her actions and vents her anger verbally in ways of which she is later ashamed. She is astonished to find that her partner remains with her even in the immediate aftermath, conflicting with expectations connected with her conception of herself:

Stephanie: I'm flabbergasted! ...I'm just completely taken aback that he's still there... It makes me happy...that he's still accepting me...that I am accepted...I'm not a bad person... He still wants to be with me...

In either account, the partner's response is seen as an objective statement on the self; a judgment is made about what the self "is" (or "is not"). Moreover, the other's gaze gives rise to a *transformation* of the self – she is "*not* a bad person".

Conversely, closeness poses the risk that the other's reaction will be overly congruent with distressing concepts of the self. Sarah's partner John regularly provides her with practical help, due to difficulties she can have in daily living. While she describes not ordinarily reflecting upon the significance of being cared for, an awareness of having an impact on John can elicit a painful experience of her self-concept. Again, the experience of the self is of the self before the other:

Sarah: I take it for granted sometimes, but I notice when he gets stressed... when I do think about it after, I feel bad, guilty...and then I feel flawed I guess, it's demeaning...

In the accounts of the undiagnosed participants, the theme of validation is more latent or absent, and evaluative descriptions of the self are marginal. This is not to suggest that the experience of being known and desired by a partner is not significant for these participants, but rather suggests that, for them, it may be less central specifically to the experience of closeness within the relationship.

3.4.1.2 Theme 1.b: Sharing Experience

Within the accounts of the undiagnosed participants, a more central dimension of closeness is the sharing of experience. A sense is given of the self and partner experiencing an event *in the same way*. For these participants, such sharing constitutes a core personal need, essential to living in the fully authentic manner required of closeness. Furthermore, an intimate sharing of experience can allow either individual in the relationship to respond to his partner in an attuned manner, not only emotionally, but also in practical ways which make it more possible for the partner to exist freely and authentically.

Emma gives as an example of a time when she had felt close to Michael an occasion on which both had succumbed to laughter as they searched in vain for

their vehicle in a car park. Her language captures the sense of identical intentionality:

Emma: ...by the third time it was just hysterically funny that we were...thinking the car was going to be there, and it wasn't there. And, the both of us laughed, laughed, and laughed ourselves up. In fact, I think I was just rolling on the floor by the end...Um, and he was laughing, too... I think it was that...I experienced it as us both sharing the same thing. We both found it as hysterically funny...

The emphasis on laughter provides a revelation not only of shared cognition, but also of *affect* – the situation has the same effect over both partners. A focus on laughter also resonates with the theme of closeness as a release from the necessity for control – Emma is incapacitated in a safe and enjoyable way.

Other accounts of sharing retain the sense of the focal experience being given primarily to one partner, but known intimately, in turn, by the other – the essence here is of selves knowing and being known to each other through the sharing of experience, rather than the partners' phenomenal worlds being identical. Such a process of exchange can be asymmetrical, and participants' accounts vary in the extent to which priority is given to the self's understanding of the partner versus the partner's understanding of the self. Caroline's description of the significance of focused conversations on philosophical topics of deep significance and interest primarily to her partner suggests a predominant focus on the experience of the other, but also a utilisation of his "special interest" as a gateway to reciprocal exchange:

Caroline: Well, for me, it's understanding just what's going on in his mind...it's about respecting each other's intelligence and boundaries, and understanding what's going on with each other.

The sharing of experience is not only about comprehension, but is also tied to responsive action – the partner who shares in the other's experiences *responds* in a congruent fashion. This can involve verbal acknowledgement and validation

of a partner's experience. However, equally significantly, a partner may take steps to make adjustments for the partner in accord with her needs. The resulting experience is one of deep attunement – not only the partner, but the environment is felt to resonate with one's needs, and relief is experienced from the need to adjust the self in line with the environment. Jane describes Stephen's deep understanding of her experiences in terms that suggest an experience not only of his subjective attunement, but, moreover, of an environment provided by the partner in which she is freed from ordinary constraints:

Jane: A specific example of closeness would be shared laughter about something... a shared reaction to an injustice that we'd either experienced, either individually, or together...the mirroring is almost non-verbal...I wouldn't ever have to say to Stephen, "Can we sit quietly now?", or "Can we have a chat now?" It happens... There's a harmony there – that's another word for "closeness", I suppose.

The attunement of either partner to the other's experience, and the responsiveness demonstrated, is, within closeness, understood to be authentically in accord with his or her nature. This pertains equally when the participant describes the sharing of experience within her relationship to be asymmetrically focused on her partner. Margot described her deep awareness of and attendance to Adrian's needs as reflective of her own inherited nature, and, thus, as an authentic mode of being:

Margot: It's almost choreographed, but there is a radar between us... It's not quite pipe and slippers, you know, when he comes home, but I think, "Today it's been very hot, Adrian feels the heat terribly – I'll have the cool, cool air flowing through the house." [...]

Interviewer: What is it about those experiences that...allows you to feel close to him?

Margot: Because...it's supportive. I suppose, coming from a family of servants, as I have...I've always had this thing about doing things for others.

3.4.2 – Theme II: Discovering the Partner

The experience of the other's intentionality towards the self – as witnessing, understanding, and accepting; as desiring or sharing in experience – is central to the ability to freely express the “authentic” self. How, then, does this knowledge of a partner develop? Each of the participants illustrates ways in which their understanding of their partners emerges over time, and almost all acknowledge that their understanding of the other can still be doubted or errant; for some participants, a full understanding of the other continually eludes them. In order to be known, then, the partner must be discovered.

The way in which knowledge of the other emerges varies between participants, and, at times, within individual accounts. Verbal disclosure plays a central role for all participants – and, yet, more frequently emerges as a means for participants making themselves known to their partners than vice versa. Partners' own words often appear secondary to their actions as a means of self-revelation. Words and speech can even exist in tension. For Stephanie and Kevin, the meanings of words are less important than the way in which they are given, and both are ultimately secondary to the demonstration of affection through the simple act of being present:

Stephanie: He's never said "I love you" first... So, when I'm feeling insecure, I'll say "Well, you never say 'I love you'... I don't think you care about me that much." But he says, "Well, the fact that I'm here shows that I do." ...I think that we both have that similarity, that, "The fact that I'm still here, shows that I care!"

All participants give statements indicating an awareness that what is experienced as “knowledge” of the other constitutes an *interpretation* influenced by the self, in particular by emotions, prior experience, and, indeed, choice. Emma speaks reflectively of her evolving understanding of Michael over the course of their relationship. She comes to the understanding, over time, that the ways in which

she experienced Michael early in the relationship as sharing in affective experience was reflective of her own pronounced feelings of love. Moreover, what she comes to learn about him changes her understanding of the significance of his earlier emotional displays:

Emma: So, at the initial stages of our relationship, I'm being in love and doing all those heightened emotional things, Michael will be responding back with them, and...when that decreased...those emotions weren't coming from Michael any more. Because, possibly...they'd just been reflected back... I can see... that, when he's in the company of other people... (.) he takes on their emotions.

For all participants, then, knowledge of the other's intentionality is an integral dimension of closeness, and yet emerges as a potentially fallible interpretation. The individual is required to "make sense" of some aspect of what is seen in the other, in order to experience closeness. In the modalities through which the other is revealed and interpreted, differences emerge between the diagnosed and undiagnosed participants, as demonstrated in the first two subordinate themes.

3.4.2.1 Theme II.a: Discovery and Diagnosis

The diagnosis of ASD represents for all participants a transformation in the understanding of the person to whom it is applied, whether it is the participant herself or her partner. The diagnosis emerges as revelatory of a significant dimension of the individual's nature. However, the significance of the revelation proves different for those to whom it had been applied than for undiagnosed partners. For the participants with a diagnosis, the predominant theme is of explanation and validation, and less emphasis is given on the significance of the diagnosis within the context of the relationship. For undiagnosed participants, however, the central significance of diagnosis is as a means for interpreting the intentionality of the person to whom it pertains. The exact nature of the difference disclosed through diagnosis will be explored in the discussion of Theme III. What I aim to outline here is the way in which diagnosis serves as a means of revelation.

The undiagnosed participants give accounts of, in the development of their relationships, finding aspects of their partners' behaviour frustrating and difficult to interpret. Moreover, each of these participants makes statements to the effect that some of their partners' behaviour could be interpreted, according to the typical way in which others are understood generally, as uncaring. Diagnosis, in this context, signifies that a different framework is needed for making sense of their partners, and the associated theory and "expert" knowledge serves as a means for re-interpreting what their partners' behaviour reveals about their intentionality. Intriguingly, the hermeneutic significance of diagnosis is analogous to a "theory of mind" – it plays a role specifically in the understanding and interpretation of the other's *actions*. For Emma, diagnosis thus provides an interpretative structure – a "language" – within which the significance of a partner's behaviour, which she did not previously possess a means of comprehending, can be understood anew:

Emma: I think, (.) it just provides a (.) language? It provides some way of understanding a person who's behaving in a way that's out of my experience of the world...when we had the language of Asperger Syndrome, and how people with Asperger Syndrome behaved, we could then put his behaviour in that context, rather than it be the behaviour of somebody who didn't give a damn.

For Jane, who actively sought out a diagnostic assessment for her partner, diagnosis had great significance for its implications as to whether her partner, in demonstrating what appeared at times to be a callous lack of concern, was behaving as he did by choice:

Jane: ...a realisation that, I have felt quite isolated in some ways... For a while, I thought he was being a bloody minded male, or he was trying to control, or being difficult...I realised, it's something more than that, it's about lack of capacity.

While, as already noted, the diagnosed participants spoke of the diagnosis having its primary significance outside the context of the relationship, a congruent

theme emerges in that the diagnosis can constitute a means for communicating to the partner the intentionality underlying their own “autistic” behaviour:

Sarah: I think he thinks it explains why I act differently to people, how I can get lost in something I'm doing and [abandon] everything else, he always used to get very frustrated that I had trouble with food and he's a fair bit more understanding now...and things I do like my OU stuff, he helps me with the phone calls and organisation of things, he understands why I constantly lose track of day and date of the month, and why I get angry at things being hard.

The revelation of the other’s intentionality can, for some participants, facilitate the sharing of experience so central to the undiagnosed participants’ understanding of closeness. Each of the undiagnosed participants indicated an awareness that their partners experienced people and environments in different terms to themselves. The shift towards interpretation of the partner’s behaviour through an understanding of ASD thus discloses previously concealed aspects of their experience. Typical examples include an awareness of a partner’s difficulty interpreting others’ behaviour, and heightened sensitivity to stimuli. Diagnosis may thus constitute a gateway into sharing the other’s experience of the world through revealing qualitative differences in the way in which either partner understands their surroundings. For Margot, this awareness allowed her to gain a greater sense of being part of Adrian’s “world”:

Margot: So, it took me a long time to think, “Oh! There are other environmental factors that get in the way of what he wants to do, which are seriously affecting him, which are real, which are huge, which I don’t even see or notice because I don’t have the same sensory things that he does.” ...It’s nice to, sort of, be part of his world...

As noted in theme I.b, the ability to share in a partner’s experience facilitates an actively attuned orientation towards the other. Caroline’s account illustrates how the illumination of a partner’s intentionality through diagnosis can provide a framework for orienting the self in relation to him:

Caroline: I realised that...I'd been getting really angry with him for being awful in supermarket – because the lights and the noise and everything! And he'd start shouting things out involuntarily. Rather than getting angry...[I] could just get Tesco's to deliver, or...if I could sense that he was gonna go into one of his [makes explosion sound]...to either try and calm him down, or prepare for it...It was almost like I could go and look for a tool-kit to be able to deal with it.

In this quotation, and elsewhere, we also see a reference to the relevant literature on ASD as the window shedding light upon the partner's intentionality, and, in Caroline's case, constituting a "tool-kit" for guiding attunement to the other.

