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Time and Space: Dimensions of Identity and Relationship in Dementia

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Summary

Research shows that the quality of the relationship in couples living with dementia is of crucial importance. Attachment needs are activated by dementia, with progressive cognitive impairment likely to cause both cognitive and emotional dis-integration in the context of the loss of opportunity for shared understanding and 'inter-subjectivity'. So much so, that lack of intimacy and reciprocity between the partners are associated with depression and predictive of moves to residential care and even mortality rates. Despite this, there is a dearth of interventions which seek to support the couple relationship where one partner has dementia. This paper describes the Living Together with Dementia intervention developed at Tavistock Relationships in London, which is rooted in the importance of containment, emotional contact and understanding, and draws on attachment-informed approaches developed in parent-infant psychotherapy applied to the caring dyad at the other end of life.

Keywords: couples, dementia, containment, attachment, psychotherapy.

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Résumé. L'espace et le temps: les dimensions de l'identité et de la relation dans la démence

Les recherches montrent que la qualité de la relation chez les couples vivant avec la démence est d'une importance cruciale. Les besoins d'attachement sont activés par la démence, avec une déficience cognitive progressive susceptible de provoquer une désintégration à la fois cognitive et émotionnelle dans le contexte de la perte d'opportunité de compréhension partagée et d'«intersubjectivité». À tel point que l'absence d'intimité et de réciprocité entre les partenaires est associée à la dépression et prédictive du passage en établissement de soins, voire des taux de mortalité. Malgré cela, il existe peu d'interventions visant à soutenir la relation de couple lorsque l'un des partenaires est atteint de démence. Cet article décrit l'intervention «Vivre ensemble avec la démence» développée au Tavistock Relationships à Londres, qui est fondée sur l'importance de la fonction contenante, du contact émotionnel et de la compréhension, et s'inspire des approches fondées sur l'attachement développées dans la psychothérapie parent-nourrisson appliquée à la dyade de soins à l'autre bout de la vie.

Mots-clés: couples, démence, fonction contenante, attachement, psychothérapie.

Resumen. El tiempo y el espacio: las dimensiones de la identidad y de la relación con la demencia

Las investigaciones demuestran que la calidad de la relación en las parejas que viven con demencia es de crucial importancia. Las necesidades de apego se activan por la demencia, con un deterioro cognitivo progresivo que probablemente cause una desintegración tanto cognitiva como emocional en el contexto de la pérdida de oportunidades de comprensión compartida y de "intersubjetividad". Tanto es así, que la falta de intimidad y reciprocidad entre los miembros de la pareja se asocia con la depresión y predice los traslados a la atención residencial e incluso las tasas de mortalidad. A pesar de ello, hay una escasez de intervenciones que tratan de apoyar la relación de pareja en la que uno de los miembros tiene demencia. En el presente documento se describe la intervención Living Together with Dementia desarrollada en Tavistock Relationships de Londres, que se basa en la importancia de la contención, el contacto emocional y la comprensión, y se inspira en los enfoques basados en el apego desarrollados en la psicoterapia padre-hijo aplicada a la díada de cuidados en el otro extremo de la vida.

Palabras claves: parejas, demencia, contención, apego, psicoterapia.

Time and Space might be seen as two dimensions that are keys to our understanding of dementia. Firstly, the temporal dimension is fundamental to understanding the nature of the experience of the emotional encounter with the



person with dementia, and I shall discuss this issue of time and identity below. Secondly, in the relationships of people with dementia, psychic space is fundamentally affected. Projective processes replace language as cognitive capacities wane and, in couples living with dementia, the relationship between partners can become claustrophobic – psychically, the dementia becomes "infectious". Typically, the defensive response to this is to seek emotional distance from the person with dementia—but evidence from research as well as psychoanalytic practice shows us that, if containment can be offered for the fragmented psychic states of dementia, then some emotional contact may be recovered, mitigating attachment insecurities. For such containment of the person with dementia to be possible, it is vital that we attend to the emotional challenges of dementia care – addressing the need for the containment of carers so that they are better able to sustain emotional contact with the partner with dementia. Here I shall discuss a psychoanalytic model of "containing the container" (Balfour, 2014), which aims to provide psychoanalytically-informed support for the relationships of couples living with dementia, so that they can be sustained with less need for recourse to the defensive 'solution' of premature foreclosure of emotional meaning and contact, which so often we witness in dementia care.

