

# Love between couples living with Alzheimer's disease: narratives of spouse care-givers

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## **ABSTRACT**

The aim of this interdisciplinary study is to describe and analyse the meaning of love in relationships between couples living with Alzheimer's disease (AD). Despite the wealth of studies describing relationships in the face of AD, little is known about the experience and changing meaning of 'love' between spouses when one of them is suffering from AD. A qualitative narrative approach was used to capture what love means for couples when one spouse is living with AD. A combination of open discussion along with a semi-guided interview was conducted with N = 16 spouses of persons living with AD. Data were analysed using Thematic Analysis. A leading theme that emerges from the interviews is that AD provides a significant indicator of the meaning and understanding of the experience of love. Five major types of relationship developments occurred after the disease emerged: love died, love became weaker, love did not change, love was enhanced and the spouse fell in love again. The need for further research is discussed. The findings of this study offer an additional perspective to the existing literature, thereby providing a more comprehensive outlook on marital relationships within the context of AD.

**KEY WORDS** – Alzheimer's disease, love, relationships, meaning, spouses.

## **Introduction**

Alzheimer's disease (AD) is an organic mental disorder associated with cortical neurological degeneration, which impairs brain functionality as well as affecting the personalities of those who live with the disease (Ageing International 2000; Galimberti and Scarpini 2012; Harris 2009). AD is the most common among various types of dementia, a general term describing a range of symptoms that include loss of memory, impaired speech, loss of orientation, mood swings and delusions (Holzer, Warner and Iliffe 2013; Livingston *et al.* 2017; Mathers and Leonardi 2000). The disease mainly has

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an impact on two groups of people: those who suffer from the disease and the family members who care for them (Potgieter and Heyns 2006; Shanley *et al.* 2011). In practice, the burden of care falls for the most part on the spouse of a person living with AD, and therefore the consequences for the spousal relationship is particularly meaningful (Boylstein and Hayes 2012; Evans and Lee 2014; Lewis 1998).

Many studies document the challenges and difficulties that relationships encounter when one partner has AD (*e.g.* McCabe, You and Tatangelo 2016; Preeyam *et al.* 2016). Of major significance is a sense of the loss of the relationship that existed up to then, the loss of former intimacy and the loss of someone close with whom the spouse has spent most of their lives (Beeson *et al.* 2000; Evans and Lee 2014; Harris 2009; Williamson and Schulz 1990; Wright 1991). However, despite the wealth of studies describing relationships in the face of AD, little is known about the experience and changing meaning of 'love' between spouses when one of them is living with AD. Furthermore, research on how the experience of love changes over the course of the disease is still in its infancy. The aim of this study, therefore, is to contribute to understanding the experience of love for couples living with AD. Methodologically, the study was based on semi-structured interviews with 16 spousal care-givers living in various settings in Israel, and it employed thematic analysis for interpretation. Findings reveal a multifaceted view of love among couples living with AD, depicting diverse responses that are due to the depth of relational bonds before the onset of AD and to the intersecting differences of culture, gender, class or education.

## Literature review

### *Discourses of love: various theories*

Love is one of the oldest concepts of human civilisation. Artifacts found in ancient caves indicate that the emotion of love was an issue of concern for early societies (Berscheid 2010). One of the most common ways to refer to love is as an emotion or as a feeling. Indeed, of the 200 words that indicate emotion, Shaver *et al.* (1987) found that the concept of love was a prime pointer to emotion or feeling.

A common division of various types of love is that between romantic love, companionate love, compassionate love and adult attachment love (Berscheid 2010). *Romantic love* involves the strong and comprehensive desire to be with someone, to share their company for its own sake and in all sorts of ways, importantly including the sexual. *Companionate love* is perceived as less intense than romantic love (Hatfield and Rapson 1993,

2009). It is also defined as love based on deep friendship, mutual trust and the desire to share experiences together (Grote and Frieze 1994). *Compassionate love* also includes a kind of profound awareness of the suffering of the other, accompanied by the wish to relieve it. *Adult attachment love* can be found in the natural tendency to form a special attachment, to weave the couple's lives together while providing each other with security and an agreeable environment (for a review, see Bowlby 1973). Although these types of love do not have clear-cut boundaries, they nevertheless manifest distinct prototypes of loving relationships. The focus of this study is on romantic love between couples living with AD.

In light of the complex nature of romantic love, various philosophical and psychological theories have been suggested for characterising the circumstances associated with its enduring nature. For selected such discussions in philosophy, see e.g. Ben-Ze'ev (2017), Ben-Ze'ev and Goussinsky (2008), Ben-Ze'ev and Krebs (2017), Brogaard (2015), Buber (1958), De Sousa (2015), Frankfurt (2004), Helm (2010), Krebs (2015), Solomon (1988) and Velleman (2006). For some discussions in psychology, see e.g. Finkel et al. (2014), Fisher (2010), Gottman (1995, 1999), Kayser (1993), Mitchell (2002), O'Leary et al. (2012), Schnarch (1997) and Sternberg (1986).

The various philosophical models for explaining romantic love can be divided into (a) *agent-focused models*, involving (i) the *caring* model referring to the lover (Frankfurt 2004; Lévinas 1961, 1974) and (ii) the *self-love* model (Bransen 2006; cf. Harcourt 2011); and (b) *relation-focused models* including (i) the *fusion* model (Merino 2004) and (ii) the *dialogue* model (Krebs 2014, 2015).

The fusion and self-love models are problematic from various moral, emotional and practical perspectives, even though the fusion model is often considered to be the essence of true love. Certainly, they are not suitable for describing long-term profound love. Accordingly, the two major competing models that adequately describe romantic love are the caring and the dialogue models. We shall examine the suitability of these two models for describing the love in a relationship where one spouse has AD.

The caring model is the prevailing model in philosophical discussions of love (e.g. Frankfurt 2004). There is indeed no doubt that caring is essential in romantic love. Caring does not merely express having a good feeling about the beloved and the wish to be with the beloved, but is accompanied by more profound attitudes and activities that seek to enhance the beloved's wellbeing. In some views of love, true love has less to do with the lover's own needs and more with concern for the other (e.g. Lévinas, 1961, 1974).

In the dialogue model, romantic love develops through interactions between the spouses. Krebs (2014: 22) claims that love is not about each partner having the other as his or her object; it is between the partners:

'Love is a relation. It is constitutively shared ... Love is not reducible to individual emotions or actions. Rather it is intertwining of two lives.' In such an approach, love develops through cultivating a new identity, termed *We* (Buber 1958; Krebs 2011, 2014, 2015; Nozick 1989; Scheler 1954; Sherman 1987, 1993). According to Sherman, the *We* form is a way of being in which the partners are attuned to each other not merely out of respect or mere co-operation, but by expanding their personal boundaries to create a sense of union (Sherman 1993). This establishes collective emotions that, according to Gilbert (1989, 2014), require a joint commitment based on the couple's readiness; thus, the couple is committed as one to a certain unified cause (*cf.* Searle 1990). In long-term love, the need to belong and to share meaningful experiences is central (Baumeister and Leary 1995; Baumeister and Bratslavsky 1999; Baumeister *et al.* 2013; Ben-Ze'ev and Krebs 2017); this is even more pronounced in old age when people tend to be more alone (Piqueras 2016), and issues of belongingness and meaningfulness are more problematic.