3.4.2.2 Theme II.b: Action as Revelation

If, for the undiagnosed participants, the behaviour of their partners can be difficult to interpret, for the diagnosed, the other becomes manifestly known through his actions. While verbal self-disclosure does feature as significant in some of these participants' accounts, narratives of specific events and periods in which the participants experience closeness to their partners centre on actions by the other through which a manifest acceptance and positive regard for the self is demonstrated. Anthony describes a brief relationship outside of his marriage in which mutual action for the pleasure of either partner formed the basis of closeness and validation:

Anthony: Everything seemed very good because we were both (.) working towards trying to please the other...during the initial stages, we had, we had our common ideas to please each other, and we were pretty close, at that stage...I felt that there was a future...

The partner's actions are experienced as demonstrating the partner's investment in the self, through efforts to please or provide care, making sacrifices, or taking risks for the sake of the participant. For Stephanie, it was a small, unexpected gift from her partner during a routine shopping trip that first allowed her to feel close to him, through the care and desire it demonstrated:

Stephanie: The fact that he'd done this to make me smile was just, you know, I actually try not to cry thinking about it. It was just really (.) lovely...I felt really close to him at that point...I just thought it was really considerate and generous and kind, and that he cared enough about me to want to make me happy...That's why it meant so much, because, during my whole life, I've been with men who have just taken everything.

In this quotation and elsewhere, we also see how the significance of a partner's actions emerges in part through a manifest *difference* to earlier experiences. Each of the diagnosed participants recounts a history of interpersonal difficulties, such as mistreatment by romantic partners, difficult relationships with family members, and a perceived requirement to hide or conceal aspects of the self. Closeness thus represents a new way of experiencing a partner. The revelation of this difference emerges in the participants' accounts through specific events in which their partners *act* in ways which break with expectations developed through previous relationships. Gemma describes being moved by her partner's attendance at a talk she gave at the National Autistic Society:

Gemma: ...she sat in the front row, and then straight after she told me that she felt like she was going to cry when I'd done my talk... That's something that my parents have never said, and never done... That made me feel really close to her.

The differing modalities through which a partner comes to be understood among the participants in part reflects the different forms of the other's intentionality involved in distinct meanings of closeness. For those participants for whom closeness centres upon the sharing of experience, a necessity exists to gain a sense of the phenomenal world of the other. Where the validation of the self is a more primary concern, the other's intentionality is understood foremost in terms of positive regard, concern, and desire – elements of intentionality intimately connected with *action*.

The finding that the diagnosed participants experienced their partners as fully revealed in their actions, while the undiagnosed participants make use of formal knowledge frameworks to interpret the other, appears at first glance paradoxical. However, the accounts given suggest implicitly that, for the diagnosed participants, the actions of their present partners can be understood through the same framework used to interpret the actions of others in general. The difference manifest in the actions of the other from earlier experiences reveals straightforwardly a different, more positive intentionality towards the self than previously encountered. In contrast, the problem for the undiagnosed participants leading to the need for a formal framework of knowledge to interpret their partners is that their autistic partners' actions appear to require a *different* framework for interpretation than that used for others in general.

3.4.2.3 Theme II.c – Exclusivity

The revelation of the other allows the experience of an exclusive relationship, in which the self is privy to knowledge not shared beyond the couple. Seven of the participants gave indications that this exclusivity formed an integral element of closeness; while Anthony emerges as an exception, this likely reflects the focus within his account on the difficulty of achieving closeness, with limited experiences through which to explore achieved exclusivity. The sharing of vulnerable or potentially shameful information which is secure only within the trusted bounds of the relationship is a prominent aspect of this theme. However, the exclusive sharing of knowledge, understandings, and even resources, constitutes in and of itself a foundation of closeness, beyond the specific emotional valence of what is shared.

A central dimension of exclusivity is the privileging of the self – the participant, in sharing something exclusively with the partner, holds a special and privileged position before the other. Caroline describes the significance of her partner Will allowing her to share his possessions – something he is loath to do with others:

Caroline: I know that when he allows me to...share something... I find that quite, really, because he's allowed me to do something that he probably

wouldn't allow any other human being to do... so, that makes me feel quite – quite privileged! [laughs lightly]

Exclusivity can also constitute a validation of the self, following on from themes of the autistic participants' experiences discussed earlier. Such emerges in Gemma's comments on the meaning of sex between Karen and herself. A mutual, exclusive gaze, encompassing the whole of both partners, allows a transformation and validation of self and other. Interestingly, what is shared is not only understanding, but rather a whole identity, known only to Gemma:

Gemma: During sex, it's a time when you both let your barriers down. And she's a person that...that person is...someone who I only, really, get to see...nobody else gets to experience that... So, that makes me feel really close to her as well. It all comes back to being valued, and being special, and I must be important to her, if she feels that comfortable to let her guard down.

Humour emerges as a particularly significant form of exclusive sharing. The significance is not simply that partners are able to enjoy laughter with their partners, but that they are able to do so in an exclusive way – through laughing together at things that other individuals would not:

Margot: You'll feel like you've got a little club member, don't you, if you laugh at something? You've got that, that person understands me, they're on the same wavelength.

Gemma: ...ways that we bond together...the inside jokes that we have with each other, about the dog – things that other people wouldn't find funny...

Amidst subtle distinctions in these remarks, a common dimension emerges of laughter as a mark of exclusivity. Margot's remarks are particularly illustrative of the importance of shared humour, as earlier in the interview she stated directly that she and Adrian "*could never be on the same wavelength.*" Humour is thus

revealed as a disclosure of shared, affectively charged intentionality. Interestingly, this dimension is not explicitly commented on by Gemma.

3.4.3 – Theme III: Autism and Difference

All participants understand ASD as a diagnosis signifying lifelong behavioural, cognitive, and emotional traits of the individual to whom it is applied. The accounts given of the significance of the diagnosis focus on the recognition of the limits of change that can be expected. ASD as a diagnosis thus signifies *essential* differences between the partners in these “mixed” relationships. An array of responses are shown to diagnosis, ranging from an embracing of the explanation and potential validation it can provide, to accounts that resemble narratives of mourning. For all participants, the various traits which lead to the diagnosis hold implications for the prospects of establishing closeness within the relationship.

For the ASD participants, the central significance of the traits associated with autism is the potential unacceptability of the self to others. These individuals spoke of difficulties in finding social acceptance, due to showing behavioural differences such as obsessional routines or high degrees of anxiety, difficulty finding others with similar interests, and also due to vulnerability to being misled and manipulated by others for their own gain. The responses of others to these differences thus represent an obstacle to the achievement of authentic being in which all aspects of the self are expressed and revealed to a partner. Interestingly, while remarks are made by these participants regarding difficulties in social comprehension and communication, these do not emerge as the central interpersonal challenges. Rather, the narratives reveal a theme of the *concealment* of the self before the powerful gaze of others. For Anthony, the requirement is to play the role of someone else:

Anthony: In many ways, it's been more of a pretence than a real doing what I wanted...I've experienced it more recently since diagnosis, and I've met other Aspies and talked to them about the way they put on a mask, they don't be themselves. They have to say what they think the other person would like to hear. I can see that I've done that myself...I am forced to talk

about trivial things. I haven't been relaxed doing what I would (.) [sigh] want to do...I think wearing the mask is a bit wearing, it's a wearing activity, that you can only maintain for so long.

A “mask” is not only “worn”, but also *wearing*, a demanding effort that cannot be infinitely sustained, and which is incompatible with the free expression of the self. Equally, however, articulating what is desired also appears effortful and painful; recognition of that which Anthony is *wanting* is itself a recognition of his ordinary mode of relating as one of *lack*.

For the undiagnosed participants, diagnosis creates an awareness that their partners' essential make-up means that they will be unable to meet some aspects of their essential needs. Most particularly, the participants find that their partners are less able to share, or share in, their experiences, including understanding and empathising with the undiagnosed partner's emotional experiences. Jane described her relationship with Stephen as one ordinarily of deep harmony, and, yet, prone to sudden disturbing lapses in Stephen's attunement:

Jane: ...when the ten per cent gets wrong, wrong, it's very wrong, and I think a lot of that is to do with (.) his (.) neuro-biological status. [...] When it doesn't happen, it's almost shock, surprise, horror. “What's going on here?...My soulmate doesn't see it the same way!” [...] It's almost like being tipped out of bed, when you're tucked up, asleep, warm and cosy, and somebody tips you out of bed – it's quite a shock...

The interruption of shared experience is experienced as a casting out from a state of assumed harmony and rest. Significantly, within the moment of conflict, Stephen is not constituted as “a man with Asperger's”, but as her “soulmate” - and so, with the implication that Stephen, as Jane's soulmate, should “see it the same way”, the experience is an *awakening* to difference.

3.4.3.1 – Theme III.a: Autism, Adjustment and Authenticity

For either partner, the differences highlighted by diagnosis thus present a challenge for the achievement of authenticity. For the diagnosed, aspects of the

self which have led to social difficulties are felt to be innate and unalterable, and for the undiagnosed, diagnosis signifies that limits will always exist in the ability of their partners to share experience. A need for adjustment to the conditions of the relationship is thus experienced – yet, this is at odds with authenticity as a core condition of closeness. A complex, at times dialectical, relationship emerges between the demands for adjustment and authenticity.

Undiagnosed participants describe an awareness of the necessity for adjustment within their relationships due to the limits of their partners' being. However the undiagnosed partners also feel a need for experiences to be shared by an attuned partner, and to abandon this need would be to live inauthentically. A double-bind can thus present in which the context of closeness creates a longing for authentic expression of the self and sharing of experience, yet present alongside this is an awareness of the limitations of the partner. A primary experience is, accordingly, frustration. For Jane, the awareness of Stephen's limitations provided by the diagnosis creates an uncomfortable demand for adjustment. The double-bind leaves questionable even the legitimacy of her feelings of frustration:

Jane: I suppose...I'm quite a self-aware person, it does help me deal with it. But other days, I don't want all that knowledge, I just want to be (.) my feelings. [...] It's almost like, it's almost like a conceited, it's – I think, "Gosh, it's me that's got to do the compensating behaviour."

For the diagnosed participants, a central concern is the limited possibility of change; a challenge is present in the need to authentically express their needs, including those reflecting traits associated with the diagnosis, in the presence of doubts about the acceptability of these to the other. To conceal the self is both an unsustainable effort and incompatible with closeness. Anthony's differences from his wife have ultimately led to them living separate lives, due to an inability to sustain pretence of feelings he did not possess. In contrast, the three female participants each speak of the need to *account* for themselves to their partners, to proactively make known their whole selves to them, in order that the self be observed, understood, and accepted as it is, including seemingly unalterable

traits. Verbal explanation of the self, informed by information about the diagnosis, can play an essential role. For Gemma, communication protects both her partner and, implicitly, herself from “surprises”:

Gemma: I thought that I owe her to be honest...and explain to her what my life is like and the difficulties that I have. So that, when we moved in together, and...made a commitment to be together, that nothing was a surprise. So, literally anything and everything, which I think can get quite tiresome for her, is talked about.

For the diagnosed participants, then, a pressure can be experienced towards self-adjustment that, as self-concealment, is incompatible with closeness. However, the tension between adjustment and authenticity is not, for all participants, irresolvable. For some undiagnosed participants, compensatory behaviours towards the other could constitute a non-ideal, but, ultimately, functional route towards eliciting attunement within a partner – authenticity can be deferred, but not abandoned. Caroline, for example, finds that proactively making her needs explicitly known to Will, while an effort, ultimately allows her needs to be met:

Caroline: If I have to go through the trouble of explaining everything that I need...it is really frustrating. But then, I know that I'll get my emotional feedback, then, sometimes you just have to grit your teeth and force yourself to do it...I think when it works is when we're both thinking, considering what we need to do. When it doesn't work is when we're just mindlessly falling through it, and not really thinking about what we need to do...this relationship takes a lot more effort than any other relationship that I've had...but I really want to make it work.

What is revealed as most fundamental to the establishment of closeness here is not an immediate harmony between the authentic self and other, but the *potential* for this to exist. Effort and “thinking” are portrayed here not as natural components of closeness, but, nonetheless, as a means to achieving potential, driven through a basic *desire* to achieve closeness to a partner.

