

ORIGINAL ARTICLE

Caring for a partner with Alzheimer's disease: Intimacy, loss and the life that is possible

LES TODRES & KATHLEEN GALVIN

Centre for Qualitative Research, Bournemouth University, UK

Abstract

In this article, a phenomenological study, we aim to contribute to a deeper understanding of caring for a partner with advancing memory loss. Our particular concern is to communicate the findings in evocative and empathic ways. Such an approach is based on a wish to complement the phenomenological rigor of Giorgi's "scientific concern" with a "communicative concern." We draw attention to the aesthetic dimensions of phenomenological description to achieve both "structure" and "texture" in the way findings are communicated. The methodology is thus complemented by a further interpretive phase after presentation of each of six general structures, and characterized as 'embodied interpretation'. This discipline is based on Gendlin's experiential phenomenology and the practice of "focusing." We suggest that by engaging with the kind of descriptions and interpretations offered, fellow carers, professionals, family and support groups could be better equipped to understand the issues discussed.

Key words: *Alzheimer's disease, partner, caring, phenomenology, Gendlin*

Introduction

Caring for a partner with Alzheimer's disease is a lived experience that is full of poignancy, steep learning, and complex coping. The intricate nuances of such a journey are beyond any words that try to characterize it. Qualitative research can however highlight important insights that may serve actionable knowledge (van Manen, 1994) and practical wisdom (Polkinghorne, 2004).

In this article, we aim to generate a deeper understanding of six related phenomena within the intimate carer's journey that had been highlighted from a previous narrative study which focused on the breadth of the carer's journey (Galvin, Todres & Richardson, 2005). The previous study had characterized the journey as a whole, but generated the need to understand further a number of discrete phenomena within the journey in greater depth. Therefore, in the present study, each of these phenomena are considered complex enough to warrant an exploration of each of their structures in their own right. See Todres and Galvin (2005) for

a discussion of the relationship between narrative breadth and life-world depth. The present phenomenological study thus examines the structures of each of the following phenomena within the broader caring journey:

- Learning to live with the loved one's memory loss;
- The experience of adjusting to more limited horizons in their life together;
- Caring in practical ways;
- Adjusting to changes in the emotional relationship and level of intimacy;
- The transition to living apart;
- Advocating on the loved one's behalf.

Each of these themes carries complex challenges: to see a loved one change in this way; to leave behind what was and attend to what is now needed; to face issues of control, how much to "take over" and how much to support a sense of personal agency and dignity; to lose the kind of reciprocity that couples work out in an intimate partnership; to face the

limits of one's own caring abilities; to channel emotional energy into advocacy on behalf of "this person who matters" within a complex system of care and processes.

Both the previous narrative study and the present phenomenological study were conducted by interviewing one carer (a husband, to be called M) on separate occasions about his experience of caring for his loved one (M's wife, to be called L). The interview in the previous study was conducted in a way consistent with a narrative methodology. In the present study, an interview style consistent with the concern to elicit situated descriptions was adopted. Following from this, our study devotes itself exclusively to a presentation of findings from the phenomenological study. The advantage of concentrating on a single case study is that the researcher can focus on the seamless, internally related dimensions of such a complex experience. Therefore, this study is not about the range of unique variations that can occur for different carers. Nevertheless, there may be a kind of "resonant" validity to the present study in that it highlights transferable possibilities for others in similar contexts.

Qualitative studies on caring generally, and caring for a loved one with Alzheimer's disease in particular, range from issues as general as 'presencing' and supporting (Chinn, 1991; Beck, 2001), comforting (Morse, 2000) and hope-giving (Farran, Herth & Popovitch, 1995), to issues specific to caring for people with Alzheimer's disease, such as carers' changed understandings over time (Phinney, 2002), their concerns to advocate for the "personhood" and dignity of the loved one (Ashworth & Ashworth, 2003) and their perceptions of the quality and nature of external care provision (Aggarwal, Vass, Minardi, Ward, Garfield & Cybyk, 2003).

The nature of reflective life-world research (Dahlberg, Drew & Nystrom, 2001), of which this study is an example, is that the qualitative themes are often transferable beyond the particular phenomenon; so caring for people with Alzheimer's disease shares qualitative dimensions with that of caring in general. Different readers and audiences, in relation to their own area of interest or caring, may then reflect on those dimensions that are particular to caring for people with Alzheimer's disease and those that are related to caring in general. In this study, we are not aiming to be conclusive about the findings beyond their applicability to caring for people with Alzheimer's disease, but we leave this possibility open. The findings could be applied to a research project that attempts some form of systematic narrative review or qualitative meta-synthesis of the carer's experience

within a range of contexts (Jones, 2004; Finfgeld, 2003).