It should be noted that the caring approach does not deny the role of interactions in love, and the dialogue approach does not deny the role of caring in love. However, they differ in which they assume to be the essence of profound love. Krebs (2014) argues that the caring model demands both too much (excessive levels of altruism) and too little (insufficient levels of dialogue). The issue is whether what seems to be too much and too little in relationships between healthy younger people is also the incorrect proportion for relationships between those in old age in general and those living with AD in particular.

On the face of it, the dialogue approach seems to be less successful in explaining love in relation to AD, in which the partners' interactions decline in quantity and quality. However, as our major concern is the development (or deterioration) of the romantic relationship, this model, which focuses on interaction in the relationship, might be more pertinent for us. Both the caring and dialogue models seem essential for romantic love in many types of circumstance, but their nature and extent can differ.

### *Love in old age when one spouse is living with AD*

A prevailing approach to romantic love in old age has been that of considering it as a 'dead horse' (Charles and Carstensen 2002). This pessimistic view has been supported by numerous studies indicating that with ageing, couples become more dependent on one another, seem to fall into a routine pattern in their interactions and in many cases perceive each other as somewhat predictable. They tend to lose the ability to surprise each other and their relationship therefore lacks excitement (Berscheid 2010).

Other studies have pointed to a more complex and less pessimistic reality. For example, Carstensen and Charles (1998) found that in old age there is a tendency to seek a general sense of wellbeing. This situation, in their opinion, does not cause feelings to ‘flatten’, but rather gives way to a richer emotional experience. Moreover, even couples who report being unhappy in their marriage indicate that they still feel better about their relationship than they did at the start of their marriage, as they have gained the ability to balance their emotions and avoid arguments. Hence, adaptive elements presented in old age usually result in developmental shifts, including better self-regulation and modifications in priorities that tend towards seeking closeness, which consequently make the relationship more meaningful (Charles and Carstensen 2010; Charles and Luong 2013; Charles *et al.* 2015). Older persons generally have more equal levels of life satisfaction, even when their objective circumstances are less desirable; hence, life satisfaction shows no decline with age (Diener and Suh 1997).

In old age, the reduced ability to share various activities presents a challenge to the dialogue model, which is based upon the spouses’ ability to share activities and accordingly to establish meaningful *We*. This is even more problematic in cases of AD; these circumstances are complex and yet an under-studied issue (Boylstein and Hayes 2012). AD severely impedes the ability to socialise, especially the capacity to converse and share a common interest with others – a feature that distinguishes AD from other afflictions such as strokes (Boylstein and Rittman 2003) or cancer (Schroevers, Ranchor and Sanderman 2006). Thus, the damage to the intimacy between the spouses is even more painful, often creating the need to find ways to reconstruct the relationship. In line with the gradual deterioration accompanying AD, we can expect gradual changes in the nature of the couple’s *We*. Portmann (2000) describes a similar relationship – that is, between patients and their physicians – as a ‘marriage without romance’. Can we say the same about couples who live with AD? A deeper understanding of the types of interactions (such as shared intrinsic activities) essential to love, and the kinds and degrees of caring, can be helpful in this regard.

Most research to date has focused on the effect of the disease on primary care-givers, namely spouses (Davies *et al.* 2001). The voice of people living with AD has been under-studied (Hubbard, Downs and Tester 2003). A significant issue in this regard is whether wellbeing and illbeing comprise opposite ends of a bipolar continuum, or are separate, independent dimensions of mental health. If they are separate as some dimensions seem to be (Ryff *et al.* 2004, 2006), then both partners can enjoy love despite one of them being ill. Although understanding love in couples living with AD entails a unique perspective, such a perspective would advance our understanding of love in more common circumstances.

Nevertheless, some issues that are related to love with AD have been explored. For example, Hayes, Boylstein and Zimmerman (2009) studied the impact of AD on couples' intimacy. They found that the disease affected marital intimacy, though not always for the worse. For instance, some of the participants in their study reported they felt closer to their sick spouses than they felt previously. This is possibly due to 'end-of-life feelings', which lead people to feel greater appreciation about what they have and to enjoy it as long as it lasts (Hayes, Boylstein and Zimmerman 2009). On the other hand, other scholars report damage to such intimacy as a result of the way healthy partners viewed their sick spouses. This position was found particularly among women taking care of their ailing husbands. In general, Hayes, Boylstein and Zimmerman (2009) concluded that most participants, both men and women, reported the disease had a harmful impact on at least one of the following aspects of closeness: emotional, social, physical, sexual, spiritual and intellectual intimacy.

Another significant issue is how we define or describe the actual romantic togetherness of couples living with AD and those who do not. Here it is useful to consider the philosophical view that emphasises the *We* element in romantic relationships. Thus, Nozick (1989) emphasises the romantic connection between the lovers, rather than their individual attitudes. He argues that what is common to all kinds of love is that our own wellbeing is intimately linked to that of the beloved. Romantic love is *wanting* to form a *We* with a particular person. However, in this *We*, the two people are not physically bound together like Siamese twins. Rather, they form a new identity. According to Nozick, while each person in a romantic *We* desires to *possess* the other completely, each also needs the other to be an *independent* and non-subservient person. In a similar manner, Krebs (2014, 2015) considers the connection between the partners to be at the centre of love, and views the basic features of the connection as shared emotional states and joint activities. The connection amplifies the flourishing of each lover as well as the flourishing of their relationship.

In this spirit, Kaplan (2001) investigated the concept of couplehood as '*We*' or '*I*' among couples living with AD while the affected spouse was hospitalised in an institution. Kaplan established a typology of five perceived types of relationship, ranging from feeling as a couple (Till death do us apart), compared to not feeling married at all. Interestingly, Kaplan found that the location on the typology scale was compatible with the nature of the relationship in the past. That is, spouses who described a strong relationship in the past also described the feeling of strong *We*. Once again, however, contradictory findings also exist. For example, Førsund *et al.* (2015) found that participants' experiences shifted between feeling as *We*, as opposed to feeling as *I*, while Loboprabhu *et al.*

(2005) argue that the relationship of couples living with AD has a high risk of failure or breakdown, and in fact its fate depends on how successfully couples deal with the disease.

