An Expanded Theory of Alzheimer’s Caregiving

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The ancient and cross-culturally prevalent pattern of caregiving suggests that long-term caregiving is species characteristic for humans. If so, then an evolutionary account of the adaptation(s) that underwrite this caregiving is necessary, particularly for the one-sided and long-term nature of Alzheimer’s caregiving. Four standard evolutionary explanations are evaluated: kin selection theory, the grandmother hypothesis, direct reciprocity, and indirect reciprocity. Each is found inadequate to explain caregiving because of the lack of reproductive benefits. These evolutionary accounts also assume that relationships are only valuable to the degree that they provide benefits and that relationship partners are predominantly motivated by self-interest. Attachment provides another explanation, which evolved initially to ensure infant protection and nurturance, but was exapted for important adult relationships. Attachment relationships naturally include caregiving and engender long-term relational commitment. Yet attachment theory is ambiguous about whether relationships are maintained for the sake of security benefits or because they have inherent value. This ambiguity undermines the explanatory value of attachment theory for Alzheimer’s caregiving. Therefore, a shared identity theory is offered that highlights the inherent value of the relationship and the loved one, transcending the predominant focus on beneficial individual outcomes. The theory emphasizes the frequent human motivation to benefit others because of their mutual commitment, shared identity, and shared goals. The conclusion is that fully understanding and supporting the arduous efforts of caregiving for loved ones with Alzheimer’s requires psychologists to fully appreciate and support the deep and meaningful motivations that often inspire the humanity seen in caregiving.

Keywords: Alzheimer’s disease, attachment, caregiving, evolutionary theory, older adults

A report for the National Academies of Sciences, Engineering, and Medicine (2016) stated that, by 2030, there will be 72.8 million Americans over the age of 65, with the greatest growth in “the ‘oldest old,’ the population that is most in need of help because they are the most likely to have physical, cognitive, and other functional limitations” (p. 1). As the number of older adults increases, new cases of Alzheimer’s disease and other dementias will rise from the current 5.5 million Americans, heightening the challenges for caregivers (Alzheimer’s Association, 2017). Despite this extraordinary demographic shift, “little action has been taken to prepare the health care and LTSS [long term services and support] systems” (National Academies of Sciences, Engineering, & Medicine, 2016, p. 1). Because family caregivers provide most Alzheimer’s care, “support[ing] caregivers is among the most significant overlooked challenges facing the aging U.S. population, their families, and society” (p. 1). This article focuses on caregiving for people with Alzheimer’s disease and related dementias. Unless otherwise noted, all references to caregiving are to this limited domain to reduce repetitive qualification of caregiving terms.

Psychologists have a crucial role in understanding the needs of caregivers and providing support through theory, research, and practice. Accordingly, the Commission for the Recognition of Specialties and Proficiencies in Professional Psychology expanded geropsychology from a proficiency to a specialty in psychology (American Psychological Association, 2011). In addition, the Institute of Medicine’s (2012) Committee on the Mental Health Workforce for Geriatric Populations reported a growing need for geropsychologists to meet the rapidly growing older adult population.

Prevalence and Costs of Caregiving in the United States

The Alzheimer’s Association (2017) reports that 15.975 million individuals care for someone with Alzheimer’s dis-
ease or other types of dementia. Informal (uncompensated) caregivers, (i.e., friends, family, or neighbors) provide the majority of elder care in the United States (National Alliance for Caregiving & AARP, 2015). Approximately 16% of caregivers are spouses, 60.5% are children, and 18.7% are other relatives, with less than 5% caring for a nonrelative (Friedman, Shih, Langa, & Hurd, 2015). Unpaid caregivers spent 18.2 billion hours providing care in 2016, averaging 21.9 hours a week per caregiver. The economic value of informal caregiving was $230.1 billion in the United States (Alzheimer’s Association, 2017).

The steep costs of caregiving have been the most prominent focus of caregiver research. Dementia caregiving is costly in physical and mental health, finances, as well as the gradual loss of the care recipient’s ability to relate fully (Lovell & Wetherell, 2011; Pinquart & Sörensen, 2011). Dementia caregivers report more stress and depression than caregivers for other conditions (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999), with 59% of the former reporting high or very high stress, and 30% to 40% reporting depression (Alzheimer’s Association, 2017). The chronic stress of caregiving is associated with adverse physical health outcomes, including higher blood pressure and mortality, dysregulation of the hypothalamic–pituitary–adrenal (HPA) axis and lower immune function (Lovell & Wetherell, 2011). Although caregiving has many significant costs, some informal caregivers report positive aspects of it. Nevertheless, millions of people continue to provide care to their loved ones despite the costs (e.g., Pinquart & Sörensen, 2011).

Alzheimer’s caregiving is quite one-sided, as care recipients become progressively less able to reciprocate benefits because of degenerative cognitive disease. This article explores this one-sided caregiving as a strong test case for benefit exchange theories of relationships. Although caregiving is often termed altruistic, the motives for altruism must be explained, not assumed.

If psychologists are to successfully provide appropriate and useful support for caregivers, it is essential to accurately and comprehensively understand why caregivers so willingly offer so much care. The enormous number of caregivers is not only a question of the scope of the need. More importantly, the number of people providing such extensive care reveals a human capacity for profound relatedness even when it is extremely costly. Because this capacity appears to be species characteristic, a full explanation must account for how humans evolved to be willing to offer extensive, long-term care. This article investigates how such caregiver motivation can be explained. A better understanding of caregiver motivations may also clarify sources of the quality of caregiving. Although many caregivers are quite devoted, some dementia sufferers are neglected and even abused. If the conceptual basis for caregiver research and interventions is flawed or insufficient, psychologists’ efforts will be undermined and skewed in unhelpful ways.