Methodological approach

To achieve detailed, concrete descriptions of each of the six phenomena (named above), a descriptive phenomenological research design was used (Giorgi, 1997; Giorgi & Giorgi, 2003a,b). The approach involved:

- Eliciting concrete, life-world descriptions for each of the delineated phenomena;
- Engaging in phenomenological analysis to explicate essential meanings by moving back and forth between the sense of the whole and its details;
- Arriving at a general, narrative description of each of the delineated phenomena, (such findings are presented in this article as "general structures").

We further modified this approach to communicate the findings in more evocative and empathic ways (van Manen, 1994; Sells, Topor & Davidson, 2004), based on trying to complement the phenomenological rigor of Giorgi's "scientific concern" with a "communicative concern" (Todres & Holloway, 2004).

Todres (1998; 2000) argued for the need to pay more attention to the aesthetic dimensions of phenomenological description and thus achieve both "structure" and "texture" in the way the findings of phenomenological research are communicated. Following other recent work by Todres (1999; 2004) that highlights the lived body's role in understanding meanings, we pursued the communication issue further by engaging in an additional phase of understanding and presentation that we called "embodied interpretation." In this way, we "stand before" the general structures as "embodied beings," and imagine in a bodily, grounded way what the general structures evoke and signify.

This embodied discipline is based on Gendlin's (1973) experiential phenomenology and the practice of "focusing" (Gendlin, 1981). Whether to call this phase "descriptive" or "interpretive" phenomenology is a matter for debate. Van Manen (1994) sees a continuum between the two. Willis (2004) distinguishes a phenomenology that "goes back to the things themselves" (scientific/validity concern) from a phenomenology that emphasizes the question of "what produces a feeling of understanding in the reader" (empathic/communicative concern). We take the view that a phenomenological study can do both, and that it may be useful to have a phase of

presentation that is descriptive and one that is more interpretive. We also believe that it is still useful to distinguish these emphases, which is reflected in the presentation of this study.

Method

M, a carer for a loved one with Alzheimer's disease, approached the authors because he knew of their interest in doing this kind of research and wanted his experience to be of use to others. M's role was strictly that of informant who also gave feedback at the end as to the personal resonance and credibility of the other two researchers' descriptions and interpretation. He wished to be identified and we have acknowledged his important role in this research.

The issue here was not one of "correspondence" with the details of what was said, but rather one of "coherence" in relation to the sense and meaning of the communication.

A life-world-evoking question was initially asked about each of the six phenomena (Todres & Holloway, 2004). This was essentially a request for concrete descriptions of each of the phenomena as they were lived through. An example of such a question is: "Could you tell me about those times when you realized that a big change was happening in your social relationships with people?" The interview proceeded in a person-centered way, seeking clarification where necessary.

This interview phase was followed by the kind of analysis recommended by Giorgi and Giorgi (2003a). This analysis resulted in general structures of each of the six phenomena, and they are first presented in a descriptive way in the findings section to follow. The main innovation to Giorgi's approach lies in a further phase of transforming each general structure into an "embodied interpretation." Each embodied interpretation is thus presented after each general structure. In embodied interpretation, the phenomenologist's embodied self and "digested understanding" becomes a locus of "dwelling" with the meanings and allowing the described phenomenon to be "let in." This "letting in" is enhanced further by being attentive to possible words, images and phrases that may be faithful to felt sense of the understanding. It involves reading each descriptive general structure in this study a number of times, while being aware in a bodily way of what such empathic engagement feels like. It is an attempt to find the "I in the thou" (Buber, 1970) in that one finds a sense of common humanity in the resonance between us in relation to the phenomenon. These empathic understandings are therefore informed by the feelings in the body as well as the details in the text. This formulating process involves going back

and forth between the general structure and the "felt sense," waiting for a "good enough" formulation that fulfils both the logic and details of the text as well as the bodily feeling of "what it may be like." This "good enough" fit is an aesthetic recognition within the researcher. M was able to confirm that the "embodied interpretations" were "good words" that were consistent with his experience. There is some controversy whether this should be a criterion for validity, or whether the reader who reads a general descriptive structure followed by an "embodied interpretation" is also well placed to assess whether the more evocative language of the "embodied interpretation" carries forward the presented descriptive general structure in a way that also deepens the reader's empathic imagination and enlivens the phenomenon.

In this conception, validity is not about correspondence but about whether the embodied interpretation carries forward the general structure in plausible and insightful ways. This means that such resonant validity is "always on the way" and never complete, because different readers apply the understandings to their own circumstances and concerns. Such a view of understanding is consistent with Gadamer's (1975) notion of an application rather than a unit of agreement.

Findings: general structures

A descriptive general structure of each of the six phenomena is followed in each case by the embodied interpretation of that phenomenon.