As intimacy between couples is a core aspect of the way they relate to one another, the intimacy of those who live with AD is likely to shift into a new form (Youell, Callaghan and Buchanan 2016). This new form is apt to be influenced by age, gender, class and ethnicity (Simpson *et al.* 2015), and will usually engage with aspects of mutual experiences to enable a joint sense of understanding within the relational dyadic context (Laurenceau *et al.* 2004). For example, in a meta-analysis, Erol *et al.* (2016) found there seems to be some consensus that female care-givers' experiences of caring for their spouses with AD include higher levels of burden and stress, as well as symptoms of depression, as compared to their male counterparts, with similar effects reported across different settings and countries. Also, more women than men tend to report they had no choice in assuming the care-giver role (Alzheimer's Association 2014). Yet another way to view this relational context is through the cultural lens of intimacy, sex, love and romance, all of which are cultural constructs (Wherry 2013).

However, to facilitate this mutual understanding, the care-giving partner usually works actively to 'mend the cracks' by containing and maintaining the intimate relationships between the couple (Youell, Callaghan and Buchanan 2016). Accordingly, it is important to recognise the various ways in which couples relate to one another, including all the nuances that underscore tenderness and sexual activity (Simpson *et al.* 2015). Davies *et al.* (1998) suggest that sexuality may serve as a means to maintain part of the marital relationship prior to the full onset of the disease, but that cognitive and emotional decline make sex rather problematic over time.

In this regard, Chesla, Martinson and Muwaswes (1994) divided the relationships between couples who live with AD into three types: (a) a continuation of their bond prior to the illness, with the care-giver regarding the person with AD as a full partner in their relationship; (b) a relationship that has been altered by the disease, with the care-giver regarding it as continuous but transformed; and (c) a relationship characterised by extreme discontinuity and distance between the couple, with the care-giver remaining committed to the person with AD. This division, according to Chesla, Martinson and Muwaswes, points to the AD sufferer's significant role in shaping the marital system while living with the disease. In other words, the reality of day-to-day care for a spouse living with AD will ultimately affect how the couple perceives their continued relationship, and how they use this continuity as a coping strategy (Walters, Oyebode and Riley 2010). This is in contrast to Kaplan (2001), who found that relationship continuity is a function of the nature of the relationship before the illness

and is not affected by daily coping. Shmotkin and Shrira (2012) similarly argue that people attribute feelings to their past, whether or not these feelings overlap or match their original anchor periods, and hence they find exceptional and complementary explanations to explain the variance between the present and the past. It seems that both factors – that is, the nature of the previous relationship as well as the new reality of care – influence the nature of love.

In summary, understanding love in the context of relationships where one spouse has AD requires a unique perspective. Furthermore, there is a lack of comprehensive studies examining whether and how such love changes during the course of the disease. Consequently, our main research question concerns the nature of the experience of love in relationships in which one of the spouses is afflicted with AD.

## **Method**

### *General*

In recent years there has been a significant change in the direction of scientific research, especially in the medical arena, towards a focus on understanding health conditions through stories that can offer greater awareness about the experience of care-giving (Boylstein and Hayes 2012; Bury 2001; Hinton and Levkoff 1999). Bruner (1990: 13) proposes this involves a two-way process in which the ‘story images life and life images the story’. Thus, the stories serve to preserve someone’s identity when it is threatened by damaging situations such as mental illness (Bury 2001). This direction fits well with the general trend in the study of AD that focuses on the couple and their marriage bond, in particular through their feelings of happiness and love during the course of their lives. With this in mind, it was decided to adopt a qualitative narrative approach, which is appropriate to the subject under investigation and to the fact that the search for meaning is a central part of coping with chronic diseases such as AD.

### *Sampling method*

Focused criteria sampling in qualitative research is important for identifying ‘participants with a wealth of information’ (information-rich participants) who can offer deep insights into the subject under scrutiny (Patton 2002: 230). In this respect, the present study’s sample consisted of spousal care-givers who, on a daily basis, provide direct care for their spouses diagnosed with AD. The sample was purposively selected to include as much diversity as



possible among the participants, such as a range in their socio-economic status, education and religious background, as well as variety in the different stages of their partners' disease and of the duration of the disease.

For the purpose of this study, the criteria for participation was defined as those who were spouses to and lived with and cared for a person diagnosed with AD, who had been diagnosed as being in the second or third stage of the disease. Accordingly, professionals divide AD into three stages that vary in length from person to person. In the second and third stages, symptoms such as memory loss, cognitive behaviours, language impairment and mood swings (to mention just a few) are usually consistent and obvious, and thus readily diagnosable (Craig *et al.* 2005). In addition, care-giving spouses were sought who came from various educational backgrounds and who had some kind of occupation and income.

For the purpose of this study, only couples who were formally married were included. Married couples who had not lived together for at least five years were not included. This last criterion was to ensure that the relationship between them was well-established and relatively constant prior to the development of the disease. Bearing in mind the potential characteristics of the disease, those spouses married to individuals living with AD who were violent or might have posed any kind of threat, whether verbal or physical (Lawn and McMahon 2014), were not included. The minimum age for inclusion in the study was 65. Historically, this arbitrary chronological age was established by Bismarck of Germany as an administrative category that coincided with pension age and categorised the person as an 'older adult' (Tokatli 1997). To this day, it remains a commonly accepted threshold for research into health and diseases in old age.

The care-giving spouses of the persons living with AD were recruited through three sources. The first source was via direct contact with families living with AD with whom the primary researcher had past contact while counselling them about how to cope with the disease. The second source was via a facilitator of a support group, which is under the auspices of the Emda Association, an Israeli organisation which provides family members living with AD with volunteer and paid services, as well as offering them seminars and other activities. These support groups are usually diverse and include people from different walks of life among Israel's population. However, they do not include support groups that have Arab and Jewish participants in the same group, due to location issues, on the one hand, and cultural and religious differences, on the other. The third source was based on a 'snowball' technique, in which participants referred the researchers to other participants. Together, these three sources enabled the researchers to locate participants to ensure a sufficiently wide spread of respondents in terms of class, belief system and stage of AD. This strategy

was designed to minimise asymmetries of power in terms of voice, accuracy and representation, and resulted in an even balance of female and male representation. Gay and lesbian couples were not included in order to avoid adding further cultural and contextual issues into the study. It should be noted that from a maximum variation perspective, the absence of Arabs and members of the LGBT community can be viewed as a limitation that needs to be rectified in future research.

Sixteen care-giving spouses of individuals living with AD who met the criteria agreed to participate in the study. [Table 1](#) summarises the personal background variables of the study's participants. Pseudonyms were used to protect participants' identities. The sample size was adjusted to the nature of the research and was applied, as Morse ([2000](#)) proposes, by careful planning of the study's methodology.