Overlapping Dimensions of Time and Identity in Dementia

Dementia brings a physical and emotional confrontation with a progressively changing person; who is the same, yet the person as they were is being diminished in their capacity and posing challenges and demands that are new and increasing as time goes on. At the same time as facing loss there is the need to adapt to these new challenges; entailing mourning as well as adjustment to the person as they are now, in their changed and changing state. Being with someone with dementia encompasses the sense of the person as they were in the past, which is part of who they continue to be; the present tense of how they are now and the shadow of the future - how they will be as the dementia progressively takes hold. These different, overlapping, dimensions of time and identity are composite and are part of the emotional encounter with the family member or friend who is living with dementia. Despite the profound challenges of this situation, I have often been very moved in my work with couples living with dementia at witnessing the life that can be possible, adjustments, adaptations and connections between people that can be maintained and developed in new ways.

Attachment and dementia



The process of dementia can be characterized by experiences of loss and separation from attachment figures (or the fear of this) and feelings of insecurity, as unwilling separation and disruption of attachment bonds can be a common part of the experience (Browne & Shlosberg, 2006).

Given the importance of attachment in dementia, what does research have to tell us about what may help with anxieties and insecurities linked to this? Van Assche *et al* (2013) point out the need to link the study of attachment in dementia with the extensive research on attachment at the other end of the lifespan and, as I shall discuss, the learning from developmental research has implications for our thinking about how to respond to the attachment needs of people with dementia.

The fundamental message of developmental research is the importance for the infant of contact with the caregiver's mind, which is crucial for establishing secure attachment (Ainsworth, 1978; Fonagy & Target, 2007). This evidence from attachment research of the importance of the "joining of minds" has important implications for the relationship between the person with dementia and their partner. This indicates how vital may be the carer's capacity to go on thinking about the experience of their partner with dementia, whose attachment relationships are changing as anchorage in their familiar relational and social world is progressively under threat.

Linking Developmental Research with Psychoanalytic Models

Both researches in infant development, as well as psychoanalytic studies, show us that, in good enough circumstances, our closest relationships can be the crucible of emotional growth throughout our lives. At the different developmental stages that we traverse, what is crucial is the sense of connection that comes from emotional contact with another mind that can understand and give words to our experience; or find other articulations or connections that go beyond words.

Following on from Freud, the psychoanalyst, Melanie Klein writing in the 30s and 40s (see Klein, 1957), offers a different view of infantile development in which the infant is, from the earliest moments of life, involved in primitive modes of relating. To give a very brief account of this, Klein described two fundamental positions, or ways of being in the world. Developmentally, one precedes the other, but there is thought to be an oscillation from one to another throughout life. In this sense they are essentially two different states of mind, each composed of a particular constellation of anxieties, defences and other feelings. The first of these, the "paranoid schizoid" position is one in which, in response to primitive anxieties, the infantile mind creates various splits, the most important being between its own loving and aggressive impulses. The world then is divided between idealized good objects and bad ones which are felt to be



persecuting, and which are located outside the self, in the object, often the mother. In this state of mind, there is a lack of capacity to experience loss as the absence of a good object, instead of which there is felt to be a present bad object, responsible for the feelings of loss and frustration. The leading anxiety is with the survival of the self. In the depressive position, as development proceeds, the infant comes to a more integrated state, in which objects are no longer experienced as all good or all bad, but as containing a more realistic mixture of qualities. There is the experience, then, of love and hatred for the same person, and this leads to feelings of concern and remorse for the loved one, because of the realisation that the object that is hated and attacked is also the loved object, upon whom the individual depends. This leads to feelings of loss and guilt, which enables mourning to take place.