Phenomenon 1. Learning to live with L's memory loss

This kind of learning essentially involved coming to terms with how M's old expectations of L's memory functioning no longer applied. This required the emotional learning of patience as well as a number of skills that would help L.

The emotional learning of patience. Through numerous experiences of L's memory loss, M first learned that he could not control or stop its exacerbation. Initially he found this extremely irritating and used the term "nauseous" to express his visceral, angry, emotional reaction to what was, to him, the repetitiveness of her saying or doing something over and over again.

His initial angry response to her forgetfulness manifested itself in an attempt to control her into being less forgetful. This was part of his caring burden and at times, he needed respite from it as his own health was suffering.

Coming to terms with L's increasing memory loss involved a complex process of learning to be patient with her behavior. This involved a number of observations and significant moments including the realization that L would become worse and unsettled in response to M's impatience. He became aware that his impatience produced a downward spiral in which L would become further unsettled and confused; M would then feel remorse and wanted to avoid this in future.

Another key moment was when M saw that L did not know how much her repetition was based on moment-to-moment memory loss. Once M recognized this, he actively engaged in a process of testing and probing for what L could and could not remember in particular circumstances. Previously he would have intervened, but later he learnt to let it take its course, if harmless. This helped him respond in a more patient and kindly way. He also learnt patience through a health professional, who helped him understand and normalize the nature of L's memory loss and the implications for her behavior, and through meeting other dementia sufferers at more advanced stages of memory loss.

Through this process of complex emotional, behavioral, and cognitive learning, M developed some particular skills for responding to L's memory loss that proved to be helpful, including:

- Validating and valuing activities just for their shared doing, rather than on the evaluation of the outcome. For example, helping L occupy her time in unstructured moments.
- Kindly talking L through her current situation that helped her know what to do next, such as encouraging her to participate in everyday tasks actively and prompting her to engage in routine and daily activities—skills such as eating that are necessary to sustain physical well-being.
- Using humor as a way to relieve his own tension and experience respite from his emotional discomfort in dealing with repetitiveness.

In summary, learning to respond to a loved one's memory loss involves an extremely challenging process; a letting go of previous expectations and the learning of a patient openness that does not take continuity for granted.

Embodied interpretation

To see a loved one change in this way. No. It is so natural to want to refuse that this is happening; that her/his memory can function as before. How deep is the urge to want to stop the exacerbation of memory loss in the loved one? It deserves at least an angry

“No,” a great refusal, a denial in any way that is possible. At times, it is also a sinking feeling, the “nausea” of an awareness that relentlessly breaks through. We need psychological strategies to temper the awareness that the memory loss cannot be stopped: anger towards self, loved one, professional. However, this is not enough to help, and helplessness, in this respect, dawns. It could be, as in L's case, that a way of saying “no” to the memory loss can affect the loved one in a negative way. She feels pressurized and upset. He feels remorse and such remorse carries a dawning awareness that this way of trying to deny the memory loss does not work. It is ironic that the passionate “no” to the memory loss is a care that can be experienced as a lack of care. As the intimate carer is able to “let in,” and accept to some degree, that the change is happening; care begins to take the form of patience. This is an evolving process, a hard-won spiral of insights and skills: awareness and acceptance of the loved one's changing limitations, actively testing out where the gaps are, learning from others who have gone before or can give guidance. Essentially the learning of patience is a shift from valuing outcome to valuing process. The intimate carer learns to “hold back” from the need to rush to an outcome such as the successful completion of a task. Instead, he learns to “be” with the process of “what movement is possible” and of valuing this for its own sake; the mere moving of a piece in a puzzle, or beginning again a sentence from scratch. This kind of patience also involves “holding” for the loved one that which he/she cannot hold: the holding of continuity. This kind of patience involves the challenging acceptance of discontinuity and the provision of continuity on the love-one's behalf.

Phenomenon 2. The experience of adjusting to more limited horizons

M is thrown into a process of withdrawal from previous social horizons and simultaneously becomes engaged with more immediate preoccupations connected with the progression of L's condition and the demands of being a carer.

There are two significant qualities to this experience. One is to do with the temporal reorganization of expectations from what was a more possible future to a now more limited future. The other is a social reorganization.

The components and qualities of temporal reorganization. There was a growing realization by M that he was being thrown into a situation that meant giving up a more active life, both for himself and in his shared

life with L. Within a short period, his life as a carer for L became an urgent project and his time and energy were absorbed in the immediate concerns of care and advocacy. These more focused engagements were “crowned” by signs of L’s physical deterioration and the coping challenges that this raised for them both. This was essentially a “bitter pill” in terms of dashed hopes for the future and a realization that renunciatory adjustments needed to be made to their long-term plans for life together.