### *Research tools*

When interviewing people in qualitative research, the goal is to explore thoughts, experiences, feelings and implications that are not always directly apparent, and thus enter into the inner world of respondents. This takes into account that their life experiences are both meaningful, as well as unique to them (Patton [2002](#)). The strategy used for the purpose of the interviews was based on a combination of open discussion along with a semi-guided interview. This strategy offered greater flexibility to explore certain topics in depth, as well as enabling new and relevant topics to emerge (Patton [2002](#)). The actual length of the interview was flexible, lasting between one and two hours as was deemed necessary, and according to each respondent's capacity and needs. The participants were given the option of choosing the location of the interview; in fact, all of them eventually chose to conduct the interview in their homes.

All interviews were recorded and immediately after the interview were tested to determine whether there were technical problems, as well as to add details or terms that were necessary to elucidate. The interviewers' comments were incorporated into the field notes by combining the researcher's thoughts, intuitions and descriptions, all of which were written up in the car, immediately after the interview. In order to not impose too heavy a burden on the respondents, the interview guide deliberately limited the number of questions, but did ask clarifying questions (probes) when needed (Boyce and Neale [2006](#)).

More specifically, the interview guide encompassed two content worlds, that of AD (including aspects of geriatrics, sociology and psychology) and that of love (including philosophy and psychology). The following are examples of questions: 'What does AD mean for you?' (an example of a

TABLE 1. *Participants' details*

| Pseudonym (gender) | Nature of love | Age | Spouse's age | Years of sickness | Years of marriage | Years of education | Origin    | Self-reported religiosity  | Occupation      | Subjective economic status |
|--------------------|----------------|-----|--------------|-------------------|-------------------|--------------------|-----------|----------------------------|-----------------|----------------------------|
| Ayala (f)          | Enhanced       | 68  | 71           | 4                 | 44                | 12                 | Yemen     | Traditional (not orthodox) | Diverse         | Good                       |
| Arnon (m)          | Renewed        | 86  | 92           | 12                | 65                | 15                 | Syria     | Secular                    | Writer          | Average                    |
| Yvette (f)         | Enhanced       | 72  | 80           | 4                 | 48                | 12                 | Bulgaria  | Secular                    | Insurance       | Good                       |
| Rami (m)           | Same           | 94  | 88           | 4                 | 68                | 12                 | Greece    | Secular                    | Diverse         | Average                    |
| Romie (f)          | Weakened       | 65  | 70           | 3                 | 40                | 12                 | Israel    | Secular                    | Accountant      | Good                       |
| Eli (m)            | Same           | 80  | 76           | 6                 | 56                | 8                  | Morocco   | Traditional                | Factory worker  | Good                       |
| Eyal (m)           | Same           | 67  | 68           | 12                | 46                | 12                 | Israel    | Secular                    | Management      | Average                    |
| Lavie (m)          | Weakened       | 77  | 76           | 3                 | 58                | 12                 | Yemen     | Religious                  | Farmer          | Average                    |
| Avinoam (m)        | Died           | 73  | 69           | 5                 | 44                | 10                 | Israel    | Secular                    | Trade           | Good                       |
| Mali (f)           | Same           | 75  | 85           | 4                 | 50                | 12                 | Argentina | Secular                    | Housewife       | Average                    |
| Assaf (m)          | Enhanced       | 75  | 71           | 4                 | 48                | 12                 | Iraq      | Secular                    | CEO             | Very good                  |
| Perla (f)          | Died           | 80  | 91           | 4                 | 57                | 12                 | Poland    | Traditional                | Diverse         | Good                       |
| Varda (f)          | Died           | 68  | 71           | 4                 | 43                | 12                 | Israel    | Secular                    | Diverse         | Average                    |
| Yael (f)           | Same           | 74  | 80           | 3                 | 58                | 9                  | Russia    | Secular                    | Education       | Average                    |
| Ami (m)            | Same           | 79  | 78           | 3                 | 55                | 12                 | Israel    | Secular                    | Management      | Good                       |
| Riley (f)          | Same           | 71  | 79           | 3                 | 49                | 15                 | England   | Religious                  | Psychotherapist | Average                    |

Notes: f: female. m: male. CEO: Chief Executive Officer.

question taken from the AD content) and 'What is the meaning of love when living with AD?' (an example of a question taken from the world of love content). To ensure the participants' full understanding, a detailed information document explaining all aspects of the study was provided prior to the beginning of the interview in order to ensure that the participants understood the process of and intentions behind the interview.

In addition, and in order to elicit the nature of the *We* versus *I* issue, the interview guide consisted of questions that sought to ascertain the nature of the couple's intimacy; whether or not it had changed in the course of the disease, and in what ways; and what the nature of their joint activities was, and whether these differed in meaning from before the onset of AD. The overall intention was to get the 'feel' of whether or not the *We* and the togetherness had changed into an *I*, and whether the relationship was more associated with the caring or dialogue model. Accordingly, questions were designed in a way that attempted to capture the nature of the couple's love. For example, questions included 'Can you describe a typical day at the beginning of your marriage; can you describe a typical day today?' and 'What was the nature of your joint activities then; and what is their nature now?' Once completed, all interviews were transcribed. In addition, each participant was offered the transcript of their interview for inspection (respondent validation), but in practice only two people requested the transcript, reviewed it and offered comments.

### *Thematic Analysis*

In a procedure called Thematic Analysis, the emphasis is to preserve the integrity of the story by generating ideas from the case as a whole, rather than from conceptual units throughout the story. In this spirit, this study focused on the 'What' rather than on the 'How' or 'Who' or 'For what purpose' (Riessman 2008: 54). To capture the narrative fully, analysis was carried out on each interview separately, while identifying the respondent and ascribing a code to each. To do this, all the passages were quoted from the interview, and then underwent 'cleaning' to exclude certain breaks, the interviewer's statements and any disturbances that occurred during the interview. A process of sorting, reorganising and reassembling the initial encodings from the individual interviews into units of meaning then took place; the main investigator and the other two researchers worked together on this, and the entire process was kept confidential. The conceptualisation of the collected data continued until each theme formed an independent unit that stood on its own (Charmaz 1988; Glaser 1978). As stated, the goal was to capture the full narrative, while recognising that the use of language was only a means, not an end.

*Ethical aspects*

Because this study entailed face-to-face interviews with people who were to be observed in person, it was necessary to take into account ethical considerations. Before the interview began, participants were asked to sign a consent form, which provided information about the research and the main investigator, the purpose of the research and the criteria for participation in it. Emphasis was placed on the respondents' right to halt their participation in the research whenever they so wished, without any detrimental effect. The consent form also noted the potential risk that the interview might cause emotional distress and suggested how these could be dealt with. A policy of benefits and compensation for participants was also described, and privacy and confidentiality were guaranteed, promising that all personal information would be protected and hidden, and would be made public only anonymously. Lastly, participants were given the main researcher's personal information and were assured that any questions they might have would be answered. They also were informed that they would be provided with the results if they so requested.