In a more fundamental way, for some participants, both diagnosed and undiagnosed, aspects of the adjustments required by their relationships disclose new ways of being and relating which come to be experienced, in time, as integral to the self. The tension between adjustment and authenticity becomes a creative dialectic: adjustment *gives rise to* new forms of authenticity. For Stephanie, the challenge to manage her responses to Kevin's failure to "adhere to routine" represents a process of personal growth; her self is not concealed, but, within limits, transformed:

Stephanie: There are a lot of times where he doesn't adhere to my routine, or he doesn't adhere to things that I need to be in a certain way because of how I, I know that I react, but, I guess, in a way, that that's him just teaching me to be a little bit more patient, and a little more adaptable as time goes on.

For Margot, the very meaning of "closeness" has changed through her evolving experience of the relationship. An expectation of natural resonance in experience has been surpassed by an embrace of partnership and the discovery of the value of difference:

Margot: It's different with an Asperger's than with a neurotypical...it's not the same closeness at all. There's a huge difference...I can never, ever be on the same wavelength as Adrian...but we've got a sort of equality, respectful thing going on. [...] I felt like I was always having to adjust myself...or having to adapt, and I didn't know why... It's fine for me to go off and do something else...It's quite a revelation actually... We're a jigsaw puzzle which can detach, and do detach quite a lot...

Separateness is constitutional to this mode of closeness; the integrity of self and other allows individual exploration. A transcendent mode of closeness characterised by a pre-reflective sharing in experience is surpassed by the disclosure through difference of the self and other as essentially separate, yet also equal in validity and mutually reliant.

3.4.3.2 – Theme III.b: Autism Facilitating Closeness

Despite each participant illustrating ways in which ASD posed challenges for closeness within their relationships, an emergent theme within the experiences of most participants is of aspects of autism, within certain contexts, actively facilitating closeness. The specific ways in which this possibility emerges varies substantially between the participants, but a common experience is of a harmony between the traits associated with the diagnosis and the respective needs of both partners, such that ASD is understood as an aid to the development of closeness within the relationship.

Several of the participants describe autism not only in terms of difficulties, but also in terms of areas of relative strength – commenting, for example, on their own or their partners’ abilities in memory or logic. These strengths are, for a subset of participants, resonant with the needs of both partners and so directly facilitate experiences of closeness. For example, Gemma describes how her “Asperger’s logic” in problem solving allowed her to respond to Karen when she was struggling emotionally with work and family difficulties, allowing both for her partner’s needs to be met, as well as for Gemma to gain a sense of self-validation:

Gemma: The reason that I like to comfort Karen is because I know it makes her feel better, but it gives me a purpose as well...like I've got value...She was starting to become fixated, and worrying a lot about people around her passing away...So, I was able to sit down with her and go through the cognitive-behavioural therapy that I had before, and bring some of my Asperger's logic into it...That made me feel really good about myself, and really confident that she wasn't going to have to go through that...distress.

The tendency of individuals diagnosed with ASD to develop “special interests” and routines also provide, for some participants, a way in which to live harmoniously together. Stephanie’s clear routines, around which her interactions with Kevin are planned, provides a clear structure within which to share a life:

Interviewer: Can you tell me about specific ways in which you experience closeness with Kevin?

Stephanie: ...there's things, like we have – well, he knows that I have my routine, and he fits himself into that routine...I expect him to be here by six o'clock on a Saturday night, and he always is...We've developed a mutual routine...He's become more part of my life.

The dialectic of adjustment and authenticity emerges in that the routine is experienced as now part of both partners' way of life – what was in some sense originally Stephanie's own inner need has become something both she and Kevin have mutually developed and share in.

Interpreting these accounts at a dyadic level, recalling the distinct dimensions of closeness identified in the accounts of diagnosed and undiagnosed participants, the possibility emerges that the interactions recounted may have congruent but distinct significances for either partner. In Stephanie and Gemma's quotations, we see accounts of the ability to freely express aspects of the self and gain self-validation; yet, it is also possible to hypothesise that, for their partners, these interactions constitute a means of sharing experience. In line with this hypothesis, Caroline provides an analogous account of engaging in deep philosophical conversations with her partner, Will. While the topic of discussion is given as a "special interest" for Will, for Caroline, the conversations also allow an opportunity for a deep sharing in experience:

Caroline: Will's very interested in...philosophical stuff...So, when we have very deep conversations about that, and really think, and really think, and really focus on what we're talking about, really focus on each other, then that's quite intimate, that's quite close.

It is not only autistic traits that allow ASD to be experienced as facilitating closeness. The sharing of the life challenges endured by the individuals diagnosed can also give rise to a sense of bonding and partnership. The quotation from Gemma given earlier in this section gives a hint of this experience

– her own struggles, which led her to receive CBT, have in turn allowed her to empathise with Karen and share her experience. Sarah also gives an emotive account of bonding through shared struggle. Her account is distinct amongst the experiences of the diagnosed participants in the priority given to shared understandings of emotional experience; yet, the focus is on the sharing of struggle – both Sarah and her partner have endured significant life challenges associated with medical or psychiatric difficulties. Despite a profound discomfort with her diagnosis and a desire to overcome the difficulties associated with autism, the life challenges she had endured, alongside her partner’s own difficulties with illness and alcohol use, ultimately draw them closer together:

Sarah: It adds closeness because all the elements we’ve shared have emotions to them...sort of moves things to a level where you are tied together – and then there’s the life we’ve shared, and all the bad things we’ve got over, makes me feel like we can get through anything. [...] The closeness and security and trust are worth so much, because otherwise, all this misery would be for nothing...it’s the sticking together when its bad that is more important than being able to ride out the good times.

3.5 Remarks on Diagnosed Female Participants’ Accounts

The unexpected gender balance among the participants provides an opportunity for some concluding remarks on the accounts of the three female participants with a diagnosis of ASD.

The thematic analysis given in this chapter discloses the core facets of the phenomenological significance of closeness equally for these participants and for the male diagnosed participant Anthony. Closeness to their partners emerges as a mode of active, authentic being in which the true self is revealed before a partner, who responds through actions which demonstrate acceptance of and desire for the self, giving rise to an experience of validation. None of the participants spoke directly about the personal significance of being a woman with an ASD diagnosis.

What emerges as distinctive for the three female participants is the concern voiced in their accounts about their acceptability to their partners due to their awareness of differences associated with the diagnosis, such as unusual ways of relating socially, meltdowns, and repetitive behaviours. The women's accounts gave considerable focus to how these differences were viewed by others, rather than their meaning in terms of the women's intentionality; others' responses to the differences appeared to take priority over the participants' own understanding. While Anthony spoke of his experiences "wearing a mask" to make himself acceptable to others, for him this was due to a discrepancy between his own interests and neurotypicals'; the difference is thus experienced as rooted in his own intentionality and agency, rather than in seemingly uncontrollable atypical behaviours. Furthermore, each diagnosed female participants articulated an understanding of herself as inscrutable to others; the behaviours that made them different were seen not to be readily understood by others. A common experience for each of these participants was, accordingly, shame. In this context, the experience of reconciliation to self, described in Theme I.a, becomes central to the meaning of closeness. In these women's accounts, a sense emerged of their experiences closeness to their current partners defying expectations developed through prior painful experiences; a surprising and transformative dimension to the experience was revealed.

Finally, it should be noted that the understanding of closeness as an experience of either partner being privy to exclusive knowledge about the other (Theme II.c) was clearly evident in the accounts of each of the diagnosed women, but was absent in Anthony's account.

4. Discussion

Within this chapter, an overview is given of the relationship between the findings of the analysis and the research questions. Consideration is given to the implications of the findings for theory and practice, and to future directions for research. The chapter ends with a discussion of the validity and limitations of the study, reflexive notes on the role of the analyst, and a consideration of the challenge posed by poststructural theory to the claims of the research.

4.1 Relation of the Findings to the Research Questions

Question One: In what ways is closeness understood and experienced by either partner in romantic relationships in which one has been given a diagnosis of an Autism Spectrum Disorder?

The central dimension of closeness, for all participants within the present study, was the experience of authenticity before a partner: closeness is manifest in so far as the individual feels able to freely express and make known their needs and desires with the knowledge that these will be understood, accepted, and responded to by a partner in an attuned fashion. An experience is given rise to of the individual “being” his “true self” within the context of the relationship. Closeness is a state of potential activity: the self is expressed through *action*, and the demand to act in a way discordant with one’s needs is experienced as a distortion of self. Closeness thus represents a release from the self-consciousness and self-adjustment required in ordinary modes of intersubjectivity.

Distinctions emerged between participants with and without a diagnosis in what was required for authentic relating. For the participants with a diagnosis, closeness represented primarily a *validation* of the self. The individual is able to act in accord with their own needs and desires before another who witnesses, understands, and continues to desire the self. The partner’s positive intentionality is revealed through actions demonstrating an investment in and desire for the self. These participants had all experienced significant social and romantic difficulties, and thus this validation could also give rise to a positive transformation of the self-concept. Within the accounts of participants without a

diagnosis, the theme of validation was latent or absent. Rather, authenticity within closeness involved the expression of a need to share experience – to understand an experience as being given identically to the self and partner, or for one partner within the dyad to have a deep insight into the experience of the other. The sharing of experience is deeply tied to a partner's responsive action, which frees the self and/or partner from the need to make adjustments and enables either to live more authentically.

Question Two: In what ways is the experience closeness facilitated or hindered for either partner?

Question Three: In what ways, if any, is autism experienced as a phenomenal object affecting closeness within the relationship?

It was necessary to distinguish between these two questions in planning the research, as the project involved an inquiry into the experience of closeness, beyond its specific relationship to autism. However, as the analysis shows the participants' understandings of ASD to be closely interwoven with experiences of closeness, these research questions will be considered here together.

A central condition for closeness as authenticity is an experience of mutual understanding between self and other: that the self is known, understood, and accepted by the partner. Moreover, the other must be experienced as known in a mode appropriate to the participant's understanding of closeness. For diagnosed participants, narratives of experiences of closeness centred upon partners' actions which demonstrated an understanding and desire for the revealed self; these frequently were characterised by explicit contrast with negative expectations of others developed through previous aversive social experiences. In undiagnosed participants' accounts, closeness was facilitated through finding ways of sharing experience; this could involve a sense of natural congruence between the self and other's experience of the world, using communication and knowledge of the diagnosis to gain insight into their partners' experiential world, or finding a common experiential focus in line with a partner's "special interest".

A key challenge to establishing closeness emergent in the accounts of undiagnosed participants was in partners not sharing, or sharing in, experience; this included, but extended beyond, a perceived lack of empathy. Within the context of the interview, participants often gave an understanding of these difficulties in terms of the diagnosis; autism was understood as imposing limitations on their partners' ability to share in experience. However, within the narratives given of the immediate experience of partners not empathising or sharing in experience, the partners' behaviour was in the first instance understood in terms of subjectivity and choice. A sense was often betrayed that the diagnosed partner was in some sense *choosing* not to share in experience or provide a desired level of intimacy. Frustration was, accordingly, a common element of the narratives.

For the diagnosed participants, the central challenge to establishing closeness was a concern with the acceptability of the self. Within these participants' accounts, a common theme was the anticipation that, due to differences experienced as beyond the individual's control, frequently associated with the diagnosis, the self was unacceptable, or even burdensome, to the other. Where participants came to understand their partners as accepting and desiring the self, surprise was often experienced.

An emergent theme across both diagnosed and undiagnosed participants was that certain aspects of the diagnosis required either or both partners to make a particular effort to ensure that both individuals' needs were met. The lack of a natural propensity towards empathy or sharing of experience, or the perceived unacceptability of aspects of the self, necessitated *work* within the partnership. While this effort was experienced as a self-adjustment, and thus in tension with the need to exist authentically with the partner, it was the case that some participants felt that, while their needs were, at times, deferred, they were ultimately met. In other cases, the adjustments required within the relationship constituted a process of personal growth and a change in what was understood as authentic being for the self. For diagnosed participants, the defiance of an expectation that the self would be unacceptable or intolerable for the other could make closeness a transformative experience; prior negative expectations thus

enhanced the depth of the experience. For either partner, the sharing of struggles which could be linked with the diagnosis could facilitate a sense of partnership and exclusivity. Despite the potential for these challenges to ultimately facilitate closeness, for all participants, there was an understanding that there were limits on the extent to which the self could be adjusted without being negated, and, for some, an impasse was manifest in the struggle between adjustment and authenticity.