Development proceeds from the very early vulnerability of a tiny baby to greater autonomy and independence in younger adulthood, followed by what is often termed a "return" in later life to similar situations that we faced in early life. Fortunately, for many of us, the gradual "return" is not too traumatic. However, from a psychoanalytic perspective, the way in which this will be experienced will depend on the extent to which paranoid-schizoid or depressive anxieties are uppermost. If there have been early difficulties in facing depressive feelings, then there will be problems in facing loss later in life. As Jacques (1965) points out, if the depressive position has not been securely worked through, then unconsciously death will be viewed in terms of the persecutory anxieties of the paranoid-schizoid position. In this state of mind, the fear of loss and loneliness may be experienced as the fear of being reduced to the level of a terrified, disorganized and uncontained infant. Sometimes patients will describe this as, for example, falling into a black hole. The fear of loneliness can be a fear of being left alone with what are felt to be bad and unintegrated parts of the self. This can be tragic for some people, as some distance may have been achieved in younger adulthood from situations of dependency, which may be associated with particular difficulties for them. At this point in our lives as younger adults we are likely to be at the point of maximum independence and autonomy. The "catastrophes" of old age, such as dementia carry the threat of being abandoned to a state of utter helplessness, which for many of us may also at an unconscious level carry fears of a traumatic return of earlier states of dependency. How one manages such fears, or faces and tolerates such dependency will depend on the internal legacy of earlier times.

The Psychanalytic Concept of "Containment"



The concept of "containment" is often used in health and social care settings, but what does it mean in psychoanalytic terms? According to its originator, the psychoanalyst Wilfred Bion (1962), if the mother is able to take in and think about her baby's distress, it can become detoxified and the baby may be able to take back in its feelings in a more manageable form. As it does so, over time, the range of feelings that the infant can encompass in its own mental apparatus, expands – and the capacity of the caregiver to take in, think about and give meaning to experience is internalised. As we are growing and developing as infants, we need this emotional connection with our mother or primary attachment figures to enable our minds to grow. Throughout our lives, such emotional contact with others allows us to experience our thoughts and feelings in ways that enhance our sense of understanding, as of feeling understood. From a psychoanalytic perspective, the common element in the emotional task facing family and other carers of people with dementia may be the importance of providing containment. In dementia, increasingly the carer partner becomes the witness, whose mind can register and think about what is happening to the person with dementia whose own capacities are progressively diminished.

Projective Identification

To understand "containment" in psychoanalytic terms, one also needs to know about the important concept of "projective identification". This describes a process that is dominant in early development, in Klein's "paranoid schizoid" position in particular, but which persists throughout life, whereby feelings, particularly frightening and disturbing ones, which the infant cannot express verbally are got rid of by projecting them out into others, who then become identified with what has been projected into them. The recipient of these projections, such as the mother, then has the chance to experience the baby's feelings, and so projective identification is both a means of communication about, as well as a defence against, feelings and states of mind which are felt to be unmanageable. According to Bion (1962), if the mother is able to take in and think about the baby's distress, it can become 'detoxified' and the baby may be able to take back in its feelings in a more benign form. As Waddell (2007) puts it:

«By the mechanism of projective identification the baby/child/elderly person who cannot understand, think or talk about his or her fragmentary or fragmenting experience, may nonetheless be able to engender in the caregiver some version of that basic experience. If the caregiver can offer a mentally receptive state of mind, conscious or unconscious, the communication can be received, modified if it is one of pain and rage, appreciated if it is one of love and pleasure and re-communicated...the caregiver's mind functions as a container for and a sorter of, the projected emotional fragments which, as a



consequence become `the contained`. Care of the very elderly, those so often lacking the capacity to speak, yet so intensely riven by extreme emotional states, requires a painful reversal of the original pattern of container-contained (the young now struggling to offer states of reverie to the old).» (p.199).