Social reorganization. There was a process of withdrawal from two kinds of social relationships. The first involved relationships that were more recent. In such circumstances, social opportunities lessened because of the unspoken discomfort experienced by all in the interaction, and because of M’s own preoccupation with the demands of caring and advocacy. This discomfort and social awkwardness occurred because of L’s changing mental condition.

M initially attempted to mediate and avoid the social discomfort and uneasiness in different ways, but described the following no-win situation:

- If he adopted a minimizing or concealing approach to L’s condition, social awkwardness would occur as her condition became obvious.
- If, however, he was more open about it, he experienced a standoffishness. To M, others appeared to be uncomfortable and to want to have a metaphorical and real distance from the realities of dementia.

The second kind of social relationship involved old friends with whom they had a long history. These relationships were more comfortable for M and L, and M believed that they were also more comfortable for their friends. M attributes this greater comfort to a joint history together, in which L’s surviving longer-term memory was more relevant than her short-term memory. In addition, these older friends were more willing and able to talk explicitly about L’s condition, which brought a greater degree of realism and acceptance to the social interaction.

M’s experience of social awkwardness and discomfort made him sensitive to the way that people with Alzheimer’s disease are stereotyped, stigmatized, and distanced. M saw the withdrawal of others as a kind of self-protective defense against their own fears and concerns. M attempted to establish his own social network without L, but a displacement of energy and preoccupation with caring hampered the possibility of meaningful, mutually satisfying social encounters. M was left with a more introverted social

life in which his more meaningful social relationships are at a distance.

In summary, M’s social reorganization involved the gradual loss of a meaningful and taken-for-granted social life in conjunction with an increasing engagement in the more immediate concerns of caring for L. He also found he was increasingly sensitive to social discomfort from the problems of stigmatization and stereotyping.

Embodied interpretation

To have your attention insistently called to the tasks of being a carer for a loved one with Alzheimer’s disease—this is a strong pull, a renunciation, and a focused attunement to what now needs to be done. The loved one’s condition becomes a pervasive consideration around which changing horizons become organized. This can be both a withdrawal from previous expectations and plans, and an increased concentration on the limitations of the changing circumstances and what is now possible. The “strong pull” is the insistent “what now” that calls; the demand for attention that the changing reality announces. The “renunciation” is the letting go of what was previously important in the light of rapidly rearranging priorities. There is little time to mourn, as the readjustment requires attention. It is a more complicated kind of mourning than that of a sudden loss, where what is lost is clearer. The “focused attunement to what now needs to be done” is not just about action but more importantly about the subtle tasks of finding the “life that is possible” in the joint journey, the changes in the relationship and the challenges of care. It is a withdrawal from previous horizons and a concentration on “this one”: living with Alzheimer’s disease, moment to moment, whatever the changing nature of this means as it unfolds. Time, with a future that was wide with more possibilities, becomes narrow. The task is then how to dwell and move from there. Old friends help. They remember a joint history and this is a sustaining resource through a changing story. Other social relationships may lose their ease and there may be a social renunciation that throws the carer and the loved one together more intensely in a new way that requires adjustment. The loved one’s carer is “on call” and this poses the existential question of what kind of simple “being together” is possible in the light of limited horizons.

Phenomenon 3. Caring engagement with changes in self-care behavior and everyday routine

The context in which this form of caring engagement takes place is the gradual but significant deteriora-

tion of L's short-term memory, in which taken-for-granted self-care, such as bathing, dressing, washing, routine and timing of appropriate activities becomes increasingly disorientated.

M noticed how natural rhythms of light and dark, as reflected in seasons of the year, could exacerbate L's disorientation of time and place. In such situations, L would try to revert to previously established routines that did not fit the external situation. On the surface, this was manifested in what appeared to be untimely and inappropriate behavior, such as not wanting to bathe or wanting to get dressed at unusual times. More deeply, there was an initial interpersonal struggle whereby her sense of agency and desire followed her internal sense of what was appropriate and timely, but which was different from M's more external orientation in terms of time and place.

M's caring engagement occurred on two levels. One, an implicit negotiation for agency, and two, explicit responsive and creative problem-solving strategies to address an increasing disorganization in time and place, as manifested in self-care and routine activities.

The implicit negotiation for agency. M had to make ongoing assessments and judgments; when and where to remove the dilemma of agency and when not to. For example, in earlier stages of L forgetting to bathe, M would prompt and remind her. However, in later stages, this was ineffective and L's feeling of agency in this matter was clearly important to her.

A creative strategy was used whereby M did not simply take control against L's sense of what felt right to her. Through serendipity and creativity, M found a way to reframe the problem from self-care to that of a sharing and bonding experience. This worked to humanize the situation and achieve successful implicit negotiation of agency; turning "you against me" into "us."