Aside from the challenges and opportunities afforded by the traits associated with autism, diagnosis itself emerged as an important mediator of understanding. A concern emerged within the accounts of both diagnosed and undiagnosed participants that autistic behaviours could ordinarily be understood as signifying a lack of care. The absence of an awareness of difference can obstruct communication regarding either partner's understanding of the other, as basic understandings about the meaning of behaviour, or experience of the world, are assumed to be shared. Diagnosis, therefore, illuminates differences and allows for renewed communication and new understandings. Among the undiagnosed participants, a theme emerged of diagnosis constituting a window opening an avenue of communication through which the other's experiential world could be understood. Among diagnosed participants, diagnosis constituted a potential means of accounting for and validating difference.

4.2 Implications

4.2.1 Closeness

The present interpretation of closeness has particular resonance with Prager and Roberts' (2004) conceptualisation of intimacy. Prager and Roberts argue that intimacy manifests through self-revealing behaviour, mutual positive involvement, and the experience of shared understandings of both partners' inner experience (including not only thoughts and feelings, but characteristic rhythms, habits, and routines): "Intimate relating is, at its core, two selves knowing each other." (p. 46) The authors suggest that a core condition for intimacy is congruence between an individual's self-concept – the schematised representation of the self – and her organismic self – the first hand experience of "inner" self-states, including thoughts, beliefs, and desires. Correspondingly, within the present findings,

closeness necessitates a congruence between the subjective sense of self and the self as revealed to and known by the other, such that what is expressed is experienced as “authentic”. As the present researcher’s understanding of closeness prior to the analysis was quite distinct from Prager and Roberts’ conceptualisation, the emergence in this study of a resonant phenomenological interpretation derived from an independent, ‘bottom-up’ analysis constitutes a strong endorsement of the central tenets of their model.

The present analysis also discloses phenomenological dimensions of closeness not fully addressed by Prager and Roberts (2004). Within the present interpretation of closeness, a core emergent experiential dimension for both diagnosed and undiagnosed participants is the *active self*: within the security that the self is known and accepted by the other, a *freedom* emerges for the self to express needs through *activity*. This finding represents a contribution to the perhaps overly restrictive focus within existing approaches to closeness on the mutual *knowledge* of self and other. The present findings also suggest that, phenomenologically, the experience of the other within closeness assumes different dimensions depending on the core meanings closeness holds for an individual. Where the central dimension of closeness is the validation of the self, the other’s intentionality is understood in terms of knowledge of and desire for the self. Where the sharing of experience is a prerequisite to authenticity, the understanding required of the other’s intentionality is more focused on the nature of his or her experience of the world.

A more ambiguous relationship emerges between the present analysis and the “self-expansion model”. Aron *et al.* (1991) argue that closeness represents the integration within the self of elements belonging properly to another. According to the model, within a close relationship, an individual comes to experience the world pre-reflectively in such a way as she understands it to be experienced by her partner. In line with this model, the present analysis disclosed the sharing of experience as a central dimension of closeness for undiagnosed participants. However, distinctions emerge between the model and the present analysis. First, the sharing of experience is of more marginal importance within the accounts of the diagnosed participants. Second, phenomenologically, the experience of the

distinction between self and other is integral in the present analysis to *sharing* – the experience is understood in the participants’ accounts as being given separately to either partner, and secondarily disclosed to the other. It is important to note that the “self-expansion model” centres on a cognitive, rather than phenomenological, conceptualisation of the self, with the assimilation of the other representing a shift in automatic pre-reflective processes, which, it could be argued, would not emerge at a reflective phenomenological level. However, Aron *et al.* (2004) do appeal to the phenomenological theory (e.g. Merleau-Ponty, 2002) in support of their theory. This mixed employment of cognitive and phenomenological accounts requires conceptual clarification.

Finally, in contrast to the demands of quantitative research, an advantage of qualitative methodology is sensitivity to the vicissitudes of language. The present research has identified not only a common framework within which the experiences of the participants can be understood – “closeness as authenticity” – but has also disclosed *differences* in the meaning of closeness between groups of participants. “Closeness” thus emerges as a signifier which can hold different meanings. This suggests a significant limitation in the practice within closeness and intimacy research of attempting to measure the quantity or quality of closeness present within relationships according to singular definitions of these constructs. According to conventional approaches, the intimacy achieved by some of the participants in this study might be assessed as “lesser” in depth or quality, while according to the present analysis, *qualitative* differences may also be manifest between individuals and couples. The pursuit of singular definitions of a construct such as closeness (or intimacy) may, therefore, risk negating and pathologising difference; research in this area may thus benefit from the adoption of a more pluralistic approach.

4.2.2 Autism

One of the most interesting aspects of the diagnosed participants’ accounts is the concern expressed regarding the other’s view of the self: these participants were *highly* concerned with aspects of the other’s intentionality, particularly as it reflected on the acceptability of the observed self. *Prima facie*, this contrasts markedly with dominant approaches to autism which conceptualise the condition

as one of impairment in adopting an intentional stance (Baron-Cohen, 1997), and, moreover, as involving impairments in self-referential cognition (Lombardo & Baron-Cohen, 2010).

In interpreting this contrast, we must first note that the phenomenological focus of the present study is distinct from the cognitive concerns of the dominant paradigm in autism research. Cognition and experience are related but distinct objects of inquiry, and straightforward inferences cannot be made about one on the basis of an interpretation of the other. Yet, such a category error is characteristic of a trend within autism literature. Baron-Cohen (1997), for example, suggests that intimacy may be beyond most autistic individual's capacity, due to the necessity of "feeling as if you really know the other person's thoughts" (p. 142). What the present study suggests, however, is that the veracity of cognition must be distinguished from the affective significance of associated experience. To suggest that an autistic individual may be less able to infer accurately intentional states in the other is *not* to suggest that an autistic individual cannot have the *experience* of "knowing" the other, nor that this experience will be of lesser import or intensity. The contrast between the present phenomenological data and dominant cognitive models of autism therefore argues for the importance of maintaining rigour in distinguishing between cognition and phenomenology.

This analysis returns us to the consideration of paradigms of absence and presence discussed in the opening chapter. To recap: the dominant approach within autism research is focused on absence: a concern to determine that which is lacking in those diagnosed as autistic, at the cognitive, neurological, and social levels. This approach is valid, and has led to helpful therapeutic interventions for autistic individuals. Yet, to say that social cognition is *impaired* in individuals with ASD is not to say that it is *absent*, nor even that it is of less concern to them. What the present research demonstrates is that intersubjectivity can hold profound meaning for individuals diagnosed with ASD; indeed, the qualitative meaning of a relationship shared considerable common ground with others who had not been diagnosed. Even where difference emerges, it is a difference between two *substantive* phenomenological modes. While there are levels of

meaning within the accounts of the undiagnosed participants which are absent from those of the diagnosed participants (such as closeness as the sharing of experience), the diagnosed participants' accounts in turn foreground experiential dimensions which are in turn latent or absent within the accounts of the undiagnosed participants (most particularly, closeness as the validation of the self). In all participants' accounts, the intentionality of the other emerges as eminently *present* in the lived experience of closeness; this stands apart from the consideration of the accuracy with which the other is perceived.

To date, the exploration of autistic presence has been mainly pursued within art; within Mark Haddon's (2003) remarkable *Curious Incident of the Dog in the Night-Time*, for example, the reader is thoroughly immersed in the vivid experiential world of a boy we can only infer is autistic. Within research, equally, an approach is required which will allow the construct of autism not to be confined to a negation. Further work, both qualitative and quantitative, is required to give voice to the experiences and values of this population.

The findings both resonate with and raise questions about the foregrounding of the "intentional stance" within autism research. The central distinction between the understandings of closeness within the diagnosed and undiagnosed participants' accounts is the importance within the latter of the sharing of experience. This lesser priority given in diagnosed participants' accounts to the other's experience is congruent with Baron-Cohen's (1997) suggestion that autism is characterised by a deficit in the ability to adopt an intentional stance. Even more striking is the resonance with Hobson's (2002) argument that the central difference within autistic intersubjectivity is the relative absence of a propensity to be "moved" to orient the self towards the other's experience. In resonance with Hobson's considerations on "being moved", undiagnosed participants did not simply demonstrate a cognitive understanding of other's experience; rather, a central priority was to *enjoy* the *sharing* of intentionality of an experience – a dimension latent or absent in autistic participants' accounts. By contrast, Baron-Cohen's (2003) emphasis on the centrality of affective empathy in intersubjectivity appears congruent but overly limited – empathy emerges as only one dimension of a broader understanding of closeness given

by undiagnosed participants as a process of each partner sharing in the other's experience and responding in a congruent and attuned manner.

However, the experience of the other's intentionality is central in the understanding of closeness for *all* participants. The findings provide an example of how the question of the qualitative meaning of lived experience stands apart from questions regarding the veracity of interpreted meaning; that which is present within lived experience retains its significance despite research which may question its veracity or cognitive complexity. Closeness, in its central dimension of authenticity, does not appear to require the inference of complex mental states characterised by the "as if" quality which is attained in the intentional stance proper (Dennett, 1987). While dominant autism research maintains a myopic focus on "theory of mind", as argued by Zahavi (2005), complex mentalization of the other appears phenomenologically secondary to more basic modes of intersubjectivity. Autism research may, therefore, benefit from utilising models of social cognition encompassing different modalities of intersubjectivity.

4.2.3 Closeness in the Context of Autism

4.2.3.1 Theory

The present research suggests a number of challenges that may emerge in the context of a close romantic relationship in which one partner has a diagnosis of ASD. For partners with a diagnosis, the knowledge that the self can be known, understood, and accepted by the other may be difficult to achieve. For undiagnosed partners, a difficulty may emerge in the inability or reticence of the diagnosed partner to understand and share in their experience.

A limitation of existing research on autistic intersubjectivity is that it has generally focused on identifying cognitive and behavioural differences between autistic and neurotypical populations, but little research has been conducted to date which explores directly the implications of these differences for the autistic individual's effort to establish relations with others. An emphasis on the cognitive modelling of autistic difference leaves unanswered questions as to the ordinary dynamic implications of difference within relationships. Furthermore, this approach is

potentially disempowering in that it localises difference within the autistic individual. The present research offers a demonstration of the utility of exploring data from individuals both with and without a diagnosis and juxtaposing these with parity, seeking to understand each as valid, and difference as existing *between* rather than within individuals.

4.2.3.2 Practice

When working clinically with either or both partners in the type of relationship which is the focus of this study, a common difficulty may be a discrepancy in the essential conditions for either partner to fully express themselves within the relationship. Moreover, an impasse in communication may arise, such that the nature of these differences is occluded, due to a lack of an awareness of their nature, or even of their existence. A twofold challenge is present for differences to be, first, communicated, and, secondly, navigated, in order that congruence within the relationship can be sought. This focus on the acknowledgement and acceptance of difference is central to at least two forms of couple therapy, Integrative Behavioural Couple Therapy (Dimidjian, Martell, & Christensen, 2008) and Gottman Method Couple Therapy (Gottman & Gottman, 2008). Although the present phenomenological research does not address “objective” dynamic processes, hypotheses may nonetheless be derived from the present findings regarding approaches couples from these groups may find beneficial when facing such challenges.

In the absence of a signifier of difference, it may be difficult for either partner to infer the need for the communication of certain aspects of their experiential world, which may be simply assumed to be shared by the other. The diagnosis of ASD itself thus represents a potentially highly valuable disclosure of important differences between partners in their modes of experience of the world (and each other), which can illuminate the need for more direct communication regarding each other’s respective experiences and needs. Psychological theory surrounding the diagnosis may itself play a role, although caution must be exercised that neither partner is reduced to the presence or absence of a diagnosis, but, rather, understood in terms of their essential needs, which always transcend diagnostic categorisation. Nonetheless, the present study suggests

that aspects of the “expert knowledge” pertaining to the diagnosis may disclose aspects of difference that partners can find difficult to identify and articulate independently.