Caregiving research and practice is generally conceptualized in cost/benefit terms, which is an instrumental or means-end approach to explaining behavior. Yet cost/benefit analysis appears to be insufficient for Alzheimer’s caregiving because it is so one-sided. Adopting a cost-counting explanation may undermine the quality of care and the capacity of caregivers to sustain their loving efforts because of the chronic cost-benefit imbalance. The central thesis of this article is that long-term caregiving cannot be explained through cost-counting, and a noninstrumental theory is needed to both explain and properly support caregiving. A corollary of this thesis is that the highest quality caregiving will be motivated noninstrumentally (i.e., not entirely predicated on caregiver benefits). Therefore, before discussing the theories that may account for long-term caregiving, it is important to set out a primary metatheoretical contrast between instrumental and noninstrumental activity that guides this evaluation of explanatory theories.

Beyond the Instrumental Portrayal of Caregiving

Several scholars have argued that a presumptive and seldom questioned form of instrumental reasoning about human action—exemplified in the predominance of cost-benefit analyses in the caregiving literature—severely constrains the understanding of relationships and caregiving (Clark & Aragón, 2013; Fowers, 2015). If human relationships can only be explained in cost-benefit terms, costly caregiving will remain mysterious despite its prevalence. Questioning instrumental thinking is difficult because it is so pervasive in psychological science and practice that an alternative is hard to see. Therefore, it is important to
consider an alternative account that recognizes that much human activity cannot be neatly separated into discrete costs and benefits.

**Instrumental Action**

One way to bring an alternative to light is to more explicitly define the three central features of *instrumental activity* (Fowers, 2010). The first is that instrumental activity has a means-end structure. The means can also be seen as costs, in that any means is costly in terms of effort, expense, or risk. Similarly, benefits are one form of ends. A fully instrumental perspective sharply separates means and ends, with means being viewed as tools or strategies that individuals use to obtain their desired end. In this means-end structure, the actor primarily values the end or outcome, and only secondarily the means.

The second feature of instrumental activity is that the effectiveness of the means for achieving a desired outcome is the sole evaluative criterion for means. In cost-benefit terms, the question is whether the costs are low enough to pursue the benefits. The high cost of Alzheimer’s caregiving raises serious questions about a purely instrumental explanation in Alzheimer’s caregiving calls for an explanation of its prevalence. The predominant approach in the literature is to ask, “How can psychologists help caregivers cope with this imbalance?” In contrast, the question in this article is, “Why are so many humans willing to devote so much time, energy, and money to care for loved ones with Alzheimer’s disease (and related dementias) and how can psychologists work consonantly with their motivations?” A comprehensive theory of caregiving must explain not just how, but also why humans willingly undertake such extraordinary care.

**Constitutive Action**

The alternative to construing all human action in means-end, instrumental terms is to recognize that, in some activities, the means cannot be separated from the end because the means embodies or constitutes the end, which Fowers (2010) termed *constitutive activity*. Spending time with friends is a common constitutive activity because the activity is identical with the end. Although one could say that spending time with friends is valuable for the sake of pleasure, social support, or future assistance, it is important to see that these ends are not separable from friendship. After all, friendship is constituted through sharing pleasures and joys, commiserating about losses and setbacks, and participating in jointly valued activities, including helping one another. Moreover, pleasure is not separable from friendship. Rather, it is found in the friendship. One does not engage in friendship to obtain a subsequent outcome of generic pleasure. Friendship itself is pleasant, and pleasure in a relationship differs from other pleasures. Thus, pleasure is not an end that is separable from friendship.
In contrast with instrumental actions, constitutive actions are not evaluated primarily in terms of their effectiveness. The value of constitutive activity is judged by how well the actions embody the end. Of course, one can evaluate the quality of caregiving instrumentally in how well it relieves an individual’s suffering or facilitates functioning. Indeed, the quality of paid caregiving is typically assessed instrumentally because the relationship is secondary to the employment. Yet many caregivers tend to see their actions as expressions of love and compassion—the embodiment of their relationships (Dhar, 2012; Harris, 2001; Kolmer, Tellingings, Gelissen, Garretse, & Bongers, 2008; Quinn, Clare, & Woods, 2015), which is especially evident when the care cannot effectively reduce suffering (beyond medication) or facilitate functionality. Many caregivers continue to do what they can, regardless of how effective their actions are.

Finally, because constitutive actions are not means that can be separated from their ends, the actions and persons that help to bring about the agent’s end are not disposable. It is not possible to separate the action of caring for a friend, partner, or parent from the goal of having a good relationship, nor is it possible to separate the friend from the friendship. Caring for one another, especially when the chips are down, is a primary constituent of love and friendship. The friendship is what it is because of who the friends are and the particular experiences they have shared, which makes those specific friendships irreplaceable. It is true that one can always make new friends, but one cannot simply switch one friend for another as a replaceable element.