The study was approved by the Ethics Committee of the University of Haifa, Israel. In addition, since this study included entering into the world of people with dementia, all other ethical aspects of research and specialised dementia considerations were assessed. These included the fact that entering into the private homes of persons living with AD might jeopardise their privacy and could cross an ethical border, since a person living with AD might be unable to object to the presence of researchers in their home because of their cognitive impairment (Jansson, Nordberg and Grafström 2001). In order to guard against this, the interviewee was present throughout the time that the primary researcher visited, so as to avoid causing discomfort or putting pressure on the person living with AD. As the researcher who conducted the interviews is a professional in the field of AD, the interview was handled with great care and sensitivity towards those people living with AD and without compromising their privacy.

*Personal reflection*

In the interests of qualitative research, it was important to recognise the primary researcher's probable bias. The primary researcher, who is a woman, has a special closeness to the topic under investigation; she was head of AD units in several nursing homes in the United States of America and also owned a private service that offered families guidance on how to cope with the disease. This was likely to influence how she experienced the participants and their world as expressed in their personal stories

(Liamputtong and Ezzy 2005). Her own subjective personal and political beliefs also played a significant role in the decision as to who to recruit and how, as well as in the way she conducted the interviews.

The other two researchers are academic men and are affiliated to the research world: one has a background in gerontology and the other has a background in philosophy. This combination of researchers – including both genders, a practitioner and two academics who come from different disciplines – made the interpretation of texts and interviews more reliable and as much as possible neutralised any personal bias (Mishler 1986).

## **Findings**

The leading theme emerging from the interviews, which sought to understand the meaning of love between spouses when one of them is living with AD, was that AD became a turning point in the meaning and understanding of their experience of love. Most participants described AD as a reference point that led them to rethink their love. Several categories of responses emerged with regard to how, if at all, AD had made a difference to the couples' love relationships. In practice, this main theme served as an overarching theme to a set of secondary sub-themes, which together opened a window into understanding love when living with AD. Below, we present the range of the sub-themes, each of which formed part of the whole spectrum of responses, as they were described by the respondents. Quotations that were based on rich and clear descriptions of participants were chosen to represent the sub-themes.

### *Love died: 'Nothing is left'*

At one end of the spectrum of responses to the 'turning point' caused by AD afflicting a spouse is the death of love. The damage to the relationship was so severe that for some people it meant the 'death of love'. Varda describes the disease's effect on their relationship as follows:

Then we were a group of friends. And we managed to start our lives on the right foot, with a beautiful house ... We had a wonderful life, by the way, amazing really. Listen, we had groups of friends, we had crazy times...

Now, when I take the key, he starts swearing at me, starts cursing me, getting angry with me. 'Where, where, where' ... and I don't know what he wants. 'Where, where, where.' I say: 'Take me by the hand, show me what you want.' But there is no one to talk to, no one to talk to. It's so hard, really hard, to help him put on a shirt, to help dress him in clean clothes, to prepare food for him.

He's very dependent, very dependent; he does nothing by himself, and showers are a battlefield. No, no need, he says he does not need to shower.... 'Get in the

shower' – I have to really push him and give him clean clothes, otherwise he would go a year with the same clothes. If I didn't take it and put it in the laundry, he would wear the same thing over and over. And everything is very difficult, because you have no one to talk to. You feel you are talking and he is staring at you and looking at you with those eyes...

The greatest love we had before ... now there is nothing left. Nothing left. Not at all, not at all. I can't even touch him.

The manifestations of the disease in daily life – the curses, anger, misunderstandings, the help needed with everyday functioning, fights about the shower and the loss of the past relationship – caused Varda's love to disappear completely, to fade out of existence. During the interview, Varda made frequent reference to the group of friends they had had, in terms of whom their togetherness and self-identity were formed. This element of 'togetherness' was very central in her life. Her husband's condition is a major problem for her socially and has brought her loneliness and social isolation. She no longer meets their mutual friends and does not attend their group events because of her husband's disability. She longs for the kind of life she once had and talks nostalgically about her past circle of friends.

The difficulty of being thrust into an isolated social situation has exacerbated the loss of love for her husband. It seems she sees herself in an 'all or nothing' situation: if she does not have it all – the relationship, the love, the social group – she does not have anything. For her, the situation that she is in offers no middle way; she sees no aspect upon which she can rebuild her life. That is why she searches diligently for a nursing hospital for her husband. This would perhaps allow her to regain some part of her past life – her group of friends and the togetherness to which she became accustomed. She is looking for a way to free herself of this 'disruption' – her husband, who has become an impediment and is now standing between her and the life she wants. When asked 'In what way is he disturbing you?', Varda replied: 'He stops me from living my life.'

*Love became weaker: 'I cannot feel the same emotion I felt before'*

Rather than feeling that their love had died completely, some of the interviewees expressed a weakening effect in their love towards their partner. For them, the AD harmed, but did not completely obliterate, their love, although it was no longer the same love it used to be. For example, Romie describes a process of 'decline' in her love throughout her marriage, while noting the additional damage of that AD caused to her relationship, leading to further 'decline' in love:

Over the years, the emotion of love faded gradually. You must build a life based on certain building blocks ... Things that are common to both of us, things that are

interesting for us to experience together, otherwise you lose the connection ... Love can remain with you for ten years, but what then? ... All those years I felt towards Nadav ... really, I think ... my grandchildren asked me: If you are constantly arguing with Grandpa, how can you love him at the same time? So I told them: 'I love Grandpa.' But this AD caused a great deal of harm to my love. A great deal ... I also feel distant from him. I cannot feel the same emotion that I felt say ... three years ago...

Romie talked about love, the way it fades away over the course of life and that in order to avoid this, one must do things together. She spoke frequently about trips they had taken together as a couple and also as part of groups, excursions in Israel and abroad. She noted that the family aspect played a large part in preserving intimacy in their marriage. However, Romie described AD as a turning point in her love for her sick husband. She said she no longer has the same feelings for him as she had before the disease, which has greatly damaged their relationship and caused her love to weaken. The emotion of love that was part of their relationship in the past seems to have waned to the extent that she can barely feel it anymore.

Lavie also described the way that AD has harmed his love for his sick wife. The couple's mutual narrative has become only one person's narrative. All the joint activities they used to share, such as eating meals together, have been lost; he eats alone, functions alone, acts alone; and there is no way, he says, not to be affected by the situation:

We met ... We met, I tell you, and the partnership started. I knew it. I saw her ... she did not see me much at home but she did not have anyone else, and I never had another woman ... that's where love began ... [For] a person who has been married nearly 60 years, it is impossible to accept it [AD] at all, something like that ... [is] very difficult. First of all, food. I'm not even talking about cleanliness. Clean, not clean, that is less important. But eating is. You're used to eating together; sitting [together] ... today I dine alone. I also have no appetite ... it is clear that when I speak of my love of today, I do not love her the same way I did then, of course not; but I love her as a human being, a human being, a woman who does not feel well, who is sick. Just like any person who, when he is sick has nowhere else to be ... You must look for more ways to support him and not make the situation worse. If you do not, for us that would be like throwing him overboard.