Creative problem-solving strategies. This was particularly important in the later stages of deterioration, when L became more seriously disoriented about time and place, and when she accepted M's intervention to remove the dilemma of agency. This involved creative forms of practical problem solving that developed in a common sense way in response to each new problem. For example, as L's ability and timing for dressing herself deteriorated, M developed a series of strategies that responded to each level of difficulty. This ranged from labeling drawers and cupboards in the beginning, to leaving out clothing, and to physically dressing her. In the later

stages, L was quick to accept M's decisive and active intervention. M found that such decisiveness removed the dilemma of agency for L and resulted in less argument and upset for both of them.

In summary, caring engagement with the loved one's changes in self-care ability and everyday routine involves a kind of care that humanizes the transition from the struggle for personal agency to being a responsive caregiver who adapts to the different phases.

Embodied interpretation

To be in a dilemma about how much to "take over" and how much to leave the loved one to her or his own devices; this is a complex concern, a "care" that can result in "too much" or "too little." Human dignity and the loved one's need to experience personal competence are at stake. The loved one with Alzheimer's disease wishes to assert a sense of personal identity that is intimately connected with a feeling of "own-ness": "my routine," "my body," "my privacy"—knowing what night means, knowing what day means, the rhythm of everyday life and the taken-for-granted habits of a lifetime. Into this coherent rhythm of own-ness comes disjunction. Meaningful links between body, mind, time, and space begin to be interrupted. Therefore, the intimate carer is called to hold continuity on behalf of the loved one. Here, the intimate carer may experience the acute dilemma of not wanting to take away the sense of personal agency and dignity that is possible. So he or she enters a changing process of "negotiation" with the loved one, in a sense, "asking for permission" to take over in areas that may require assistance. How do these issues of "control" not obscure the experience of care? This is a very challenging existential question. M found ways in certain situations to humanize the "taking over" by linking them with intimate sharing and bonding experiences—perhaps the sharing of a new diet or bathing together—where "I" and "you" can become "we" or "us." In later stages of deterioration, the dilemma is less acute: the intimate carer may become less ambivalent about representing "real-time continuity" and the loved one may be more ready to accept the intimate carer's intervention.

Phenomenon 4. Changes in emotional relationship and level of intimacy

The changes in their emotional relationship were characterized by three essential phases: a drifting apart, a complex and highly significant kind of reconnecting, and times of effortlessly being together.

Drifting apart. Both L and M had difficulty accepting and coming to terms with this sense of drifting apart in their relationship. They had ceased to be “man and wife” in an intimate and meaningful way and this was characterized by M as “just two people . . . putting up with each other.” This sense of loss was experienced as yet another component of mourning. A further form of mourning involved having to readjust their previous aspirations for retirement and their view of the kind of life they would have had together: finding some way “to make the best of a very bad situation.”

Reconnecting in a complex and significant way. Through a serendipitous event, M and L found themselves in a situation characterized by a transitional quality between physical care-giving and physically intimate mutual relating. Previously, M had been exclusively focused on the physical care-giving demands of L’s condition. Following this event, M was able to reconnect with L as a person, in a very simple, direct, and tactile way, but which stopped short of full sexuality: they began showering together as an intimate way of solving bathing routine problems. This mixing of task and intimacy blurred the boundaries between instrumental care-giving and mutual relating. This new transitional quality proved to be a significant backdrop for regaining something that they once had, as well as for finding a new way of reincorporating this into the complex realities of changing roles.

These opportunities for physical intimacy continued and became more directly intimate (kissing and cuddling). Such moments of physical intimacy and “skin to skin” contact also functioned as a background feeling that “took the edge off” and broke through the struggles of control and resistance between them in their increasingly disparate and fixed roles.

Although these intimate physical interactions were not characterized by full sexuality, they were moments that M valued highly. These ties of intimacy were viewed as “the biggest and most monumental step forward other than drug therapy”.

Effortlessly being together. M experienced a distinction between “care-giving time” and simply “being” with L. Care-giving was often filled with instrumental tasks and strategies to help L in routine and everyday tasks and in helping her maintain a sense of continuity. The effortless flow of time could not just be taken for granted. Within the care-giving time, there were important “pockets” of simply “being” in which the flow of time became effortless.

This was positively influenced by two kinds of support:

- An improved medication regime that helped L’s concentration so that they could enjoy each other’s company more by simply being together.
- Increased support from a local health professional, who took the pressure off M and made him feel cared for. This gave him a sense of psychological respite, which helped him feel that he did not have to do everything or be on constant alert.

In summary, the way that L and M were able to reconnect physically in a simple, tactile and unspoken way, provided the basis for a sustaining quality that saved the relationship from being merely functional.