There is little doubt that at least some people approach caregiving as a means-end activity, with the actions separable from their ends (e.g., guilt reduction, reputation, or self-esteem). Yet for many caregivers, such an explanation would be ill-fitting, perhaps even deeply offensive. For these individuals, caring for a loved one is not an activity that is separable from some desired outcome. Rather, they approach caregiving as integral to or expressive of a long-term, caring relationship. Caregiving partly defines the relationship, wherein the loved one, the relationship and the caregiving behavior are valued for their own sake. This kind of valuing is inherent to relationships that are unique and irreplaceable, such as with parents or a spouse. It seems more plausible that long-term caregiving is often motivated more by commitment, shared history, and attachment than by benefits to the caregiver. The question of caregiver benefits is addressed as theories of caregiving are evaluated in subsequent sections. If high-quality caregiving is best understood as a richly meaningful activity undertaken by committed loved ones, approaching it as a means-end activity is likely to impoverish and undermine caregiving. An instrumental perspective renders caregiving a chore to get through rather than a devotion and reducing the costs of chores is generally preferred. An instrumental understanding of caregiving is blind to the inherent value of those relationships, reduces the prospects for loyal, meaningful affiliations, and impoverishes the capacity for humane caregiving.

The distinction between instrumental and constitutive activity guides the evaluation of a selection of theories of caregiving, beginning with evolutionary accounts. The limits of general evolutionary accounts will suggest the need for another explanation, and attachment theory is a very good candidate. Ambiguities in attachment theory indicate that this account is insufficient on its own. The article concludes with a new theoretical framework and its applications. An alternative theory is necessary to fully recognize the irreplaceability of loved ones and the noninstrumental nature of high quality, enduring caregiving. This article focuses on caring for individuals with Alzheimer’s because its challenges so clearly illuminate the shortcomings of an instrumental portrayal. The shared identity theory presented here can support high quality caregiving and suggest more appropriate interventions to support and guide caregivers’ efforts.

**Evolutionary Explanations for Caregiving**

The theoretical analysis begins with evolutionary theory because caregiving appears to be ubiquitous enough to be characteristic of humans as a species. This ubiquity is only possible if there is a set of evolutionary adaptions that underwrite caregiving and can thereby explain this human capacity. The contemporary caregiving literature overwhelmingly focuses on proximal (contemporaneous) relationships between caregiver stress, coping resources, and symptoms. This focus on contemporary associations among variables can illuminate how this capacity is exercised, but these relationships cannot explain why humans became capable of offering so much costly caregiving. This degree of other-benefitting effort demands a comprehensive explanation.

To understand what it means for humans to offer long-term caregiving, it is important to examine some ultimate explanations for why the capacity for caregiving evolved and why it continues to shape behavior. An ultimate explanation accounts for caregiving as a set of adaptations that improved evolutionary fitness in the deep past. Cosmides and Tooby (1992) proposed five criteria to evaluate whether a behavioral pattern is an evolutionary adaptation: (a) the behavioral pattern appears to be ancient and ubiquitous (i.e., it is species characteristic); (b) it appears to have originated as a way to increase reproductive success; (c) it is cued by a heuristic; (d) it does not require formal instruction; and (e) it is a complex, nonaccidental activity.

**Temporal and Cultural Prevalence of Caregiving**

Although Alzheimer’s caregiving is a mostly modern challenge resulting from increasing lifespans, there are sev-
eral fossil examples of caregiving for older or infirm adults who could not have survived without significant aid. These include a *Homo erectus* individual that had only one remaining tooth several years before dying (Lordkipanidze et al., 2005), an adult female *Homo ergaster* with debilitating hyperparathyroidism A (excessive intake of vitamin A; Cameron & Groves, 2004), a *Homo heidelbergensis* individual with spinal injuries and degenerative lesions (Bonmati et al., 2010), and a *Homo neanderthalensis* individual with multiple fractures, including atrophied bones (Hublin, 2009). The fossil record for ancient *Homo* interactions is very sparse, making it nearly impossible to prove any behavioral pattern beyond doubt. Yet these examples provide evidence for an ancient pattern of caring for debilitated adults. Walker and Shipman (1996) expressed a common belief that such individuals survived for an extended time because “someone else took care of her... Her bones are a poignant testimony to the beginnings of sociality, of strong ties among individuals” (p. 165). This evidence that ancient hominin provided extensive care for infirm individuals suggests that adult caregiving adaptations are ancient in the *Homo* lineage.

Informal dementia caregiving occurs widely across cultures as well. In the United States, Pinquart and Sörenson’s (2005) meta-analysis revealed that caregiving is widespread across ethnic groups. Pharr, Dodge Francis, Terry, and Clark (2014) reported that, among ethnic minority respondents, caregiving is “deeply rooted in the cultural subconsousness, arising ‘naturally’ without conscious though” (p. 3). For many caregivers, religious beliefs help shape motivation for caring, as described by Stuckey (2001): “caregiving could be compared to a life’s mission—almost like a reflection of their spirituality” (p. 80). Over 46 million people have dementia worldwide, with more than 60% of them living in developing countries (Alzheimer’s Disease International, 2015). Dementia caregivers in developing countries tend to be women and 25% to 50% of caregivers reported living in three-generation households with extended families (The 10/66 Dementia Research Group, 2004).

The evidence for the long history and cross-cultural prevalence of caregiving suggests that this behavioral pattern is species characteristic for humans; that humans are adapted to provide care for infirm loved ones. Although Alzheimer’s disease was very likely rare prior to the modern era, contemporary Alzheimer’s caregiving is very likely to have the same evolutionary sources as earlier forms of caregiving for older adults. Explaining this costly and often unrequited behavior can shed valuable light on the humanity of caregiving.

**Caregiving Heuristic, Training, and Complexity**

The heuristic for caregiving is simple: the incapacity or vulnerability of a close companion. There is abundant evidence that this heuristic is operative (Penner, Dovidio, Pilavin, & Schroedter, 2005; Piff, Kraus, Côté, Cheng, & Keltn, 2010). The inclination for caregiving does not appear to require instruction, judging from its ubiquity. Of course, one can learn to be a better caregiver, but the basic capacity appears to be part of an ordinary repertoire for humans. In addition, caregiving is clearly a complex set of behaviors that could not occur accidentally.