Love has changed from being a conjugal love to a more general love, a kind of compassion for someone who is sick and needs help. Lavie described his marital relationship as 'old-style', one in which the woman's role was established according to past conventions – she was the housewife who cooked, baked, cleaned and raised the children. He recounted how she always made Lavie regular meals, kept a spotless house and never said 'no', because 'that's how things should be'. But 'AD has changed the picture', and with it came a change in the way he felt towards his wife. His love for his beloved spouse turned into the compassion he would feel for any sick human being.



*Love did not change: 'It is the same'*

On the broad spectrum of how spousal love is affected by the turning point elicited by AD, a 'middle-ground' approach is characterised by a natural continuity, involving almost no change at all. Love always existed (or never existed) before the onset of AD and the disease had no impact upon it nor did it alter it. Riley describes the continuity of her love, which has undergone no real changes:

Love? He was very gentle and still is gentle ... a gentleman, not pushing himself ... [Our relationship] was full of so many things. It was not that I was crazy about him. It was quiet, it's something basic, and [for me] this is really 'it'. Look, for me my husband was a spouse, he was a friend, he was a partner, he was the father of my children and he was also a lover. He was five people in one person, and that's it ... Regarding our relationship – it did not change ... I think it's always been the same. Had it not been the same I couldn't have handled it. Perhaps even before when it [AD] was not so obvious, but today it is.

Riley describes the cornerstones of her love for her husband based on the five roles that she feels he fulfilled successfully: those of husband, friend, partner, father and lover. She sees her love as peaceful and stable, something that has accompanied her throughout life and also now throughout the disease. This love forms the basis of her ability to cope with her husband's condition. It also challenges the concept of 'natural continuity' since we can assume that Riley's desire to maintain equilibrium for the sake of both partners' security was backed up by action and efforts: 'I promised the universe that I would take care of him ... of course it is not always easy and that's okay.'

In a similar vein, Yael describes the continuity characterised by the absence of change, but her case is different: she speaks about a lack of love both before and after the onset of AD. According to her, she never had love in her relationship, and AD did not change the situation but simply perpetuated it:

For me, love was never there. No. He is illiterate. He attended only four years of school. Simple, simple like a child. Also, he immigrated to Israel at the age of 15. His parents did not send him to school, only to work. He worked in ... an ice-factory. Poor boy. He grabbed a girl; all the boys his age were already married, so he grabbed a youngster like me and [it was] come on, let's get married.

I think neither of us liked each other ... he was violent. He was violent all the time, but recently, you know, he would have killed me if he could, if he could, if he had the courage, I do not know what ... there was not a drop of pity ... We do not have anything in common today. I do not know ... what kind of relationship was there.

Listen, I've never had a relationship in which someone actually saw me or bought me gifts ... [the sort of relationship] I read about, that I see with my children. My son

and his spouse, he buys her jewellery all the time. [He is] constantly thinking about spending and spending ... you know, let's go to the theatre, or go to the movies. Living their lives. He is disabled, and they live. And we – nothing, no life, really not living. Listen, there are many older couples who do not [really] live life, but they loved each other. And there was something they loved, something that remains. Here, nothing; there is nothing. I love the furniture, the apartment. Nothing else. Really empty ... Everyone wants love. Everyone. No, it is hard to live without love. It's a fact. If I could ever find a partner for love ... I don't know, I am not familiar with it. Only from people's stories ... I would have gotten fat from pleasure. I would be ready to die after six months, having felt that joy and satisfaction, and then go.

During the interview with Yael, a recurrent issue increasingly emerged – the lack of love in her relationship. She said that if she had not got married, she would have become a prostitute, adding that she remained in her marriage because she does not think highly of herself and does not believe her abilities could have sustained her. She described her spouse as being verbally and physically violent and as having terrorised everyone in the family and turned her into a frightened and threatened woman. Yael said that their children were also afraid of him and did not love him. According to her, he took no part in raising their children, but instead always tried to get rid of them. She described how she used to stand on the veranda of their home for hours, waiting anxiously for their children to return home safely, as their father refused to drive them or fetch them. The onset of AD did not cause any changes in their love, or rather in their lack of love. It did not lead to any transformation or to a renewal of love, neither on her nor on her husband's side.

*Love was enhanced: 'I love him even more'*

On that same spectrum of options, describing the 'midpoint' in which nothing has changed, the second half of the spectrum depicts growth and renewal of love. Assaf describes how the disease caused the love he feels for his wife to strengthen:

...if the expression of compassion is some kind of giving, no matter what kind of giving it is, then it cannot be done without any kind of emotion, and without being real. When I speak of my love for Sarah, I think it has grown much stronger with the disease...

I can say humbly that prior to the onset of AD I did not pay any attention to what Sarah was doing or not doing. What kind of a question would that have been? She ran the whole world. Why would I even have to ask what was she doing then?

Assaf explains that before the disease, each of them was busy with his or her own world, and their two worlds were very different. He never had to think for a moment about what his wife was doing because she 'ran the whole

world', as he put it. This changed with the disease. Assaf noted that now his wife is his main concern. He thinks about her all the time, calling home to check whether all is well and actually manages the disease when he is at work. Epistemologically, he approaches love as unconditional: 'I'll tell you the truth. The term you spoke about [love] ... It is a very, very evocative term for me.' So from two people's love that converges, where each partner contributes to the wholeness of the marriage, love has now become mainly one-sided, and it is precisely this condition that nurtures and strengthens his love for his wife.

Another example of love increasing after the onset of AD is described by Ayala:

[Love?] there is no end to such a thing. There is no explanation for this. I love him so much. I can kiss him like that, with all his drool falling from his mouth. Do you understand that? That's my love ... I love him even more because I am always with him now. I don't have other things on my mind. Nothing but him ... Love is more powerful now. More powerful. I can't explain it. I no longer find any interest in the people around me – my kids come or don't come; that's ok, I don't care anymore.

Ayala's account illustrates how the love she feels for her husband has grown and deepened for reasons similar to those cited by Assaf – the inclusive nature of the disease. Like him, she regards her partner's AD as the prime event in her life, an all-encompassing experience that leaves no room for anything else, not even for her children whom she really loves. According to Ayala, the disease demands so much of her that she needs to focus all her attention on her beloved husband. One might have expected someone in her situation to contemplate the loss of her previous life and her relationship before the disease, but actually the opposite has occurred. Her focus on her husband is actually enhancing and strengthening her love; instead of becoming submerged in sorrow and loss, Ayala has arranged her life around the treatment of her husband and has imposed limits on 'interference' from the outside, and this is a source of containment.