This highlights the importance of trying to understand the communications of individuals with dementia, as often conveyed through projective processes. Windows of clarity, of a briefly more integrated state may be opened for the person with dementia by trying to understand them, thereby making emotional contact and finding some way – either in words or action – of conveying that understanding. Even in the profound losses of dementia, there might be moments of recovery, of "ripening" amidst the "rotting" (Waddell, 2007). To what extent, as the pressure of the illness increases and capacities are lost, more persecuted states of mind may begin to dominate is unclear – but the clinical evidence is that, to some degree at least, this depends on how much containment can be offered by the partner without dementia. However, the situation is different from that of infancy where there is development of mind and growth towards separation and greater somatic and psychic integrity. Needless to say, the situation of dementia reverses this developmental trajectory; what is ahead is increasing dependency, loss of autonomy and mental functioning and ultimately, death. Whilst recovered understanding and moments of mutuality and emotional contact may be of crucial importance in dementia, they can be difficult to achieve, and they will diminish as time goes on, facing the couple – both person with dementia and their partner - with considerable psychic challenges. This raises the question of what supports may be needed to help the couple facing such a challenging emotional situation at this stage of life, which does not contain the hope for the future which sustains the 'nursing couple' of mother and infant.

The Couple with Dementia

In a relatively healthy adult relationship where projections are not too fixed, partners may be able to act as containers of difficult feelings for one another in a flexible way. The difficulty for the couple living with dementia is that, even in good enough relationships where projections may once have been more fluid, this is changed by the illness. The person with dementia loses more and more their anchorage in the world. "I get frightened when he goes out of the room" is a comment often made, expressing the insecurity felt by many people with dementia. The partner without dementia can feel tremendous pressure when faced with their partner's vulnerability and need, where the memory of the reassurance that they will be back soon is lost a few minutes later. As language is lost so increasingly projective processes replace verbal communication. Now



increasingly the burden shifts to the carer partner to provide a containing mind. Feelings of frustration, hatred and resentment on the part of the partner without dementia can arouse tremendous guilt – and there can be a great need for the clinician to help such feelings to be acknowledged and expressed. There is a need to "contain the container" – to help the carer partner to process their experiences, so that they are able to be emotionally available to their partner with dementia. Dementia can, in a sense, feel infectious – and the concept of projective identification is useful as a way of understanding this; how the dementia is also a couple experience, with unconscious as well as conscious areas of experience that are held within the couple.

Case example

A dilemma which couples of all ages can struggle with, is the threat of loss of individual identities in the relationship and for this couple, this longstanding difficulty had been exacerbated by the dementia. At the start of the work, they said they felt like "Siamese twins" — as they were "thrown back upon themselves" by the dementia. This was a claustrophobic situation which was familiar, although the dementia had robbed them of their established defences, their previous "escape routes"—having before had separate bases, often working for long periods apart.

He was immersed in her world of dementia -he said that he wanted to live through it alongside her, but felt he was struggling to keep his head above water. He felt submerged at times, he said, and was strongly identified with her experience. He described how he was trying to keep his own mind alive, through reading – though he struggled to write or engage in his creative work. Now he felt it was as though he didn't exist anymore. His role was gone and at times he felt that she was the one who seemed more content and to be coping better – he felt anxious, cut off from people – displaced from his old roles, from himself. He was not working on a writing project and he had lost his anchorage in his sense of creativity and purpose. He had health problems of his own, requiring treatment and he was frightened of that, he said. The old struggle, of how to manage each of their individual needs, which were felt to threaten to negate the other's, had not gone away, appearing now in a new guise, of whose health would take priority. On one occasion, they'd had a row about whose needs should prevail and he'd felt she was "putting the knife into him". This is perhaps an image that captures the projective identification, of how her state of mind was projected into him, and was infectious, as he put it.

At one session, he commented on how, before, he had been talking of being overwhelmed and fearing that he couldn't manage things and was unable to think clearly. On reflection, he said, these were feelings that one might expect



her to be having, and somehow he had been having them. He thought more about this and began to recognise that whilst these feelings of losing his sense of identity, his capacity to work and his connection with the world, were part of his own experience, they were also perhaps feelings which were hers as well. The intensity with which he felt them gave him an understanding of what she might be going through, he said. As he reflected more on this, he felt he had an insight into her mind, into her experience.

As time went on it seemed that he wasn't so much in that state of mind and had recovered more his sense of himself, his own mind and intellectual life – and he started writing again. I think his identification with her had maintained the lack of psychic separateness between them and perhaps functioned to avoid the experience of loss, though it had compounded the resentment and claustrophobia of the situation. It seemed that, as he felt he had more internal and external support and was more anchored in his own, separate mind, he was then able to be alongside her and to engage with her, without withdrawing so much in anger or frustration.