**Caregiving As an Adaptation**

The concept of adaptation is central to evolutionary accounts, wherein a design feature is selected because it improves individuals’ reproductive success. Similarly, characteristics that hinder reproductive fitness are selected against (Cosmides & Tooby, 1992). Adaptations are characteristics that solve recurrent problems, serve specific functions, and enhance individuals’ reproductive success, and therefore spread in a population to become characteristic for that species. Therefore, evolution, as an impersonal process, has a built-in (and appropriate) means-end structure, wherein evolutionary change has an outcome (reproductive fitness) that is fostered by a set of contingently effective means (the adaptations).

Caring for someone with Alzheimer’s potentially decreases the caregiver’s direct fitness through significant costs to physical health, psychological well-being, and mortality (Alzheimer’s Association, 2017). Caregiving can also substantially decrease the resources available to a caregiver’s descendants (another direct way to influence fitness). Such apparent fitness reducing helping is known as the “problem of altruism,” defined as other-benefitting behavior that reduces the actor’s fitness. This problem has preoccupied many psychologists and evolutionary scientists for decades. Simply labeling behavior as altruistic is not explanatory. The real question is whether any version of this instrumental evolutionary explanatory approach (i.e., kin selection, grandmother hypothesis, direct or indirect reciprocity) can explain caregiving.

**Kin Selection Theory**

A well-known solution to the “problem of altruism” is Hamilton’s (1964) *kin selection or inclusive fitness theory*. This theory suggests that organisms help genetically related others because any fitness sacrifice is repaid by fitness benefits to its kin, thereby increasing the likelihood of passing on their shared genetic design to future generations. According to kin selection theory, altruistic behavior will be selected for if the reproductive “benefits to the recipient, weighted by genetic relatedness of the recipient to the actor, outweigh the costs to the actor” (West, Griffin, & Gardner, 2007, p. 237). One reason Alzheimer’s caregiving does not yield inclusive fitness benefits is because the recipient is
typically postreproductive. Therefore, there are no indirect fitness benefits for the caregiver.

The Grandmother Hypothesis

Hamilton (1964) also proposed the *grandmother hypothesis* to explain that human females survive beyond postreproductive years to assist their grandchildren, who can pass their shared genes on to future generations. It is obvious that caregiving will not enhance fitness by enabling people with Alzheimer’s or other dementias to assist in caring for grandchildren.

Direct Reciprocity

A third evolutionary solution to the “problem of altruism” is *direct reciprocity* (Trivers, 1971), wherein costly benefits are reciprocated. This social exchange need not occur immediately if the organisms involved can track the benefits received and provided. Because these exchanges involve benefits that individuals often cannot obtain independently, the exchanges can achieve a “net benefit” for both parties (Cosmides & Tooby, 1992).

Although direct reciprocity can account for many prosocial behaviors, it cannot explain long-term caregiving, particularly for persons with Alzheimer’s, because the basic condition of balanced costs and benefits is impossible. The cost-benefit ratio in this caregiving is radically unbalanced in favor of the recipient. Informal caregivers provide older adults with extensive assistance in activities of daily living such as feeding, toileting, dressing, grooming, bathing, walking and transferring, managing finances, shopping, preparing meals, and managing medications (Mendes, 2011). Given the caregiving load, caregivers are unlikely to even attempt to track benefits and costs. The imbalance of giving behaviors means that a caregiver adaptation based on a direct cost/benefit calculus would be selected against.

Indirect Reciprocity

The best potential evolutionary explanation for other-benefiting is *indirect reciprocity*. In indirect reciprocity, third parties benefit those with an altruistic reputation (Nowak & Sigmund, 2005). A special case of indirect reciprocity is *costly signaling*. When an actor is publicly seen to benefit others in a resource or energy costly manner, it can signal the actor’s desirable characteristics (e.g., relative strength, health, ability, bravery, or kindness) to third parties and result in status benefits (McAndrew, 2002). Thus, drastic costs in the caregiver relationship could be repaid in social status and reputation benefits for the caregiver.

Although indirect reciprocity can account for some caregiving behavior, this reputation-based caregiving does not seem to explain more arduous, long-term, and private caregiving. Isolated bouts of assistance to others, such as providing directions or helping colleagues at work, may provide the actor with future reputation-based benefits. Caring for an individual with a degenerative illness is a long-term activity that usually occurs relatively privately (in one’s home or in an extended care facility). An indirect fitness explanation would have to explain how private behavior could be due to an adaptation based on public recognition. Because it is not in public view, it does not appear to be an instance of costly signaling.

On the face of it, long-term caregiving does not seem to fit the central criterion for an adaptation: effective promotion of the caregiver’s reproductive fitness. In contrast to the clear reproductive benefits of infant caregiving, there is no evidence that caregiving for older adults ever promoted reproductive fitness. Alzheimer’s caregiving today is far more likely to reduce fitness (e.g., impairing one’s health, hindering the ability to nurture descendants) than enhance it. Therefore, caregiving cannot be directly explained in terms of the “end” of reproductive benefits, rendering these instrumental explanations ill-fitting. Given this view of adaptation, how can this form of caregiving show up reliably enough to appear to be part of a design feature for humans?