A different angle was expressed by Yvette who described the change in her husband as follows:

I think then [love] changed for the better ... Jerome [is now in] a situation where he has lost the need to protect his distance ... not his distance, his machoism [which meant he had] to show as little as possible. [That's] what they taught him at school. All men are dumb; you know how it is...

Yvette states that her love 'has not changed', but her husband's love for her did change – with the onset on the disease, he lost his inhibitions, so she can now enjoy him telling her how much he loves her: 'He says he loves me, and

he really loves me, and I'm beautiful, and I'm lovely. And he articulates all those expressions he once was afraid to say.' So although her own love has not changed, Yvette can now enjoy the new, transformed love that her husband with AD is able to offer her.

*Falling in love again: 'From Alzheimer's grew a renewed love'*

At the other end of the spectrum that delineates changes in the experience of love after a spouse has been struck by AD, and in contrast to the themes of 'the end of love' or even 'the absence of change', one participant described how his love has been reborn as a new entity, in a form and manner that previously never existed. Arnon articulates this rebirth of love in the following passage:

Love that comes from both of us is what I call 'falling in love again'. I mean, falling in love again, in all its meanings, as a result of AD. At first I called it 'love and a sex life'. I wrote a song called 'Expression, Touch, and Look' and explained it by saying that even when one's sex life cannot include the normal sexual activity of intercourse, there is a sex life in touching each other. 'Expression, Touch, and Look' – I took this to be an extension of a sex life. Today I doubt this extension of a sex life ... When she caresses me, I find it pleasant; that's an exaggeration, at times when her hands are cold! And I tell her 'Warm your hands up before you touch me', but she doesn't – she puts her cold hands under my pyjamas. And I tell her jokingly: 'For years I waited for this.' Back in the forties and fifties, we did not have the time to engage in such things like cuddling. We went straight to sex. That's the silliness of young people.

Arnon describes the birth of a new love, a kind that was not there before the outbreak of the disease. When they were young, they did not make time for the small comforting gestures of love. Since the onset of his wife's AD, however, a new kind of love has developed. It is based on a multitude of expressions, touches and looks that are the expression of a different intimacy and form a new and different sex life, one which the couple enjoys throughout their daily lives. Arnon sees this as similar to winning a prize: 'I won.' He stated that this love is actually the 'fuel' that keeps him going and allows him to continue to deal with the disease despite its difficulties. His face was beaming when he said this, and he was in a hurry to end the interview so he could return to his wife as he was missing her.

As to the other seven spouses that are not quoted here, the changes that they reported that their love underwent did not all relate to an enhanced or reduced quantity or quality of love. Instead, their descriptions include other types of change. For example, Mali experienced the change as bringing new peace and quiet: 'Yes, from the moment Ely fell ill, life calmed down. I mean, there's no longer that desire to go out, [only to] sit together.' Eyal says he continues to love his wife out of respect to the person she was, but not in the same way it was before the disease: '[This is] a love that has

everything but no sex ... It's a person you know and you do not forget that she was very, very special. Extremely modest.'

## Discussion

The aim of this study has been to describe and analyse the meaning of love in couples living with AD. Because qualitative analysis has a comparative nature (Glaser 1969), one cannot ignore the inevitable question of whether this love is unique to the experience of living with AD, or whether it fits within the broad and all-encompassing nature of love in old age in general. Within the narrative approach of qualitative research, the stories from the world of those spouses who are caring for partners with AD serve to define the marital relationship as it has been altered by the disease (Boylstein and Hayes 2012).

There is a dispute concerning the relation between love and age, and in particular whether love diminishes with age, remains the same or even increases (Charles and Carstensen 2002, 2010; VanLaningham, Johnson and Amato 2001). Our findings present a multifaceted picture that is not focused on the quantity of love, *i.e.* whether there is more or less love, but rather on the complexity of love when living with the disease. A common assumption is that age, let alone AD, poses a high risk to loving relationships (Loboprabhu *et al.* 2005). Instead, the findings of this study raise the many forms that love can take in the face of AD, forms that enable us to view love through a different lens. For example, love that was based on romance changed into love for a life partner, involving daily routines such as dining together; then when faced with AD, this partnership love transformed into compassionate love for a sick person who needs care. Also, love for a whole family including the children is now exclusively directed towards the husband afflicted with AD.

As the literature indicates, qualitative studies conducted in the field (such as Hayes, Boylstein and Zimmerman 2009) suggested that spouses of persons living with AD have reported the disease affected various aspects of their intimacy in their relationships. In this sense, our findings fit with some of these conclusions, particularly those that point to negative changes. However, in contrast to the findings of Hayes, Boylstein and Zimmerman (2009), the current study demonstrates the diverse experiences expressed by the participants. While some indicated the challenges they face in communicating with their spouse living with AD, such as carrying on a conversation or maintaining their sexual life, most of the participants stated that intimacy between them gained a different meaning that was not there prior to the disease. Some reported their physical intimacy continued, some indicated their sexual intimacy was maintained and some participants noted differences in their emotional intimacy.

Quantitatively speaking, most participants reported greater intimacy with their spouses living with AD.

In this regard, those couples who described no essential change in their overall loving attitude seem to oppose the widely acknowledged view that there is a risk of the relationship failing due to the disease (*e.g.* Loboprabhu *et al.* 2005). However, since the findings of the current study depict a wide range of complex responses varying from the death of love to falling in love again, it is reasonable to postulate that in many cases, the overall attitude will remain the same, while its actual implementation will be different. Hence, we do not speak about more or less love, but rather about differences in some aspects of the complex romantic experience.

The findings of this study are also partly compatible with those of Kaplan's (2001) typology. Five different types of relationship with AD were proposed in her typology, ranging from the extreme feeling of being a closely united couple, a sense of a '*We*' (Till death do us part), to the extreme feeling of not being married at all, of being simply an '*I*' (I do not feel married). Our study is also relevant to the findings of Hellström, Nolan and Lundh (2007), who investigated the strategies that spouses use in order to sustain their couplehood when living with dementia. In discussing their findings, they use the terms '*We*' and '*I*' to ascertain the strength of the marital relationship. Their three themes of 'sustaining couplehood', 'maintaining involvement' and 'moving on' suggest that, with time and as the disease progresses, the '*We*' feeling fades away and feelings of '*I*' take its place, as opposed to Kaplan (2001) who suggested there is no connection between the two. To complicate the discussion further, Førsund *et al.* (2015) find the '*We*' and '*I*' distinction to be rather problematic, while Loboprabhu *et al.* (2005) argue that there is a low chance of achieving the feeling of '*We*'.