Embodied interpretation

To lose the kinds of reciprocity that couples work out in an intimate partnership. The loved one inevitably becomes more dependent in many ways. The intimate carer becomes focused on more instrumental dimensions of caring for the loved one. This is a loss and constitutes a gap or “hole” that emerges when simple, intimate partnership recedes. Such simple, intimate partnership may be longed for, as the instrumental challenges of care come to define the relationship more and more. There may be attempts at distraction by going away, or attempts at substitution by engaging in other activities. Still, the longing for simple intimate partnership may bubble in the background. The kind of intimate reconnection that is possible appears to be quite different from a reciprocal ongoing partnership of roles. It is less the project of partnership and more the possibility of simple moments of intimately being together. From project to moment—intimacy appears to be able to survive in the latter. Given the increasing “brightness” of the emerging polarization of roles (carer and cared-for), moments of simply ‘being together’ can break through. This is sometimes given in physical touch, or in silently sitting or walking together. This “being” seems to require moments of unoccupied space and time. Ways of supporting such free moments of “no consequence” are a great gift and help.

Phenomenon 5. The transition to living apart

For M, the timing of eventually living apart was not a decision that he actively took alone. Rather, he found his own health deteriorating and other professionals stepped in to suggest the need for living apart.

Through this process, he decided that the more time L could spend in professional care, the better it would be for both of them. The way the separation occurred was important. L moved to her care home for an initial respite break. After a period of being upset, L appeared to adapt to the situation. Earlier experiences (“taster days”) or brief separations appeared to help her settle to new living circumstances.

M was surprised to find that initially, during this respite, he did not miss her and experienced a relief at “not having to do anything.” Through this initial trial separation, the adjustment to a more sustained living apart began. M’s adjustment as a carer involved three forms of coping during the transition: circumstantial, emotional, and meaning-making.

Circumstantial. M’s own poor health at the time of their parting focused him initially on his own recovery process and he was forced to recognize the limits of his own caring capacity.

Emotional processing. Emotional processing involved the transition from guilt to reconciliation. After an experience of initial relief and respite, there was a period of feeling terribly guilty and a self-questioning about whether he had done the right thing. It was important and helpful for M that one of the health professionals (a community health nurse), “a person with trained good ears,” functioned as an empathic and active listener to M’s feelings of worry and guilt about the separation. He felt it was important and valuable to “pour out his inner soul” of having carried the burden. As part of this adjustment, it also helped him to see over time that the quality of the care L received was good, and this reassured him. He felt grateful for this and characterized it as a “loving care” and “trusting care.” Part of his emotional adjustment involved a cognitive reconciliation with the decisions that were taken. He came to feel that he had done the right thing compared with passively letting circumstances take their course.

Meaning-making. Already during the first “trial” respite break, M began to think about how he could re-engage with his life in a different way. He had already begun to advocate on L’s behalf to ensure that she received the best medical treatment possible. After his own health recovered somewhat, M returned to an active life in which he could share the experience of caring for L with others, and act on his strongly felt desire to raise awareness about Alzheimer’s disease. This form of meaning making and helping others has been successfully productive and

it gave him a sense of purpose. This busy life of meaningful advocacy helps M cope with what he experiences as the ongoing emotional challenge of missing their moments of intimacy and the effects of their separation. This emotional challenge has surfaced more in recent times as the busyness of his engagements recede. He is left with the challenge of how to occupy himself, “The worst thing for me is to be faced with having nothing to do.”

In summary, the move to living apart has involved two central challenges: how to conscientiously accept and make sense of the separation, and how to live towards a different life of meaning, alone.

Embodied interpretation

To face the limits of one’s own caring ability; how can this be resolved? Part of this emotional process involves experiencing a degree of helplessness in the face of unrelenting circumstances. The intimate carer may reach a time where he or she feels the intense burden of the caring tasks and the feeling of aloneness that sometimes comes with this. He or she would like to carry this burden; it is a care that he or she wishes to give. So, there is often an inner resistance in the carer to the idea of living apart. The carer is painfully aware of the loved one’s need for things to stay the same. In this case, the carer is conflicted about his own need for things to stay the same and the need for things to move on. There is a tragic awareness that their life together has come to this. It is extremely difficult for the carer to be deliberate in his or her decision to seek alternative living conditions for the loved one without him or her. When it happens, it is understandable that it may need to be done in phases, with respite breaks and brief separations. Understandably, there can be guilt at times because “who knows for sure” when a time of alternative living arrangements is necessary. It is an almost impossible decision to take alone, and the intimate carer may be greatly helped by another’s listening ear. The intimate carer may even feel initially relieved if there is professional intervention to take the decision out of his or her hands. However, this sense of relief may be mixed with lonely self-questioning and further feelings of guilt. Some kind of justification of the separation helps to resolve this aspect of the parting to some extent. Such cognitive reconciliation can be partially achieved by seeing signs that some positive benefits have occurred in the quality of care that the loved one receives. It seems important for the intimate carer to see this and to experience such reassurance. When a degree of reconciliation to the parting has occurred, the intimate carer faces the challenge of another change of personal role: he or she becomes

less instrumental in the care and this can open up the task of finding new meaning in a life alone. The other central challenge is what kind of “visitor” the intimate carer becomes. There is inevitably a variety of responses to this question. Living apart is an accentuated “fork in the road” and a “saying good-bye” that comes and goes.