Caregiving as an Exaption

Rather than rely on general mechanisms of evolution, it may be better to see caregiving as an extension or exaption of a well-established set of adaptations such as prosociality or attachment. An exaption is a preexisting feature that becomes beneficial in a novel way without having evolved to fulfill that function (Gould & Vrba, 1982). A common example is feathers, which initially evolved for insulation, but were exapted for flight.

Prosociality

Recently, scholars have made a strong case for humans as prosocial animals (e.g., Crocker, Can Evello, & Brown, 2017; Keltner, Kogan, Piff, & Saturn, 2014). Extensive theory and research indicates that helping and kindness behaviors are adaptive and ubiquitous. The evidence is strong that humans often benefit others and that other-benefitting increases meaning, happiness, and bonding with others. As Keltner et al. (2014) stated, “kindness, it seems, may very well be a basic instinct” (p. 430). Research on prosociality tends to focus on short-term helping with strangers due to being studied primarily in laboratory studies. When long-term caregiving is discussed, it is treated as a compelling example of prosociality. Although scholars have presented evidence for prosociality, no one has argued for the exaption of basic prosocial inclinations to the rigors of long-term caregiving—a significant theoretical gap. In addition, the prosociality literature typically treats givers...
and receivers of benefits generically, without close attention to the specific relationship between them. A case could be made for prosociality, but it has not been done, and doing so would require extensive theoretical work, which is beyond the scope of this article. In contrast, the exaption of attachment to caregiving in adult relationships is well established.

Attachment

The four general evolutionary explanations discussed above portray relationships instrumentally, as serial benefit exchanges. Caregiving relationships, often characterized by deep commitment and devotion, may not be entirely explicable in social exchange terms. In contrast to a benefit exchange perspective, caregiving is endemic in close relationships. Thus, the exaption of attachment is promising as a more direct, fulsome, and ultimate explanation for caregiving for four reasons: (a) individuals become attached to specific persons, (b) caregiving is a design feature of attachment, (c) human attachments are often long-lasting, and (d) although one can reestablish attachment security after losing a loved one, some attachments are irreparable.

Infant–parent attachment is universal in mammals, with the adaptive functions of feeding and protecting the young (Belsky, 1997). Bowlby (1969/1982) argued that infants are designed to connect emotionally with a primary caregiver through an attachment behavioral system, which includes proximity maintenance with the caregiver, who provides safe haven and a secure base. Bowlby stated that caregivers are also designed to act based on a complementary caregiving system, which motivates responsiveness through physical contact, soothing, and nurturance. These systems increase the parents’ reproductive success by promoting the infant’s survival.

Researchers have identified four attachment styles: secure, anxious-resistant, avoidant, and disorganized (Main & Solomon, 1986). Attachment security enables emotional self-regulation and thriving in relatively safe environments (DeKlyen & Greenberg, 2008). Many attachment theorists recognize, however, that less secure attachment can be adaptive in less safe environments or with less responsive caregivers (e.g., Belsky, 1997).

Adult Attachment

Bowlby (1969/1982) emphasized that attachment is not limited to infant–caregiver relationships. Rather, attachment processes have been exapted to parent–adult children relationships and romantic partnerships. Adult attachment is an exaption because the same attachment system that had already evolved for infant caregiving became beneficial in a novel way in adult relationships. He suggested that early attachment experiences establish a prototype, which informs relationships throughout life. Hazan and Shaver (1987) found a very similar attachment system in romantic relationships to the infant–caregiver relationship, with romantic partners enacting similar physical contact behaviors (e.g., kissing, hugging, nuzzling), as well as separation distress and safe haven behaviors. Hazan and Zeifman (1987) reported that parents and romantic partners are the primary sources of adult attachment security.

Providing Care to a Parent

Although this article focuses on the general design features of attachment, attachment styles are differentially related to caregiving behavior (Cicirelli, 1983, 1993; Collins & Feeney, 2013). Adult daughters’ attachment security was positively associated with emotional caregiving behavior and commitment to the care (Carpenter, 2001) and negatively associated with subjective burden in providing care (Cicirelli, 1993) and psychological symptoms (Crispi, Schiaffino, & Berman, 1997; Daire, 2002). Chen et al. (2013) reported that adult child caregivers’ attachment security was negatively related to criticism, hostility, and overinvolvement (expressed emotion) toward their parents with dementia. They also found that attachment security moderated the relationship between the perceived difficulty of caregiving and expressed emotion. In other words, caregiving relationships with stronger attachment appear to be more caring and less burdensome.

The power of adult attachment also emerges in the deleterious impact of parental loss on adult child caregivers’ psychological and physical well-being (Leopold & Lechner, 2015; Marks, Jun, & Song, 2007). Even before losing one’s parent, anticipatory grief indicates the importance of the parent–adult child attachment. Anticipatory grief is positively related to attachment in the caregiving relationship (Lindgren, Connelly, & Gaspar, 1999). The loss of unique and long-lasting relationships (e.g., parent–child or romantic relationships) gives rise to the most powerful and enduring grief, suggesting that the relationships had irreparable value to the child.