A particular area of concern may be the understanding of the diagnosed partner’s behaviour; frequently in the present data, undiagnosed partners made inferences about the meaning of their partners’ behaviour in terms of what it would typically be taken to signify (c.f. Bentley, 2007). Intriguingly, however, the present findings suggest that the diagnosed partner may be less puzzled by the meanings of her partner’s actions, as what is sought by the present participants is a manifest expression of acceptance, investment, and desire, which can be readily inferred by direct displays of care and affection. Cognitive-behavioural strategies for exploring the meanings attributed by either partner to the other’s behaviour, or for understanding how one’s behaviour might be understood by one’s partner (Baucom, Epstein, LaTaillade, & Kirby, 2008) may therefore be helpfully informed by information regarding the diagnosis. Such work to make known either partner’s experiential world may in itself constitute a means of experiencing closeness, through allowing both the sharing of experience, as well as revelation and validation of the self. Care should be taken that difference is not localised within the diagnosed partner, as both will have meaningful understandings of closeness which are valid in their own terms.

Differences being made manifestly known, a second challenge is to explore the potential for congruent expression of both partner’s needs within the relationship. The accounts included in the present study illustrate how congruence can emerge even where the experiences through which partners’ needs are met are interpreted in very different ways by either partner. For example, a discussion focused on a “special interest” can allow both for the diagnosed partner to freely express her interests, while also serving as a medium for a neurotypical partner to make known and share inner experiences. However, the recognition, in some instances, that either or both partner will not be able to freely express some aspects of their needs within the relationship may indicate the necessity of an adjustment of expectations; for some, difficult decisions about the sustainability of the relationship may be required. Alternatively, questions can be raised about

the possibility of change. Is the potential present for either partner to explore new ways of being within the context of the relationship which might be experienced, not as an effortful self-adjustment, but as a process of personal growth?

Finally, clinicians should be sensitive to nuances in the language of closeness and intimacy, and take care that preconceptions as to the validity of the typical meanings assigned to these terms does not become oppressive, nor an obstructive to communication. While some clinical researchers have recommended that the provision of a working definition of “intimacy” or “closeness” for couples can facilitate goal setting (e.g. Moss & Schwebel, 1993), the present findings suggest that the personal needs which clinicians attempt to signify universally through these terms can, in fact, vary significantly between different individuals and relationships.

4.2.3.3 Autism and Closeness as Gendered Constructs

As argued in the opening chapter, autism and closeness are gendered constructs. While Baron-Cohen’s (2002) “extreme male brain” hypothesis may be controversial, it does highlight the overlap between autistic features and cultural ideas of masculinity. Conversely, the construction of closeness (or intimacy) within research, with its focus on verbal sharing of emotive experience, falls within the arena of contemporary constructions of femininity (Wood & Inman, 1993). With three out of the four diagnosed participants in the present study being female, the findings allow some consideration of the potential significance of gender in the phenomenology of closeness in the context of autism.

Significant commonalities emerged among the accounts of the female participants that distinguished them from the one male participant. Most salient was the finding that the diagnosed women were each acutely aware of the experience of being seen as different by uncontrollable traits associated with the diagnosis, such as anxiety, meltdowns, and interpersonal difficulties. While the male participant described experiences of having to “mask” his difference and conform to social expectation, he alone articulated autistic difference as stemming from differences in interests and priorities he associated with autism (such as wanting to talk about weighty scientific matters, rather than trivia) –

differences that he suggested made him sometimes feel others to be inferior. That is, the male participant claimed a sense of *agency* and *justification* around that which made him differently. In contrast, the female participants' experiences gave greater priority to experiences of *shame* surrounding difference. While none of the participants linked these experiences to gender, it is striking that only the male participant articulated significant congruence between his preferred identity and his autistic traits. The possibility emerges from this that social constructions of gender may compound the sense of alienation for females with the diagnosis, as it will be more difficult for them, as women, to assume a social identity which can accommodate both autistic traits and socially sanctioned femininity. In contrast, the development of such an identity within a woman's social systems may facilitate an experience of positive connotations of autistic traits, as well as a sense of agency and validity in showing signs of autism.

The participants' understandings of closeness also hold gendered dimensions. The sharing of experience can be understood as a conventionally feminine priority in intimacy (Wood & Inman, 1993), and emerges as a central dimension of closeness for the undiagnosed participants, all of whom are female. However, this theme was latent or absent in the accounts of the diagnosed participants, both male and female. The diagnosed participants' experience thus emerges as distinct from a mode of intersubjectivity that is both "neurotypical" and "feminine". Recourse to a straightforward binarism which would in turn equate the "autistic" with the "masculine" is, however, precluded by diversity within the diagnosed participants' accounts. Most intriguingly, the understanding of closeness as a sharing of exclusive knowledge (Theme II.c), which also resonates with constructions of femininity (Wood & Inman, 1993), assumes greater prominence in the narratives of the female diagnosed participants, and is absent in the male participant's account. In this respect, the diagnosed women's lived experience shows complex gendering, again posing questions as to the interface between autistic subjectivity and the social construction of masculinity and femininity.

The director of autism research at Yale University, Ami Klin (as quoted in Murray, 2008), has dubbed women with autism as "research orphans". The needs of this group remain extremely under-researched. The present findings give some initial

evidence for the importance of constructions of gender in autistic identity, experience, and intersubjectivity.

4.2.4 Further Clinical Implications

Beyond work with romantic couples, the findings hold implications for direct work with people with autism, as well as with people to whom they are close, romantically or otherwise. There is currently a very limited body of literature pertaining to clinical work with non-learning disabled adults with autism. However, recent work in this area has argued for the utility of cognitive behavioural work with this population, adapted to account for information processing differences associated with autism, and there is provisional evidence for the benefits of group CBT interventions for anxiety and social difficulties (see Gaus, 2011, for an overview).

The present findings indicate important issues pertaining to social identity and self-esteem for this group. The diagnosed participants each showed an awareness of differences in their interests, motivations, social engagement and behaviours from most of those around them. Each of them was, in turn, highly concerned about others' evaluations of them, such that their very experience of self was deeply affected by others' judgments. (Intriguingly, this would seem to run contrary to what might be expected under a condition of "mindblindness".) The accounts given by several of these participants of a history of victimisation resonate with other research findings about the experiences of autistic individuals in adulthood (Kapp, Gantman, & Laugeson, 2011). Both participants' accounts, as well as my own experience during this project of engaging with diagnosed individuals in various forums, suggests that the experience of "being different" can lead for many individuals to profound questions about identity. As such, direct clinical work with this client group needs to include consideration of social identity and self-esteem. Perhaps due to the differing priorities of research which seeks to explain the nature of autistic difference, the clinical literature to date includes little reference to issues of identity and self-esteem, and these needs are not included in a recent overview of clinical applications of CBT with this group

(Gaus, 2011); the present research suggests, however, that these issues can be highly important.

Clinical work can also include a focus on addressing interpersonal cognitive and behavioural difficulties which may pose barriers to inclusion (Kapp, Gantman, & Laugeson, 2011). The present work suggests considerations that can be incorporated into clinical work addressing interpersonal difficulties.

First, it should not be assumed that the opacity of other individuals' minds will be an immediate concern for the client. Within the accounts of the diagnosed participants in the present study, there was, somewhat unexpectedly, minimal reference to difficulties understanding others' behaviours and intentions. This is not to say that theory of mind issues are not central considerations in clinical work, but, where included in formulation and intervention, this may be challenging for clients if they have not previously understood their interpersonal difficulties in such terms.

Second, the present research's inclusion of the views of both diagnosed and undiagnosed individuals illustrates the importance of attending to the meanings assigned to difficulties at a systemic level. When describing barriers to the experience of closeness, the undiagnosed participants' accounts suggested that their partners' difficulties in empathising and sharing experience were frequently interpreted as indications of a lack of interest or concern. Congruently, three of the diagnosed participants were particularly concerned about others' perceived inability to understand the meaning of their own atypical behaviour and its relation to the diagnosis. The findings illustrate how the interpersonal challenges need to be understood in a genuinely intersubjective context, and direct work may benefit from including individuals to whom the client is close, in order to consider the meanings that arise in relation to difficulties at a systemic level. Systemic interventions may not only help the diagnosed individual to consider others' minds, but may furthermore allow them greater insight into his or her own.

4.2.5 Directions for Future Research

There remains a dire need for more research into the romantic experiences of individuals with autism and their partners. Quantitative research is required to establish the scale of need and outcomes at a population level. Research may address the degree and variability of satisfaction of different needs connected with closeness, such as sexuality and empathy, and the correlates of positive and negative outcomes, both in terms of traits of either partner as well as in the specific strategies pursued within relationships. However, further qualitative work is required to provide a conceptual framework within which quantitative data can be interpreted in terms of the lived experiences and values of these populations. The present research has focused on the *meaning* of participants' experiences; an alternative qualitative approach, such as grounded theory, may provide a useful exploration of the *processes* through which these experiences arise. At present, the intimate needs of these populations are neglected in the clinical literature; further research will provide a framework through which these needs can be understood and worked with at a clinical level.

A note should also be made about the viability of further research on this topic. Recruitment for the present research was slow and labour intensive, requiring nearly six months to obtain a relatively small sample, despite minimally restrictive inclusion criteria being employed. While, at one level, this may be indicative that the populations from which participants are drawn may be relatively small, it also likely illustrates the difficulty of engaging participants with a diagnosis in intensive qualitative research. As the development of NHS services for autistic adults expands in the wake of the Autism Act (2009), clinical services may form a more viable route for recruitment of this difficult to reach population. Alternatively, some compromise of homogeneity might be accepted and participants recruited from across the English speaking world, although consideration would have to be given to whether the diagnostic practices involved in meeting the inclusion criteria are variable across countries, as appears likely. Difficulties with recruitment may be less pronounced for quantitative approaches using online interfaces, which involve less direct and less intensive interpersonal demands.

4.3 Critical Review

4.3.1 Validity

The present study aims to provide a hermeneutic framework for the research's audience. The phenomenological understanding of "truth" is quite distinct from a naive correspondence theory – truth consists in disclosure: "To say that a statement is *true* means that it discovers the beings in themselves. It asserts, it shows, it lets beings "be seen" in their discoveredness. The *being true (truth)* of a statement must be understood as *discovering*." (Heidegger, 1996, p.201) All understanding of the world is interpretation from an engaged position of openness to discovery. As such, the quality of the present project may be chiefly assessed in terms of what Spencer and Ritchie (2011) refer to as the criterion of contribution: the extent to which it facilitates the reader's interpretation of the phenomenon of concern. I have argued above that the analysis given here provides new perspectives on a topic which has so far received little attention in research, and is based on a thorough analysis of the data.

A potential limitation to the validity of the findings concerns the quality of the primary data on which the analysis is based. As discussed in the Introduction, current cognitive models of autism propose that the condition involves deficits in the self-awareness upon which phenomenological approaches rely (Frith & Happe, 1999). Furthermore, Willig (2008) argues that interpretative phenomenological analysis requires participants to demonstrate a high degree of articulacy and reflective ability. The validity of phenomenological research using the accounts of individuals diagnosed as autistic may thus be called into question. However, I would argue that these objections are based upon premises at odds with the hermeneutic underpinnings of IPA. Implicit in either argument is the assumption that the account provided within an interview constitutes a means for accessing inner experience which can be of greater or lesser communicative quality. However, a hermeneutic phenomenology would suggest that experience is always already manifest *as an interpretation*; the veracity or complexity of the accounts given is beside the point. Where participants' accounts seem removed from the sophisticated complexity of philosophical phenomenological texts, this can be argued to simply be a reflection of the nature of the experience for the individual, which may be less

characterised by detailed introspection and attention to the nuances of phenomena. In any case, the current analysis reveals comparable thematic depth in the accounts of diagnosed and undiagnosed participants, arguing in favour of the validity of a phenomenological approach with individuals diagnosed with ASD.