Phenomenon 6. Advocacy sustained by passion and know-how

By living through his complex experience of learning to care for L, M developed both a passion and know-how that were demonstrated through his advocacy for L in particular and his concern to improve care for people with Alzheimer’s disease in general. There were three kinds of advocacy that M actively engaged in:

- Representation, mediation and decision-making on L’s behalf;
- Raising awareness about neglected areas of concern in both the care and understanding of Alzheimer’s;
- The passionate perseverance to be heard and ensuring his advocacy made a difference.

Representation, mediation, and decision-making on L’s behalf. M described a level of advocacy in which he acted as a mediator between L’s lived concerns and her difficulties in expressing these concerns during medical consultations. The need for this came not only from M’s awareness of L’s lived difficulties in expression, but also from his awareness of the limited insights of professionals into the nuances of L’s problems. This was compounded by the bureaucratic/political constraints within which care options were offered. At times, the need for this form of mediation was felt by M to be urgent, and he would have to become “extremely firm” in representing the perceived need. In this decision-making process, he had to consider L’s unique life and condition as a whole (for example, L was also dealing with a malignant tumor).

The process of participating in this complex decision-making had to take into account M’s understanding of L’s capacities and emotions, different professionals’ advice, his knowledge of L’s idiosyncratic reactions to different medication regimes, and finally, his expectations about the kind of help and support they would get, both socially and medically.

Raising awareness of neglected areas of care. Beyond advocating specifically on L’s behalf, M became

passionately aware of some general issues regarding the care of people with Alzheimer’s disease. He wanted to raise awareness of these concerns within a broader public arena and share his own experiences, perspectives, and expertise. Two specific concerns are incontinence care, and new and emerging drug regimes.

Incontinence care. M has become aware of the extent to which incontinence care is a particular problem for males looking after females. He expresses empathy for other male carers in this situation and acknowledges his own privileged position whereby his background enabled him to cope. He feels that more can be done by health agencies to address these issues with specific reference to technical aids and medication.

New and emerging drug regimes. M is concerned about how different agencies and professions compartmentalize the problems of caring for people with Alzheimer’s disease, and he is strongly adverse to those medical professionals who see the disease as primarily a social problem. In cynical moments, he wonders if this view is driven by cost considerations. He advocates strongly for new and improved drug regimes because he has noticed the significantly improved quality of life that L has since she started on new medication. He laments the fact that other sufferers may be deprived of this regime because of bureaucratic/political constraints, and lack of awareness and resources.

The passionate perseverance to be heard. A degree of perseverance at different times, has been an important dimension for M in sustaining his advocacy. Such perseverance was indicated by seeking recourse beyond individual healthcare practitioners and agencies, to higher authorities that were responsible for political and executive decisions at different levels (for instance, M was prepared to seek legal recourse if necessary). This level of advocacy was fuelled by a number of experiences of not feeling heard in his mediation and advocacy role, and where simple negotiation in local situations did not appear to make a difference. There were some occasions in which he successfully achieved improvements in L’s treatment. As a consequence of his success in this higher level advocacy, M also achieved a sense of greater cooperation at the local level and began to feel cared for. He reflects on the need for a wider advocacy service.

In summary, this kind of advocacy was expressed as giving a voice to L’s needs from a

perspective of really knowing her, perseverance in negotiating complex systems and a desire to influence the care of people with Alzheimer's disease in general. This was driven by M's passion, prior experience, desire to share know how and overriding concern for L's well-being. The need to be heard and to make a difference in all these ways resulted in M experiencing some satisfying improvements.