In a qualitative study, Dhar (2012) reported that emotional bonding or the security of attachment was frequently evoked to explain dementia caregiving behavior. Respondents explained that gratitude toward their parents influenced them to provide care. Of course, these individuals may simply be expressing an extremely long-term version of direct reciprocity, which seems implausible because direct reciprocity is not only a matter of repaying debts. Rather, it involves an ongoing exchange, the continuation of which is the point of the reciprocity. One could also suggest that filial loyalty is just a more appealing narrative than believing that caregiving is caused by impersonal forces. Although self-reports of motives are always open to doubt, they should not be dismissed without clear, contradicting evidence.
Pair Bonding and Caregiving

Pair bonding is an important exaption of the preexisting caregiving system that emerged in the Homo lineage to facilitate rearing slow-maturing offspring (Eastwick, 2009). Adult romantic attachment is often integral to caregiving for spouses with Alzheimer’s disease. Nevertheless, this caregiving relationship is linked to depressive and anxious symptoms, financial burdens, physical health declines, and mortality (Lovell & Wetherell, 2011; Pinquart & Sörensen, 2011; Sallim, Sayamanpanthan, Cuttian, & Chun-Man Ho, 2015). Moreover, partners of individuals with dementia also lose emotional support and intimacy, mental stimulation, having a helpmate, and recreational companionship (Mittelman, Zeiss, Davies, & Guy, 2003). These difficulties do not prevent continued care for their loved one (Lovell & Wetherell, 2011; Pinquart & Sörensen, 2011). Partner caregiving is facilitated by secure attachment to the spouse (Harris, 2001; Perren, Schmid, Herrmann, & Wettstein, 2007).

The attachment literature broadens the range of motivations for caregiving beyond the instrumental motive of increasing fitness. In contrast to the general evolutionary explanations, attachments are personal and directly include caregiving as an integral aspect of “meaningful and enriching connections with family members” (Dhar, 2012, p. 248). Research suggests that many caregivers prioritize motives focused on valuing the relationship with the care recipient and feeling responsible for them (Kolmer et al., 2008; Quinn, Clare, & Woods, 2015). Researchers have studied caregiver motivations as extrinsic (caregiving as a duty) and intrinsic (caregiving as a valued activity; McLennon, Habermann, & Rice, 2011; Quinn, Clare, & Woods, 2012). Intrinsic motives were related to meaning (Quinn et al., 2012a), caregiver competence (Quinn, Clare, McGuinness, & Woods, 2012b), and caregiver satisfaction (Lyonette & Yardley, 2003). Extrinsic motivation was positively related to caregiver stress (Lyonette & Yardley, 2003), burden, and feeling captive in the role (Quinn et al., 2012b), as well as caregiver anger, depression, and anxiety (Romero-Moreno, Márquez-González, Losada, & López, 2011). The instrumental/constitutive distinction helps explain caregivers’ experiences, with intrinsic motivation (a form of constitutive activity) being associated with positive outcomes and extrinsic motivation (a form of instrumental activity) being related to negative outcomes.

Expanding Theory on the Caregiving Relationship

The caregiving and attachment systems seem to provide a good evolutionary explanation of caregiving and fulfills Cosmides and Tooby’s (1992) five criteria for an evolutionary adaptation. The caregiving system appears to be ancient and ubiquitous. Infant caregiving originated to solve the strong selection pressure of mammalian infant survival and it has been exapted to adult attachment relationships to facilitate child rearing. Caregiving is cued by a heuristic of incapacity in a loved one and it does not require formal instruction. Caregiving is clearly a complex, nonaccidental activity. Moreover, attachment-based caregiving focuses on a specific individual and a longstanding relationship, which help to explain long-term caregiving.

Despite this explanatory strength, questions remain about the sufficiency of an attachment theory account. Whereas the one-sidedness of infant caregiving directly fosters parents’ reproductive success, dementia caregiving is costly from an evolutionary viewpoint. In contrast, ordinary adult caregiving is typically framed as mutually beneficial because the adults care for each other, as needed. The first question about attachment-based adult caregiving is whether it can explain one-sided adult caregiving. In addition, the benefits of caregiving are usually framed in terms of facilitating an individual’s attachment security. What motivates caregiving when the care recipient is unable to contribute to the caregiver’s attachment security?

Answering these questions may be best approached by applying the instrumental/constitutive activity distinction cited above. Attachment theory is ambivalent regarding the instrumental/constitutive distinction. Consistent with an instrumental interpretation, attachment figures provide care and comfort to people in their lives. The basic schema is a provider-recipient relationship and the primary goal is the attachment security of the care recipient. This provider-recipient relationship can be seen in instrumental terms wherein the provider and the caregiving are mere means to the outcome of attachment security. In adult relationships, such an exchange can work to both individuals’ advantage because they can alternate in the provider and recipient roles, as needed. If the partner and the relationship are more means, they are replaceable if they are ineffective or unsatisfying. Such an instrumental portrayal makes it difficult to understand how long-term, one-sided caregiving for an irreversible disease can persist when the caregiving provides no attachment security for the caregiver. Yet most caregivers do not abandon the person with dementia when the relationship becomes costly. It is questionable whether this approach fits the facts and the phenomenology of many caregivers.

It is important to recognize that some caregivers may appropriately see caregiving in instrumental terms because they may experience the caregiving as thrust on them as a necessity or duty. Yet the way that caregivers and psychologists construe caregiving can shape caregivers’ experience. Research indicates that the more a person is extrinsically or instrumentally motivated, the more burden, role captivity, and psychological distress he or she will experience.

If an instrumental approach misses or distorts important aspects of caregiving, can attachment relationships be reconstrued as a form of constitutive activity (wherein the
actions constitute the ends and are therefore valuable? Attachment relations can also be understood in terms of the provider giving care because he or she values the recipient’s welfare and a caring relationship. Seeing caregivers as motivated to support the recipient’s welfare and caregiving as worthwhile in itself (rather than just a means to obtain benefits) is a constitutive interpretation of attachment theory that can account for long-term caregiving. The difficulty is that both the instrumental and constitutive interpretations are plausible for attachment theory, and the theory is neither constructed nor expressed in a way that clarifies which is most correct. Thus, attachment theory is helpful as far as it goes, but it does not appear to contain the theoretical resources to fully account for long-term caregiving. For this reason, it is necessary to explore theoretical viewpoints that are unequivocally constitutive to supplement the attachment account.