Nonetheless, one substantial concern can be raised concerning the production of and approach to the “primary data” upon which this research is based. In approaching the interview process, I accepted that it already constituted a stage of interpretation. Considering this, my practical strategy was to keep my questions as open as possible, refraining from using terms or probes which might detract from participants’ framing of their accounts in their own language. The underlying assumption was that this would help to ensure that the accounts provided were genuinely representative of the lived experiences they described. Therefore, where differences then emerged in thematic content and priority – such as the differential priorities given to closeness as “validation of the self” versus “sharing of experience” - this was interpreted as being reflective of qualitative differences in participants’ lived experiences. However, the strategy of avoiding the introduction of my own interpretations within the interview also *precludes* the active pursuit of disconfirmation. The possibility remains that variables within the interview setting itself – such as the participants’ ease with the setting, or specific agendas which they might have brought to the interview themselves – rather than differences in the *quality* of their experiences, may have influenced the accounts given. I am left wondering what the responses of the participants would have been had I in some way asked questions concerning these themes to those whose accounts did not originally feature them. Implicitly, the approach adopted also retains a stance towards the interview transcripts as essentially “raw data”, which is somewhat at odds with the hermeneutic foundation of the study.

An alternative approach that could have been adopted would be, instead, to embrace the hermeneutic dimension of the interview setting, approaching it as an opportunity for negotiating understanding with participants in a dialogical, or even Socratic, fashion. Such an approach is suggested by van Manen (1990), and

termed by Dinkins (as cited in Roulston, 2010) as a process of “interpre-view”. Interpretations could be brought out in the questioning process, which itself could be conducted over two or more meetings. One concern about this approach would be that the Socratic interrogation of experience could expose aspects of participants’ accounts with which they might be uncomfortable, leading to a defensive concealment, rather than disclosure of experience; alternatively, the interview itself might come to be guided by the interviewers’ concerns. However, as well as being consistent with a recognition of the interview as a process of interpretation in and of itself, such an approach would hold the advantage of negotiating understanding in a more collaborative fashion than the present study.

4.3.2 Limitations

As a phenomenological project, the present research does not address objective intersubjective processes, such as “practical” ways in which partners establish closeness in the context of a diagnosis of ASD, nor the *types* of difficulties that may be present. The findings address only *subjective* experiences; no attempt has been made to synthesise the findings to produce a dyadic and dynamic model of closeness as a process. Rather, what this study aims to provide is an understanding of the way in which partners make sense of their experiences of closeness, and aids and obstacles to establishing it, which may provide an interpretative framework for clinical work with individuals from these populations, and for future research which may seek to explore empirically questions that this research does not address.

A further question which is not fully addressed in this study, nor, so far as I have been able to identify, within the wider research on closeness, is the juxtaposition of experiences of closeness to *desire*. References were made by participants to desire and “want”, as I have sought to bring out in the analysis, and, in particular for the diagnosed participants, the experience of being desired was essential to the experience of closeness. What merits further consideration in future research is the relative phenomenological meanings and interplay of desire and closeness. What is the experience of desire, what are the conditions of its phenomenology, and how does it relate to a sense of being *close* to a partner?

My own tentative reading of the present participants' accounts suggests that the partner's desire becomes phenomenologically central within the process of the revelation of the authentic self before the other, such that the subjective sense of self becomes identified with the self objectified in the other's intentionality, and the very sense of the self becomes contingent on the partner's desiring response. (Intriguingly, this theme seems more present in the accounts of the diagnosed participants.) Nonetheless, desire did not emerge as a central theme in its own right in the findings. This may be partially due to practical issues – desire was not addressed in the research or interview questions, nor actively sought out in the analysis. However, the latency of the desire in participants' accounts of closeness may also implicate limitations in what language is able to signify. Lacan (as interpreted by Fink, 1997), perhaps the last century's foremost thinker on the desire of the Other, argued that, while the very essence of language is bound up in the question of the desire of the Other, as an object of perception, the Other's desire eludes signification. An empirical phenomenological investigation of the experience of a partner's desire may therefore require closer attention to the form and structure of participants' accounts, rather than the semantic content which is generally made the focus of IPA.

Finally, while no claims are being made regarding the generalisability of the present analysis, the restricted nature of the sample is, nonetheless, a notable limitation. In terms of culture and ethnicity, the participants were all British born. As a central aim of the study was an exploration of the central experiential dimensions of closeness, the inclusion of a broader sample may have yielded greater depth in the exploration of commonality and diversity in the data. More profoundly, the homogeneity of the sample occludes important issues regarding socially constructed dimensions of closeness, which need to be acknowledged and explored even within a phenomenological framework. The sample gathered is also overwhelmingly female. The relationship between autism and gender is one requiring further exploration, both in view of the gender imbalance in diagnosis and the currency of the "extreme male brain" hypothesis (Baron-Cohen, 2002). The small sample precludes any inference about the possible significance of the gender imbalance among those recruited, but it would be

interesting to explore in population-level quantitative research whether females diagnosed with AS have greater success at sustaining romantic relationships.

4.3.3 Reflexivity

In returning to the consideration of the reflexive aspects of this work, my aim is to consider the implications of the way in which my own understandings of closeness and autism have influenced the analysis. As I have already argued, from a hermeneutic phenomenological perspective, reflexivity is a condition of all understanding; the reflexive element of qualitative research is of value in so far as it discloses a way of understanding the phenomena which is accessible and of utility to the reader's own interpretative positioning. The challenge is to demonstrate a dialogical position towards the data through which discovery, rather than dogmatism, emerges.

In the second chapter, I stated that my understanding of closeness centred on a deep sharing of experiences, such that an experience is felt to have been given, or understood, in deeply resonant ways by either partner. Furthermore, my longstanding understanding of autism has been that it represents a fundamentally different mode of experiencing the world and intersubjectivity, and I have found the "mindblindness" hypothesis (Baron-Cohen, 1997) a useful framework for understanding autism. As such, I approached the research with an expectation that "closeness" might, within an autistic mode of experience, signify a qualitatively different experience than for non-diagnosed participants; alternatively, I expected that they might describe difficulties in understanding the concept.

Revisiting the analysis, the establishment of a common dimension of closeness – authenticity – may in part reflect an effort not to allow my own given understanding of the construct to dominate the findings. Nonetheless, the sharing of experience, so central to my own understandings, emerges as a central subordinate theme. Moreover, autism does emerge as a locus for a different understanding of closeness from my own. This may appear suspiciously congruent with my initial positioning relative to the constructs. Has my interpretation been restricted by my given understandings? In favour of the

validity of the interpretation, I would respond that I was aware over the course of the collection of data of the congruence between my developing understanding, even prior to formal analysis. For example, within latter interviews, I sought to explore, through non-leading probes, potential exemplars of the sharing of experience in the diagnosed participants' accounts. Furthermore, as reflexivity is inevitable and essential to all human understanding, the fact that alternative interpretations are possible does not diminish the validity of an analysis. Rather, the potential for alternative readings may even be celebrated as an opportunity for further discovery and exploration.

The findings of the analysis, as well as shifts in my own understanding of the phenomena, also give evidence that a dialogical approach towards the data has been taken. The emergence of "closeness as authenticity" as the foremost dominant theme was a surprise to me, reached slowly through laborious repeated readings and analyses of the data. Furthermore, I was impressed to find that issues of social comprehension did not constitute a central thematic dimension of the experiences of diagnosed participants, despite my own preconception that it should, and that the commonalities between the understandings of diagnosed and undiagnosed participants were as significant as differences, if not more so. The analysis, furthermore, disclosed to myself new understandings of closeness and autism. Through the course of this research, I have come to perceive the importance within my own relationships of being able to openly express my "inner experiences" and "dispositions" – that is, I have come to understand authenticity as an important aspect of closeness in my own life. Furthermore, I have become increasingly aware that, for all the importance of experimental research into autistic difference, there remains a paradigmatic distinction between cognitive and qualitative approaches to the experiences of those diagnosed autistic, such that assumptions cannot be made about the latter on the basis of the former. These shifts in my own understandings, and the demonstrable difference between the findings of the analysis and my initial positioning, argue strongly that the analysis has been based on a suitably dialogical approach to the data.

4.3.4 Reading Critically

Language constitutes, inevitably, the medium through which this investigation is undertaken; the research question itself centres upon the relation between experience and two key signifiers, “autism” and “closeness”. Yet, the nature of the research question and analysis is phenomenological, seeking to explore “lived experience”. An assumption is thus implicit within the approach that language constitutes a system of signification which corresponds unproblematically with phenomena and makes the participant’s account readily interpretable. Language is a servant, rather than master, of experience.

However, these claims are challenged by poststructural theory. Most significantly, Derrida (1973) levelled a forceful critique at the conceptual foundations of phenomenology. The signifier, for Derrida, acts as a supplier of the signified; it runs ahead of it. Yet, Western tradition, exemplified by classical phenomenology, is predicated upon the idea of the signifier as simply “tagged onto” the object. If the objects of experience are themselves produced through signification, then the claims of phenomenology to be an exploration of experiences manifestly present prior to the language used to describe them are, according to the terms of poststructuralist theory, undermined. Indeed, Derrida’s critique proved ultimately fatal to phenomenology as a movement (Moran, 2000). It can be argued that phenomenology still constitutes a valid mode of inquiry, provided the *epoché* is taken to apply to experience *as given*, which is almost always through the medium of acquired significations (Rodemeyer, 2008). Yet, if language remains the inevitable medium of research and communication, profound questions are raised about the claims that can be made for what research discloses.

A critical reading of the present research, informed by Derridian critique, would understand that what is represented in the analysis is first and foremost *text*, a complex of language that cannot claim to “signify” the experiences of participants. This does not diminish the value of the reading; phenomenological analysis can still constitute a valuable hermeneutic tool which will be understood and employed by the reader in any number of ways which may facilitate a multiplicity

of interpretations of further research and clinical encounters. What are at stake are simply the claims that are made for what the work “represents”.

I am not happy, however, to abandon the phenomenological claims of the present project – while the critique precludes a naive claim that even the clearest of communication suffices to convey experience straightforwardly, I feel that the disclosure, if not construction, of phenomena remains a central function of language. Nonetheless, if the concerns of poststructural theory are taken seriously, as I believe they must be, analytical questions are raised not addressed in the present work. A fully critical reading would seek to explore what the data discloses about the participants’ experiences, but, moreover, how the dominant discourses within language structure not only participants’ *accounts* within the interview, but also the experiences themselves. How do participants engage within the interview with “closeness” and “autism” as social constructs? Moreover, how do the discourses associated with these terms structure lived experience? And is it possible to explore the participants’ experience of the signifier itself? “Closeness” and “autism” are not value free terms giving simple expression to experience: they are vehicles for social ideals, in relation to which an individual cannot position themselves without concern for the social ramifications of their discourse.

IPA has been argued to be a valid methodology for the exploration of the interface of lived experience and social discourse. Eatough and Smith (2006) have provided an exemplary idiographic exploration of the complex relationship between discourse and the hermeneutics of experience within the paradigm of IPA through an idiographic analysis of a participant’s account of anger. However, the project for a critical phenomenology raises profound conceptual issues which have not yet been adequately addressed in the literature – indeed, the standard textbook on IPA (Smith *et al.*, 2009) gives no consideration to issues of social construction. This remains an area in need of further theoretical refinement. With the development of a more robust critically informed interpretative framework, phenomenological research may further the causes which motivate the present study: to give priority within writing to the *experiences* and *values* of

autistic individuals and those close to them, towards allowing for the proper emergence of *autistic presence*.