As more psychic separateness emerged between them, they were more in touch with the emotional pain of the losses they faced. At one session, he spoke about the loss and the changes that they had to adjust to as a couple, and added that it also made him think of the past – how there had been real costs of his decision to live away from her for all that time when they were younger. There had been impacts on her, on the family – losses, and time that they could not have back. "I always thought that there would be more time, but some things are lost and

that's it – they don't come back and you don't get a second chance."

He was faced by his guilt and by the limits of reparation that were possible at this point, now that the dementia was in process and things could not, in reality, be 'made better' any more. As he became more able to tolerate these feelings, and to articulate them, he spoke of his wish to make it up to her, for his unavailability before; and although the clock could not be turned back, there was the sense of reparative processes beginning to emerge, of the wish to make some repair whilst there was still time. He began to engage with her more closely when he was with her, allowing more emotional contact between them. She seemed to recognise this:

"The other night, we were going to sleep with our fingers linked together – touching our hands, and that hasn't happened for a few weeks", she said. Her experience of emotional contact with him and with me in our joint discussions seemed also to lead to a shift in her state of mind. At times she could feel more hopeful.

"There are things I look forward to – seeing people, family – walks", and she said she had thought of taking up music again, "... there are things I can do to hold back the AD, not to give up", she said. "If I could find a teacher who would take someone like me, with my difficulties – what could be recovered and held



on to?" In our work, it seemed, she felt that there was an interest in her and her feelings and perhaps the experience of this helped her to feel her mind to be alive; for a moment in time she could hold onto the music inside herself, so to speak.

Although such contact is very important, in dementia this will be increasingly difficult to sustain, raising the question of what should the aim of psychological intervention be? Perhaps one answer might be in helping to support the couple so that they might be helped to avoid premature foreclosure of emotional involvement with one another, keeping alive, whilst they can, an imaginative engagement with their own experience. What felt to be of significance in the work, was their experience of my seeking to understand – and that it was the act of trying to understand, rather than of any special "understanding", which enabled an atmosphere of emotional contact and meaning-making to emerge as part of a shared communicative endeavour. In this sense, I am reminded of Enid Balint's comment that "the process of psychotherapy is more akin to learning a language than a joint journey of explanation or research..."

Conclusion

Historically, there has been a neglect of the experience of dementia as a focus of study that could help shape our understanding of how best to help those living with the illness, and this has only begun to change in recent times. This may be a reflection, at the group or societal level, of the difficulty in allowing close emotional contact with the experience of those living with dementia that has been explored here at the level of the couple; an example of our human tendency to withdraw from things that we would rather not know about, dementia facing us, as it does, with the prospect of the loss of capacities that we think of as fundamental to who we are, to our very personhood. This neglect matters because, if an understanding of the experiences of people with dementia and those living with them is not more at the heart of our approaches to dementia care, then we will fail to learn how best to support people with the emotional challenges they face. Significant change in the quality of our services will only be achieved if the experiences of people living with dementia can be brought out of obscurity into the open; if the "private lives" of these more intimate aspects of experience can be put at the centre of our thinking about dementia, allowing us to develop greater understanding of the emotional supports that are needed to help sustain relationships and to hold people in their familiar relational context, supporting the resilience of couples and families living with the illness.

To this end, we need to draw on what we know from research and clinical practice about the importance of emotional contact and containment in



mitigating attachment insecurity and supporting the person with dementia's anchorage in the world of meaning and human relationships. From the beginning of our lives, we need to be understood, to link with others whose capacity to take us in and understand our emotional states enables us to develop emotionally, and to feel secure. Whilst this is crucial at our beginning, it continues to be true throughout our lives and becomes truer again as we move towards our end. The presence of another, understanding mind is vital as mind is lost in dementia. In developing this idea, this chapter has discussed the importance of attachment needs across the lifespan, linking this to the psychoanalytic concept of containment in dementia care and the importance of this for supporting the emotional resources of couples and families and enabling them to live more emotionally satisfying lives together, with dementia.

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