The results of our study show a rather diverse and complex picture concerning the issue of '*We*' versus '*I*'. For example, on the one hand, one spouse (Lavie) specifically mentioned that the couple's relationship had turned from a '*We*' feeling into an '*I*' feeling as their intimacy had been lost due to the disease: 'It is clear that when I speak of my love today I do not love her the same way I did then, of course not; but I love her as a human being, a human being, a woman who does not feel well, who is sick.' But on the other hand, another spouse (Arnon) described the beginning of a new love, a kind that was not there before the onset of the disease: 'Love that comes from both of us is what I call "falling in love again". I mean, falling in love again, in all its meanings, as a result of AD.' This diversity is evident throughout the entire study.

It seems then that '*We*' versus '*I*' differences constitute a kind of continuum. This requires distinguishing where the different types of love are located along this continuum, in contrast to the strict version of romantic

love that prevails in our society. Accordingly, Portmann (2013) claims that both ageing and AD can transform a romance by increasing sexual generosity in which the 'We' acquires a different, more complex, form. In the case of AD, such generosity can take two major forms: (a) allowing the person with AD to initiate sexual relationships with other people – these would mainly be individuals living with AD in the institution in which they reside; and (b) sexual self-generosity, where the unaffected spouse allows him- or herself to find romantic and sexual fulfilment outside the marriage, rather than waiting for the death of the sick spouse.

Yet there are further complications to this picture. Differences of culture, gender, class or education might have also played a role in participants' stories. For example, Varda's story of loss and division might be related to the loss of supportive social networks due to an isolated social situation, but could also point to the gender and/or cultural differences that are noted in Erol, Brooker and Peel (2016).

By the same token, we can understand the rebirth of Arnon's love for his spouse as a result of the increase in physical affection, expressions of fondness and renewed intimacy. However, it is possible that Arnon, who is intelligent and highly educated, has the adequate mental capacities to construct for himself a story of renewed love and, in the process, has deepened the dyadic bond between his spouse and himself.

Therefore, perhaps the one-size-fits-all approach ought to be avoided in trying to understand the care-giver's experience (Hellström, Eriksson and Sandberg 2014). Instead, it might be more useful to evaluate individual needs and to tailor interventions for specific groups in line with factors such as culture, religion, class and education (Erol, Brooker and Peel 2016).

As to the distinction between the caring and the dialogue models, the picture seems to be somewhat clearer. Most participants described the AD as a turning point in their relationship, whether for good or for bad. But one issue remains the same: the unique characteristics of the disease impair communication and joint activities. Moreover, most participants described their love in a compassionate manner and in the context of their daily routines of caring. For example, Assaf describes how his love for his wife is now based on compassion: 'if the expression of compassion is some kind of giving, no matter what kind of giving it is, then it cannot be done without any kind of emotion, and without being real.' Another spouse, Ayala, who had arranged her life around the treatment of her husband and had asked her children not to come and interfere with her caring routines, regarded her spouse's AD as a source of containment. Even Arnon, whose love had been reborn in new ways that had never existed before, did not describe his relationship in terms that are associated with the dialogue model (such as mutual discussions, shared trips and the

like). Having analysed the descriptions of most participants, we can suggest that they fit better with the caring model, given the very unique nature of the disease. There are circumstances in old age and in AD in which the damage to the physiological and mental capacities is so significant that the sufferer can no longer participate in a meaningful dialogue. Advocates of the dialogue model could argue that in such cases love might be resent, but it is no longer the profound romantic love that typically exists between adult couples; rather, it has become a one-sided love, lacking profound joint interactions. In the same vein, the mother's love for her baby is mainly that of caring and not dialogue, since the baby has not yet developed the ability to engage in complex dialogue.

Regardless of the specific models of love, the marital relationships can be described from the following perspectives:

1. The *causal* perspective: describing the effect of AD on these marital relationships (e.g. Hayes, Boylstein and Zimmerman 2009).
2. The *phenomenological* perspective: describing how the partners (and especially those with no AD) currently view their relationship in the face of AD (e.g. Førsund *et al.* 2015; Kaplan 2001).
3. The *coping* perspective: describing strategies for coping with and sustaining the relationship in the face of AD, including as the disease progresses (e.g. Hellström, Nolan and Lundh 2007; Hyden and Nilsson 2015).

The present study focuses on the first and second perspectives, while the interviews conducted in this study also provide some information on the third. Future research is needed to examine the complex relations between the various aspects arising from each perspective.

To sum up, love relationships of spouses living with AD are a complex and diverse phenomenon. But is this complexity unique to couples living with the disease? There is no clear answer to this question. The results of this study can shed light on possible relationship developments among all elderly couples, especially those in which there is a health imbalance between the two partners. The five major types of relationship development following the emergence of the disease – that is, love died, love became weaker, love did not change, love was enhanced and the spouse fell in love again – might be found among the loving relationships of other couples in old age. The same holds true for marriages that have lost their sense of 'We' and become an 'I' relationship. Nevertheless, this study uncovers other (sometimes surprising) processes of loving relationships among couples living with AD. The added value of this study, therefore, is that it represents a pivot in its field, bringing the topic of love and AD to the forefront of the research arena.



As with any research, it is worth noting its limitations, and indeed in this study there are some. First, on the level of the sample: all participants were married, Israeli and Jewish, and there were no couples from other religions or nationalities or who were living in other forms of relationship. In addition, the sample was small, although not too small for a qualitative study. As stated, the study consisted of 16 participants only, which is a small sample. While it could have been broadened by recruiting different participants, such as members of other religions and/or couples living together outside marriage, the limited representation enabled the research to go into greater depth on various issues. Second, it is also worth noting that despite the purposive sampling strategy that yielded some diversity, the majority of the sample's participants were educated and middle class, a fact that might have played a role in the broad understanding of the topic under scrutiny.

Finally, although the present study attempts to explore the love relationships of couples living with AD, there still is a need for further research into why some couples' love falls at one end of the spectrum of increased closeness while the love of some others falls at the other end, with their love fading. In this regard, more research needs to be conducted on the phenomenology of love under the conditions imposed by AD (*see e.g.* Hellström, Nolan and Lundh 2007). This would further clarify what makes certain couples more resilient to the effect of the disease, while others are battered by it. We have suggested that a significant factor is the depth of their loving relationship before the disease appears. There is no doubt that other factors play a significant role in maintaining, enhancing or increasing marital love under the pressures imposed by AD. Another relevant area for future research would be to compare the loving relationships of couples living with AD with other elderly people, including both those who are reasonably healthy and those who are suffering from different impairments to their physical and mental capacities.

### **Acknowledgements**

The study was approved by the Ethics Committee for Human Experiments, University of Haifa (number 234/15).

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*Accepted 8 August 2017; first published online 26 October 2017*

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