5. Conclusions

The research uncovered three core thematic dimensions in the experience of closeness for eight participants in romantic relationships in which one partner had a diagnosis of ASD: closeness as authenticity, discovering the partner, and autism as an essential difference. Emergent subordinate themes revealed certain distinctions in the experiences of diagnosed and undiagnosed participants, but commonalities were as salient as differences. A central requirement for the mutual experience of closeness is that both partners feel that they are fully understood, accepted, and responded to by their partners in an attuned fashion. Differing personal needs of either partner can pose both challenges and opportunities. The findings of the analysis suggest ways in which existing approaches to clinical work with individuals with autism as well as couples in which one partner has a diagnosis can be adapted to address the needs of people in this type of relationship when they are facing difficulties in establishing closeness.

The findings show some concordance with dominant approaches to autism and closeness, but also demonstrate the limitations of dominant paradigms in understanding lived experience. Research into autism, as well as closeness, overwhelmingly adopts quantitative methodologies in order to establish causal models of the constructs. This study demonstrates the way in which qualitative approaches may provide a distinct contribution, allowing the experiences of autistic individuals and those close to them to be heard and understood in their own right.

The romantic experiences of people with autism and their partners is an area in urgent need of further research. Large scale quantitative studies are required to determine the scale need at a population level, and establish the correlates of different outcomes. However, qualitative research is required to give meaning to future research in terms of the values and lived experiences of these groups. It is hoped that the present study will make a distinct contribution towards this end, and will be an initial step towards building a greater understanding of this area.

6. References

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Appendix A: Evidence of Ethical Approval for Present Study

UNIVERSITY OF EAST LONDON

APPLICATION FOR THE APPROVAL OF A RESEARCH PROGRAMME INVOLVING HUMAN PARTICIPANTS

Please read the Notes for Guidance before completing this form. If necessary, please continue your answers on a separate sheet of paper: indicate clearly which question the continuation sheet relates to and ensure that it is securely fastened to the report form.

1.	Title of the programme: Autism and the Experience of Closeness: An Interpretative Phenomenological Study
	Title of research project (if different from above):
	Name of researcher (s) (including title): Mr Josef Schwaerzler
	Nature of researcher (delete as appropriate):
	(b) students
	If "others" please give full details:
	Student number: u0933897@uel.ac.uk
	Email: u0933897@uel.ac.uk
2.	Name of person responsible for the programme (Principal Investigator): Dr Robyn Vesey
	Status: Clinical Tutor, Department of Clinical Psychology
	Name of supervisor (if different from above): Dr Ken Ganon [Second Supervisor]
	Status: Research Director, Department of Clinical Psychology
3.	School: Psychology
	Department/Unit: Clinical Psychology
4.	Level of the programme (delete as Appropriate):
	(c) Postgraduate (research or Professional Doctorate)

Approved on condition that standard safety precautions are taken when interviewing in a participant's home or other private location.

RS
12/5/11.

Appendix B: Exemplar Recruitment E-Mail

Dear -----,

I am a Trainee Clinical Psychologist in London and am carrying out research, as part of my doctorate, on romantic relationships in which one of the partners has a diagnosis of an Autism Spectrum Disorder (including Asperger's Syndrome). I am writing to ask whether any members of your organisation, or those you support, might be interested either in taking part or passing on information about the research project.

The research concerns ways in which people with ASD and their partners experience closeness in their relationships. For the research, I aim to interview both people with the diagnosis and 'neuro-typical' individuals in a relationship with someone with ASD about their experiences, although I am planning at this stage to only interview one person from any couple.

At present, very little research has been carried out regarding romantic relationships in which one or both partners is affected by ASD. I therefore hope, through the project, to develop within the clinical and research communities a greater understanding of the values, experiences, and needs of people with ASD and their partners.

I have attached an information sheet giving basic information on the research for anyone interested. If anyone is interested in participating, or is curious about knowing more about the research, they can contact me by e-mail at u0933897@uel.ac.uk, and I will be happy to provide further details.

Yours sincerely,

Joe Schwaerzler
Trainee Clinical Psychologist
University of East London

Appendix C: Application Letter for Amendments of Recruitment Procedure

Josef Schwaerzler
46 Chilver Street
Greenwich
London SE10 0RH

Dr. Mark Finn
Ethics Board Chair
School of Psychology
University of East London
Water Lane, Stratford E15 4LZ

22nd August, 2011

Dear Mark,

RE: Ethical Approval for Clinical Doctorate Thesis Research – “Autism and the Experience of Closeness”

I am writing to request to make amendments to the recruitment procedure for my research outlined in my original ethics proposal.

The original proposal states (page 2, Item 9) that I will recruit for the study “through the National Autistic Society, as well as networks used by affected individuals, including support groups and online forums.” I have been in the process of recruiting through these avenues, but feel that the process of recruitment would be significantly aided by pursuing additional possibilities. I will not be contacting potential participants directly, but want to create additional avenues for recruitment.

I am therefore requesting approval to send information about the study, including the approved information sheets, for recruitment purposes to the following groups

to ask them to disseminate information about the project to people they know who meet the criteria and might be interested in taking part:

1. Personal contacts, including colleagues and friends, who may themselves know individuals who meet the inclusion criteria for the study, and to whom they could in turn send the information. I would *not* include in the study any existing personal acquaintances.
2. Institutions, such as university departments or private companies, that may have among their members, students, or employees, individuals who meet the inclusion criteria.
3. Individuals meeting the inclusion criteria who have put this information about themselves in the public domain (e.g. through published books or internet postings). In sending information to these individuals, I will not invite them directly to take part, but will, rather, ask if they are able to send the information to interested parties. I would, however, accept any responses from the individuals I have contacted expressing an interest in taking part.

I would also like to request permission to establish a website with basic information about the research, through which potential participants could learn about the project and contact me for further details.

I understand that as Chair of the School of Psychology Ethics Committee you may be able to approve these changes by Chair's action. Alternatively, there may be further information or school processes required. Please let me know whether it is possible for you to approve these changes, and if so, whether any or all of these amendments is approved, or if they might be approved subject to revision.

Yours sincerely,

Josef Schwaerzler
Trainee Clinical Psychologist
2009-2012 Cohort

Appendix D: E-mail Confirming Approval of Amendment to Recruitment Procedure

From: Mark Finn

To: Josef SCHWAERZLER

Cc:

Subject: RE: Clinical Doctorate Thesis - Request to Amend Procedure

Attachments:

Sent: Fri 26/08/2011 11:40

Dear Josef,

Thank you for your email.

I have considered your proposed amendments in relation to recruitment and am happy to unconditionally approve these.

While you don't raise this directly, if you at any stage post recruitment adds on websites, it will be necessary to have approval from the website manager first.

Please consider this email confirmation of the approval.

Best wishes,

Mark

Appendix E: Interview Schedule

1. Please tell me some details about your relationship.

Prompts: How long have you been with your partner? Living together/married? If not, how often do you see your partner? Children? How long have you known about your (partner's) diagnosis? How was this found out? Understanding of diagnosis?

2. What does "closeness" mean to you?

Possible prompts: What do you understand by the word "closeness"? How significant is it to you?

3. In what ways do you experience closeness in your relationship?

Possible prompts: At what times do you feel close to your partner? What allows you to be close at these times? What is it that you experience when you feel close with your partner? Are there any difficulties in establishing closeness?

4. Can you describe an experience in which you have felt close to your partner?

Possible prompts as per question 3.

5. What do you think "closeness" means to your partner?

Possible prompts as per question 2.

6. How do you think your partner experiences closeness in your relationship?

Possible prompts as per question 3.

7. How important is closeness in your relationship?

Possible prompts: To you? To your partner? What else is important?

8. In what ways, if any, does ASD/Autism/AS affect closeness in your relationship?

Possible prompts: For you? For your partner? Positive and/or negative aspects? Differences in experience you attribute to presence of ASD?

Appendix F: Research Information Sheet



Josef Schwaerzler
Trainee Clinical Psychologist
University of East London
Stratford, London E15 4LZ
U0933897@uel.ac.uk

Autism and the Experience of Closeness

You are invited to take part in a research study exploring the experiences of closeness in romantic relationships in which one partner is diagnosed with an Autism Spectrum Disorder (ASD, including Autism and Asperger Syndrome). Before deciding whether you wish to participate in the study, it is important that you understand why the study is being done, and what it involves. Please, therefore, take the time to read through this information sheet before deciding whether you wish to take part.

Who is carrying out the research?

I am a Trainee Clinical Psychologist at the University of East London. The research is supervised by a Clinical Psychologist, also based at University of East London.

Why is the research important?

People with a diagnosis of ASD may feel intimate relationships to be very important to them, and develop romantic relationships with others without a diagnosis of ASD. However, little research has yet been done into relationships developed by individuals diagnosed with ASD. The research will seek to explore how people in relationships in which one partner has a diagnosis of ASD experience closeness within these relationships.

By taking part in this study, you will be aiding the development of an understanding of issues that are of importance to individuals with ASD diagnoses and people in relationships with them. This information may produce greater

understanding of the experiences of individuals with ASD and their partners, and highlight issues of which others need to be aware when close to or supporting people with ASD or their romantic partners.

Who is being asked to take part?

For this study, I am looking to recruit:

- a) Adults who have been formally diagnosed with ASD for more than 1 year previous to taking part in the study, who do not have a diagnosed learning disability, and are, at the time of taking part in the study, in romantic relationships with individuals who do not have diagnoses of ASD.
- b) Adults without diagnoses of ASD who are in romantic relationships with individuals who do have ASD diagnoses, who have been aware of their partners' diagnosis for more than 1 year, and whose partners do not have a diagnosed learning disability.

At present, I am only looking to recruit one partner from any couple. Your partner does not have to give consent for you to participate. However, for anyone taking part, it is important that you are committed to your relationship (that you are not currently thinking of ending the relationship) and have been with your partner for at least 1 year at the time of taking part in the study.

What does taking part involve?

If you agree to take part, I will meet with you for an interview about your experiences of closeness within your relationship. The interview will last approximately an hour. I will record the interview on a digital recording device for later transcription.

I am able to book a room for the interview at the University of East London. Alternatively, I can meet with you at your home or another private location to which you have access. I am able to travel to locations within two hours' commuting time from central London, but unfortunately can not travel further due to time restrictions. I will be able to reimburse any travel expenses incurred for your travel to the interview.

Alternatively, should you not wish to meet for an interview, or should you live a significant distance from London, it is possible to conduct an interview over the telephone or via Skype, or through e-mail.

What will happen to the data from the interview?

All your details and responses will be kept highly confidential, and will only be seen by myself and my supervisor. The recording of the interview will be deleted after transcription. When the data has been transcribed, it will be anonymised, with names and any other identifying details (such as areas of residence, place of work, etc.) regarding you, or others discussed in the interview, altered.

After the information has been transcribed, it will be used in the writing of a report on the research, which will be submitted to the university. The data may also be used in papers to be submitted to academic journals or presented at academic conferences. Within the report and potential papers or conferences, excerpts from the anonymised transcripts will be included.

As with any piece of research, if information is disclosed which clearly shows that you or someone else is at significant risk or harm, confidentiality could not be maintained, and I would be obliged to discuss these issues with your GP or appropriate services. I would try to first discuss this with yourself.

Do I have to take part?

No. Participation in this study is entirely up to you. If you agree to take part, you will have the right to cancel or withdraw from the interview, and to withdraw from the study entirely at any time, in which case your responses would not be used in the study. If you decide to withdraw from the research, you do not need to give any reason for this.

What are the potential benefits and risks from taking part?

Many people find that they enjoy talking about experiences that are significant to them. Your participation in this research may give you satisfaction for having

contributed to the development of knowledge which may be of benefit to individuals with ASD diagnoses and their partners.

Some individuals may find it difficult to talk about these experiences. If you experience distress during the interview, you will, if you wish, be able to decline to talk about difficult topics, or to withdraw from the interview, without stating a reason. If your responses suggest that you are experiencing significant distress, I will suggest you speak to your GP or another professional from whom you might receive support.

Who has reviewed the study?

The study has been reviewed and approved by the University of East London School of Psychology Ethics Committee.