A Shared Identity Understanding of Caregiving

The widespread depictions of caregiving in cost/benefit terms assumes that relationships are best understood with respect to the benefits they provide to individuals. Of course, relationship benefits are important, but there are three lines of theory and research that demonstrate that many human relationships have a constitutive form.

Communal Orientation

Clark and her colleagues’ (Clark & Aragón, 2013; Clark, Mills, & Powell, 1986) research program has illuminated an alternative to benefit exchange theories of relationships, called a communal relationship orientation. In relationships defined by benefit exchange, both partners assume that benefit provision is contingent upon receiving equitable benefits in return. In contrast, communal relationships are motivated by mutual concern for one another’s well-being (Clark & Aragón, 2013). Individuals respond to a partner’s needs without expecting the benefit to be repaid. Efforts to cost-count and directly reciprocate benefits are generally unwelcome in communal relationships; they may even give offense. A communal orientation is more common in close relationships (marriages, friendships, and parent–child relationships), whereas cost-counting typifies short-term or casual relationships (Clark et al., 1986).

Alzheimer’s caregiving follows communal norms rather than cost-counting norms. The extensive time and effort expended in caregiving is provided according to the loved one’s needs, not in hope of recompense from the recipient. Although both partners generally give according to the other’s needs in communal relationships, Clark and Aragón (2013) clarify that, at times, one partner gives more to the other person, and long-term caregiving dramatically exemplifies such one-sided giving. The caregiver assumes greater responsibility for their incapacitated loved one because they directly value the loved one’s safety and comfort.

Collective Identity

From a slightly different perspective, Brewer (1991) questioned the common assumption that individuals always act based on narrow self-interest. She presented theory and evidence that broadens self-interest to include the ways that individuals identify with groups and with loved ones. She argued that individual identity is not fundamental because it is partially constituted by shared identities, a prime source of which are attachment relationships. Her work highlights the often-forgotten portion of identity dependent on other people. She calls this collective identity, and her research clarifies that it often motivates behavior (Brewer, 2007).

According to Brewer (2007), individuals act in self-interested or other-interested ways depending on whether their individual or collective identities have been activated. When one’s collective identity is activated, one is likely to sacrifice resources for others’ benefit, but one’s focus will be on self-benefit when acting as an individual (e.g., De Cremer & van Dijk, 2002). Brewer explained that when one identifies with others, benefits to them are also benefits to oneself because one’s actions are based on a collective identity. She clarified that “when the [operative] definition of the self changes, the meaning of self-interest and self-serving motivation also changes accordingly” (Brewer, 1991, p. 476). Clearly, individuals often act self-interestedly, but people also act for others’ benefit, with Alzheimer’s caregiving as an example. This view suggests that collectively identified individuals will often act primarily for their loved one’s welfare. Substantial evidence corroborates the role of collective identity on cognition, emotion, and behavior in couples (e.g., Badr, Acitelli, & Carmack Taylor, 2007) and groups (e.g., De Cremer & van Dijk, 2002).

Shared Goods

The key commonality of the communal relationship and collective identity concepts is that both obviate the tired dichotomy of egocentricity and altruism. That is, agents do not have to choose solely between egocentric benefit and selfless other-benefit. Rather, it is possible to act in ways that are good for everyone involved. Aristotle (1999) also saw individuals as partly defined by their relationships and group memberships. He saw high quality relationships as essential for a good human life, which has been confirmed by abundant evidence (Fowers, 2015; Tomasello, 2014). As Aristotle (1999) put it, “No one would choose to have all good things all by himself [sic], for man is a social and political being and his natural condition is to live with others” (p. 264). A central feature of important relationships
is being a shared good rather than an individual good (Fowers, 2005). Individual goods can be pursued and achieved by individuals independently, but shared goods are only available to collectives, from dyads to large groups. Relationships are shared goods because they can only be achieved with other persons. Other examples of shared goods include justice, democracy, and team victory.

When a relationship is a shared good, the partners value the relationship itself, not just the benefits it provides. Thus, some close relationships are not just means to an end. An important relationship matters to the participants even when they are not receiving benefits. In Aristotle’s (1984) concept of philia (loving relationships), each individual values the welfare of a friend or family member for his or her own sake. He saw “philia toward anyone as wishing for him what you believe to be good things, not for your own sake but for his, and being inclined so far as you can, to bring these things about” (p. 2200). Part of what it means to love someone is to care about his or her welfare and seeing that person’s welfare as important as one’s own.

A close relationship is partly constituted by a shared history. Every friendship and family relationship occurs over time, and the memories of shared experiences, from tragedy to intimacy and achievement, are held in common by the relationship partners. The shared history partly comprises the shared identity and the individuals’ commitment to one another. As Brewer (2007) pointed out, one’s collective identities are central to one’s overall identity. Shared history is one reason that important relationships are irreplaceable because that shared history shapes one’s identity and cannot be easily discarded. Mutual commitment, collective identity, and the long-term, shared good of a relationship combine to make some close relationships irreplaceable.

Shared identity theory, which includes the communal, collective identity, and shared good features of relationships, clarifies why caregivers are willing to expend so much effort and expense for loved ones with Alzheimer’s. To the authors’ knowledge, the three theories have not been applied to Alzheimer’s caregiving before beyond a brief mention in Fowers (2015). The devotion and one-sidedness characteristic of many caregiving relationships may be due to the deep attachment, identification, and commitment to the relationship partner’s welfare that grows out of long-term attachments. These human capacities can explain the possibility and frequency of devoted, long-term caregiving. Shared identity evolved to solve the central problem of human belonging, and an extended evolutionary account of shared identity is available in Fowers (2015).