Embodied interpretation

To take the gap, to want to go the extra mile; this may be the felt position of the intimate carer. Based on a unique knowledge of the loved one and on an intimate connection with "this person who matters," there is an emotionally alive energy to want to enter any perceived neglected space between the needs of the loved one and the possible responses, either professional or situational, that might be available. How should the carer speak or act based on this emotional energy and unique knowledge? This may depend on personal style. In M's case, he drew on previous expertise in 'going the extra mile'. Others may find their own way of doing this. "Taking the gap" can be a lonely responsibility and could become a burden. How to understand it and how to say it well to the right people may become a challenging preoccupation. In some cases, "going the extra mile" may require perseverance in the face of others who may not yet understand the felt significance or importance of something the carer has seen or noticed. To be an intimate mediator between life with the loved one and the outside world is a steep learning curve. He or she learns a lot about what support and care is possible and available, and learns from "within" about what is needed. The carer may become aware of how resources and help are part of a larger picture of health and social care services in general. The emotional energy to help make a difference may then exceed their particular situation, and the carer may join with others to advocate more generally on behalf of people experiencing the challenges of living with Alzheimer's disease. This could be as local as helping other carers, or as political as lobbying pressure groups for change. When done well, it could be a powerful form of advocacy, welcomed by relevant professionals and bodies. Whether just for them as a couple or for all sufferers, it appears important to the intimate carer to make a difference. Thus, knowing how to use this unique know how and emotional energy is a core task for the intimate carer.

Implications and value of study

The researchers were asked to attend a local support group for carers' of people with Alzheimer's disease in order to communicate their findings of both the previous narrative study as well as this phenomenological study. In responding to these findings, it emerged that each person (carer) in this group could relate personally to the findings with particular unique nuances and variations. Each spoke further about differences or similarities, and each took the experience forward in different ways. We were happy with this because it served our concern not just to rest with the communication of "propositional knowing," but how to turn this into the possibility of 'experiential knowing' (Heron, 1996; Reason, 1994). Propositional knowing refers to general assertions that are abstract, such as "a tranquilizer is good for anxiety." Experiential knowing, on the other hand, goes further in that it relates the knowledge to our personal lives and experience; it allows us to see these experiences in a new light. Experiential knowing requires rich, evocative details to affirm personal meanings that have practical significance. This kind of phenomenological research includes attention to both the structural and textual, empathic, embodied dimensions, and we believe it possesses enough nuanced details to potentially turn propositional knowing into experiential knowing for readers.

Finally, we would like to close with some practice-related implications of this study by raising the following questions that focus on the carer's experience:

- How can professionals, family and support groups recognize better the "irritation" and anger of carers as part of a mourning process that needs containment and help?
- How can professionals, family and support groups help the intimate carer to move gradually from valuing "successful outcomes" of the loved one's memory and actions, to valuing "process" for its own interactive sake and value?
- How can professionals become more aware of the practical wisdom in the intimate carer's remembrance of what is important to the loved one?
- How can professionals and support groups better understand, and respond to, the carer's struggle and dilemma of not wanting to take away the sense of personal agency and dignity from the loved one, while still managing the tasks of everyday routine and safety?
- How can professionals, family and support groups help the couple to have moments of

“simple being,” where the instrumental role of the carer is relieved?

- When making the transition to living apart, how can professionals, family and support groups help the partner in the transition of role from “intimate carer” to “intimate visitor”?
- How can professionals, family and support groups help the carer find an appropriate level of advocacy that acknowledges his/her intimate knowledge while giving him/her permission to accept the limits of his/her caring abilities?

These questions all follow the descriptive general structures generated from this study. Each question demonstrates the value of a phenomenological level of analysis that reveals specific experiential nuances that may also be transferable to other carers, such as: impatience as a resistance to mourning; how patience can be won by shifting from an emphasis on outcome to an emphasis on process; the intimate carer’s important role in remembering what was important to the loved one; the dilemmas of caring for both the dignity and safety of the loved one; and a number of other important insights that are revealed by these descriptions.

An important question, however, is whether the “embodied interpretations” added any value to the way the findings were presented. The rationale for this phase is to serve the communication of findings in more evocative ways that may support readers in understanding what a phenomenon may be like in an empathic way. The value of such empathic understanding is a kind of knowledge that is not so much about new information, (new contributions to propositional knowledge) but about the possibility of enhancing the “emotional intelligence” of audiences. This may be particularly important in the caring sciences where putting an experience together as an embodied whole may serve as an important intuitive reference that can support acting in caring and ethical ways. In finding a way to be faithful to descriptions, and expressing this in more evocative ways, the prose of “embodied interpretations” may help to make an experiential phenomenon more present, so that it can live in ways that exceed any summary and find a meaningful relationship with readers own lives: it is the kind of knowledge that “touches.” The readers themselves may best judge the extent to which this works for them. Such “resonant validity” was confirmed when we disseminated the findings presented in this article to a local support group for carers’ mentioned previously. They were moved, and said that they wished for health professionals to understand these dimensions in such qualitatively rich terms.

Finally, we would like to suggest that by reading both the detailed information articulated in the descriptive structures as well as by reading the more ‘evocative’ sense of the “embodied interpretations,” fellow carers, professionals, family and support groups could be better equipped to understand and respond to the “life that is possible” in this poignant journey. The challenge then becomes how to disseminate such studies and emerging discussions and activities beyond the readership of an academic and professional community. That, however, is a topic for another article.

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