Contacts for Further Information

For further information about the study, you may contact myself, using the details given on the first page. Alternatively, should you wish to speak to my supervisor, please contact:

- Dr. Maria Castro, Clinical Tutor, Department of Clinical Psychology, University of East London, Stratford Campus, E15 4LZ. Tel: 020 8223 4409. E-mail: r.vesey@uel.ac.uk

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact the Chair of the Psychology School Ethics Committee:

- Dr. Amanda Roberts, School of Psychology, University of East London, Stratford Campus, Water Lane, London E15 4LZ

Appendix G: Consent Form

Josef Schwaerzler
Trainee Clinical Psychologist
University of East London
Stratford, London E15 4LZ
U0933897@uel.ac.uk



Autism and the Experience of Closeness

Consent to Participate in Research

Before participating in the research, please confirm the following (tick boxes as appropriate):

1. I have read the information sheet and understand the purpose of the study, and understand what I will be asked to do as a participant.

2. Any questions that I may have had have been answered to my satisfaction.

3. I understand that I am free to withdraw myself and my data from the research at any time without stating a reason, and understand that there will be no adverse consequences for me doing so.

4. I understand that my personal details will be kept strictly confidential, and will not be distributed in a way that could potentially be used to identify me, except in the event that a failure by the researcher to pass on information shared would pose a significant risk to myself or someone else.

5. I consent to participate in the study as outlined in the information sheet.

Participant's Signature: _____

Participant's Name (please print): _____

Researcher's Signature: _____

Researcher's Name: _____

Date: _____

Appendix H: Extract from Research Diary

Keep a keen eye out for references to third parties - how do they figure? What is their role? Exclusivity of presence, but "others" still seem to loom...

In reference to certainty - keep an eye out for just "I mean" - what is there to connect them?

Also - maybe make eye list of names there that might merit further exploration

Check for how closure emerges as a "need" - ? kind of body/embodiment?

Reflective note: it is interesting that P1's views on closure were so close to my own - but also just as different the emergence (which)!

Questions of how to refer to topic trait when they are not members as such - stable? Need to be done but cautiously

Also of visual metaphor (language is interesting)!

Does "big know" in a subject's terms require triangulation in intentional objects - c.f. Merleau-Ponty + intentionality

On authenticity (attainment - not that this holds a reflective quality (for most) in the gesture, not how to be reflected in a more frequent and I say big - check the out against Heidegger!

When I say "achievement", important to clarify how, and towards what, and what is affected.

Critical note - (!) - is a phenomenological approach appropriate in big enough to account for the "reality" of external circumstances? Merleau-Ponty (normal!) view of individual people and problematic phenomenology (and makes it explicit - partly in Merleau-Ponty's work).

↳ c.f. "LAD" - what to attribute here?

Final note - I'm surprised the internet didn't come up more frequently (prominently)

"Big word" may become useful for transcripts, but still it remains - look out for the with analyses

Appendix I: Extract of Annotated Transcript for Participant One (Emma)

P: ...gradually, since then, we're becoming closer. So, it is a changing thing. I'm not sure that we'll ever – well, I'm hoping it will be back to a time of more openness and honesty. But, *now*, I'm not sure if that's a bit of a (.) dream, rather than the reality, because, Michael and I don't have that level of communication yet. Whether we will in time, I don't know. Hm...

Can be definition of "closure" actually changed

I: Can you tell me about an experience that you have had where you've felt close to Michael, you've felt closeness?

P: Um. [Pause] Do you mean, like a little, tiny snapshot of an experience when we did something, or...?

I: Whatever, whatever that would bring to mind for you, just, um, an experience.

P: Okay well, uh, what it brings to mind is a time when we both just, uh, were *laughing* about a situation that was ridiculous. And, it was quite an extreme, I thought it was quite an extreme funny, a funny thing, when, when we'd forgotten where the car was parked. So, we were walking around places to find it. [Laughs] And Michael kept saying, "I'm sure it's here, it's here." And we'd arrive [laughs] and it wasn't there, and so then he'd say, "Okay, okay, it's over here," somewhere else. And then, we went. And we must have done that about three times, and by the third time it was just hysterically funny that we were walking around and around places, *thinking* the car was going to be there, and it wasn't there. And, the both of us laughed, laughed, and laughed ourselves up. In fact I think I was just rolling on the floor by the end, 'cause it was just so funny. Um, and he was laughing too. So there, that was a particularly close moment.

Not a situation, but with specific reference to its normality

I: And what, what about that moment allowed you to feel close to Michael?

P: I think it was that we both shared the same – or it - *now* I question it, but then, to me, I experienced it as us both sharing the same thing. We both found it as hysterically funny as... *Now*, I look back and think, quite possibly... And it, and it's interesting, and I'll ask him, when I get, you know, when there's a moment this evening, if he even

*Uncertainty
Fantasy
Do I think about this?*

*Closeness - becomes someone's reality
→ laughing
→ shared experience (intentionally)
→ intensity ("laughing")
→ (con)gratulate -- self
other
→ ? watching the other? the perception, the awareness is a reflection but
Reflections
of the momentary
(temporality)*

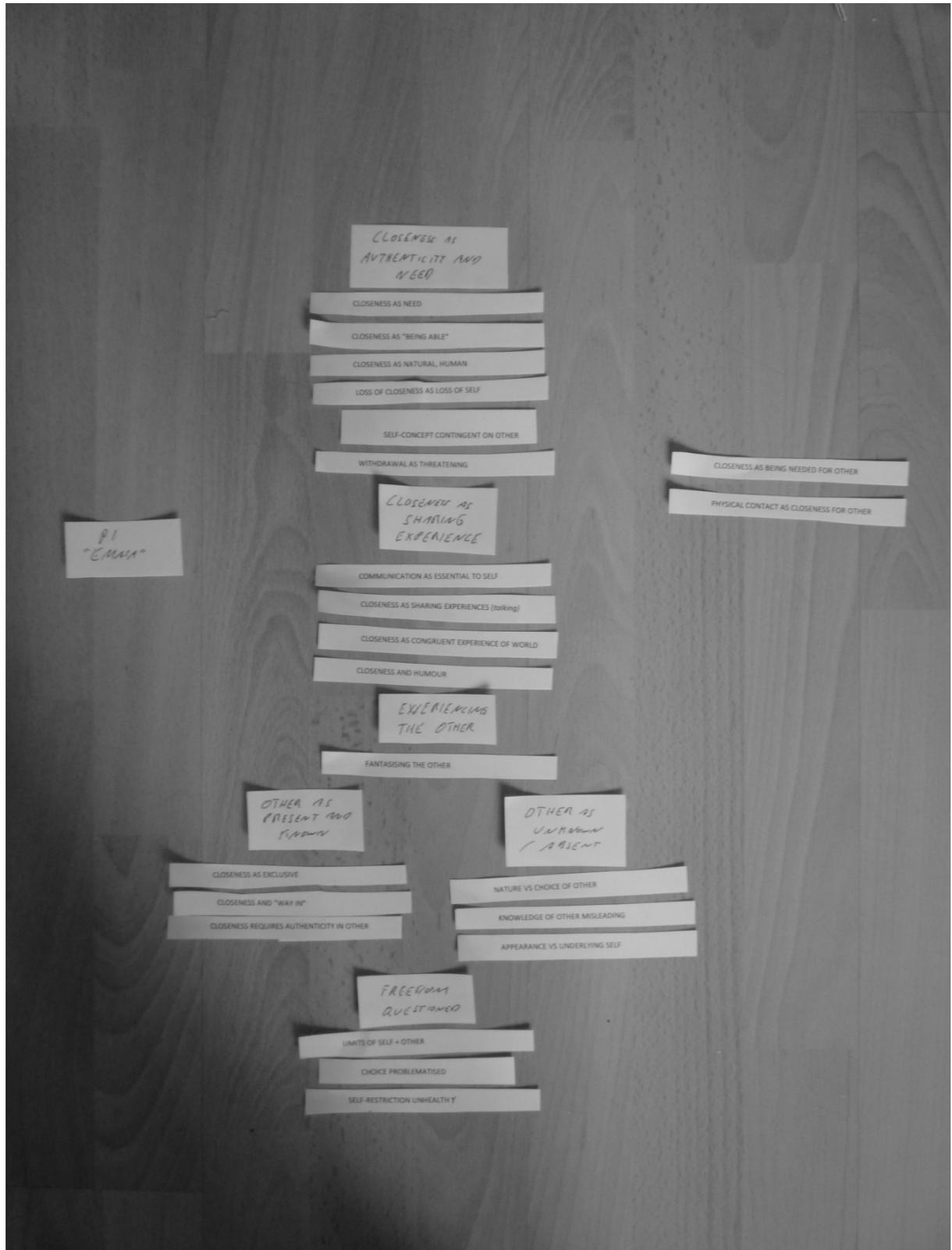
*Difference unity
Thinking reflection
of closeness
unity*

Appendix J: Extract from Compilation List of Instances of Emergent Themes⁴ for Participant One (Emma)

1. Closeness as “being able...”: 10.14-221, 18.5-6, 22.5-6
2. Closeness as sharing experiences: 10.14-21(*), 18.3-7, 20.3-4, 22.6, 27.18-19
3. Closeness as exclusive: 10.18-19, 19.13-15
4. Closeness as “way in”: 12.6-7, 20.17-23(*), 33.2-4
5. Withdrawal as threatening: 12.20-22
6. Closeness as frightening for partner: 11.10-11
7. Closeness & Humour: 13.11-22, 13.24-26
8. Closeness as congruence in world: 13.11-22 (other *known*), 13.24-26(*), 20.17-23
9. Knowledge of other misleading: 13.24-14.1, 14.10-13, 14.15-17, 14.10-11, 21.6-8
10. Appearance vs underlying self: 14.1-2, 14.11-13(*), 21.6-8, 28.7-11
11. Closeness requires authenticity: 15.23, 16.2-3, 18.10-12
12. Loss of closeness as loss of self: 16.2-9, 17.18-19
13. Self-restriction “unhealthy”: 18.1-4
14. Closeness as natural, human: 19.4

⁴ Numbers following themes indicate page and line numbers; bracketed asterisks denote useful illustrative quotations.

**Appendix K: Fragment of Original Thematic Map for Participant One
(Emma)⁵**



⁵ As laid out on the author's study floorspace.

Appendix L: Final Thematic Analysis for Participant One (Emma)

Closeness as Authenticity and Need

Closeness as Need

Closeness as “Being Able”

Closeness as Natural, Human

Loss of Closeness as Loss of Self

Closeness As Sharing Experience

Communication as essential to self

Closeness as sharing experiences (talking)

Closeness as congruent experience of world

Closeness and humour

Experiencing the Other

Fantasising the other

Other as Present and Known

Closeness as Exclusive

Closeness and “Way In”

Closeness Requires authenticity in other

Other as unknown / absent

Nature vs Choice of other

Knowledge of other misleading

Appearance vs Underlying Self

Freedom Questioned

Limits of Self and Other

Choice Problematised

Self-restriction unhealthy

Different Meanings of Closeness

Closeness as Being Needed (Other)

Physical Contact as Closeness (Other)

AS as Non-Communication

Communication problems (*verbal exchange, comprehension*)

Closeness Precluded by Difference

Relationship is not close

Problem as difference, not ASD

Current relationship defies held meaning of closeness

Doing alongside vs sharing

Partner resists closeness / closeness is frightening for other

Partner does not share emotionally

Impasse in desire for closeness

Other becomes Lost

Anxiety as barrier

Partner “mirrors” emotions

Revelation of the other becomes dramatic

Testing the partner

Diagnosis and Reinterpretations

Diagnosis provides framework for re-interpreting

Diagnosis as explanation and vindication of self

AS behaviour appears as thoughtless

AS as unsettling expectations

Diagnosis as “something wrong”

Maintaining Hope

Relationship as a work in progress

“Skills” for solving problems

Living in a “Mad World”

Adjusting the Self

Self invested with responsibility and power

Self as frightening to other
Acting as interpreter
Monitoring the self
Avoiding emotional self expression
Finding other sources for needs
Avoiding thought
Choice problematic
Closeness Deferred
Sadness

Struggle can produce authenticity