Conclusions and Implications

The prevalence and arduousness of Alzheimer’s caregiving seriously challenges the adequacy of instrumental and egocentric understandings of human relationships. The caregiving costs are too high to be recouped in any plausible way. Reproductive benefits are not forthcoming, and anything close to equality in benefit exchange is impossible. Attachment theory helps to explain the importance and longevity of caregiving in relationships and hints at the irreplaceability of the care recipient. Attachment theory was formulated ambiguously regarding the instrumental/constitutive distinction, which means that attachment theory does not clarify whether individuals and relationships have inherent value. The shared identity theory presented here complements attachment theory and provides an account of how many long-term, close relationships and the relationship partner have inherent and irreplaceable value.

In shared identity relations, the paramouncty of the loved one’s welfare is a continuing expression of a loving relationship rather than a cost-counting gambit. Caregiving is not something new when dementia ensues, for mutual care is an abiding element of ongoing adult attachments. What is new with the advent of Alzheimer’s disease is the increasing one-sidedness of the care. The shared identity perspective clarifies that caregiving is not always just an enormously costly burden that psychologists and others try to ameliorate. Rather, one form of caregiving is a continuing pattern of loving activity that meaningfully and enduringly expresses the importance of the relationship and the afflicted person. In these relationships, caregivers and their loved ones mutually value one another, often for a lifetime, which provides the ultimate reason for this costly, but deeply committed activity. This mutual valuing eventually becomes quite one-sided, as the loved one loses their human capacities inch by inch, but the endurance of the loved one’s welfare as a valued end is readily intelligible as the continued expression of a long history of shared memories, activities, and goals.

Of course, support and coping strategies can also help caregivers through these difficult times. But to the extent that scholars and practitioners understand all caregiving relationships in purely egocentric and instrumental ways, the care and devotion that moves some caregivers to such exertions will be distorted and demeaned. Those who approach caregiving with constitutive motives can be best supported by acknowledging and encouraging their devotion rather than misinterpreting their caregiving as motivated by instrumental, self-benefitting concerns.

The practical upshot of the instrumental/constitutive activity distinction is that it seems wise to consider two

1 A good is a desirable end or aim, such as money or friendship.
2 It is interesting that Tooby and Cosmides (1996) attempted an evolutionary solution to “the puzzle of friendship” with a version of irreplaceability. However, what is irreplaceable for them in close friendships are the benefits individuals receive from one another. They do not portray the person or the relationship as irreplaceable; they locate all the value in beneficial outcomes.
general forms of intervention for caregivers. Professional assistance is often formulated in cost/benefit terms with a focus on coping strategies to reduce caregiver costs (e.g., Lindquist, Tam, Friesema, & Martin, 2012). The cost/benefit approach can be beneficial, and it may be the most appropriate one for some caregiving relationships. Some caregiving is mostly or entirely obligatory and much-needed care is provided, but the caregiver is primarily extrinsically motivated by “guilt, duty, responsibility and lack of choice, associated with the growing dependence of the older person” (Lyonette & Yardley, 2003, p. 499). Research suggests that caregiving based on obligation or extrinsic motivation leads to greater caregiver burden. In these relationships, focusing primarily on coping and burden reduction seems appropriate and useful.

When individuals indicate or demonstrate an interest in intrinsic or constitutive motives for caregiving, a strong focus on burden reduction may be misguided and even demeaning. Psychologists can support intrinsic motives for caregiving by acknowledging those motives, developing interventions that enhance caregivers’ memories of the relationship and the person they value, attending to and encouraging the meaning the caregiver finds in the relationship and in caregiving, and in identifying positive aspect of providing care. One example of such an intervention is the Legacy intervention, which includes a life review of the caregiver-recipient relationship through creating a scrapbook with photos and audiotaped stories (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008). Psychologists may also be able to assist carers and recipients to maintain their valued relationship as much as possible by encouraging the care recipient’s active participation as a partner (consistent with safety).

There are indications that the precaregiving relationship plays a strong role in the degree to which caregivers are intrinsically or extrinsically motivated (e.g., Quinn et al., 2012b). Because the precaregiving relationship is already temporally established prior to intervention, an assessment is necessary to determine whether interventions following the shared identity theory would be appropriate and helpful. Although interventions are unlikely to alter caregiver motivations, tailoring the intervention to fit recognized differences in motivation is more likely to be beneficial. In situations where change is unlikely, change-oriented interventions will tend to be frustrating and possibly counterproductive and acceptance based interventions such as Acceptance and Commitment Therapy may be more helpful (Romero-Moreno et al., 2011).

It seems vital to broaden available theory of caregiving beyond an egocentric, instrumental form of activity to include the possibility of constitutive and shared activity emerging in long-term, important attachments. It also seems apparent that deep human attachment finds one of its finest expressions in caregiving for loved ones with Alzheimer’s. It is important for psychologists to clearly recognize the full range of motivations for this important form of caring. As Alzheimer’s disease strips away the human capacities of its sufferer, there is an opportunity for the humanity of the caregiver to shine through. This humanity should not be diminished with egocentric and instrumental understandings. Rather, this devotion should be understood, supported, and honored as an expression of a longstanding loving relationship that has value in itself; a value so deep that it cannot be effaced even by horrific disease.

References


McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with...


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