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Family caregiving for older people from a life-span developmental point of view

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Introduction

This chapter will address family care as an important phenomenon in inter- and intragenerational relations, that will become more and more important in Europe given the current demographic and social changes (see Ferring, 2010). We start with the observation that the occurrence of age-related diseases, functional declines and inabilities to perform daily activities are 'normal' parts of the later life of many older people. Family members are then among the first and most important providers of care; among these, spouses and the adult children represent the main caregivers (for example, Wolff and Kasper, 2006). Emerging impairments of older persons and the subsequent need for care likely initiates a change in the prior marital or child-parent relationship as well as in the life course and individual attributes of caring spouses or caring children. These changes will continue as the disablement progresses and the demand for care increases as epitomised by the term 'caregiving career' (Pearlin and Aneshensel, 1994; Aneshensel et al, 1995). It is therefore obvious to analyse family caregiving from the perspective of a discipline specialised on change over the life course, that is, life-span developmental psychology.

This has, however, only very rarely been done in prior research. As a notable exception, Robert and Jarrott (2008) applied the metatheoretical assumptions of life-span developmental psychology proposed by Baltes (1987) to the field of family caregiving for older adults (see also Shifrin, 2009). In this chapter we will make reference to more specific core concepts of life-span developmental psychology such as critical life events (for example, Filipp, 2007; Filipp and Aymanns, 2010), developmental tasks (for example, Havighurst, 1948; McCormick et al, 2011), development-related desires and goals and intentional self-development (Brandtstädter, 2001, 2011). As will become evident later, these concepts allow for a comprehensive and coherent picture of family caregiving for older people. This applies in particular with respect to the positive experiences of caregiving (for example, Carbonneau

et al, 2010) in addition to the negative ones ('burden') and with respect to possible developmental gains resulting from family caregiving such as competence development and personal growth.

Caregiving situation as critical life circumstances: demands and adaptation

The incidence of a disability of an older relative and the corresponding demand and provision of care often meet the definition of a 'critical life event', which is an event that leads to a discontinuity and destabilisation of prior action orientations and life orientations (see Filipp, 2007). If, however, the disability does not arise suddenly (for example, from a broken limb or a slight stroke), but rather slowly (for example, gradual development of Alzheimer's disease) and if it is not just temporary, but more lasting and requiring long-term care, it seems more appropriate to speak of critical life *circumstances*. Critical life events and critical life circumstances are, in general, not intentionally produced by the person who experiences them, but are unwanted events or states of affairs.

What makes the disablement of an older relative and the subsequent care provision 'critical' for family carers? First and out of a developmental psychological perspective, the changed life situation is object to self-regulative efforts as these are conceptualised in action- and emotion-theoretical approaches (for example, Brandtstädter, 2001). Viewed from such a perspective it is the extent (a) to which the event or circumstances interfere with desires and goals of their caring spouses or adult children and (b) to which these interferences cannot be easily overcome with existing action routines. Desires and goals have a positive valence that motivates and attracts the person to achieve these; non-achievement of goals and desires will result in feelings of frustration and other negative feelings and initiate individual coping behaviour. In the following, we will elaborate the interference of critical events and circumstances with individual desires and goals with respect to four mutually related issues:

elements of the caregiving situation, desires and goals of family carers, caregivers' appraisals and emotions in relation to caregiving, and action possibilities of family carers.

Elements of the caregiving situation

In the following chapter, it will become evident that caregiving represents a truly complex situation comprising several sources of potential strain (and gain) for both the recipient as well as the provider of care. Caregiving challenges a multitude of desires and goals of family carers, frustrating some of these and fulfilling others. Discrepancies between the demands of the caregiving situation and the individual desires and goals thus constitute the various realities to which family carers may adapt more or less successfully.

Disablement of older relative

Older peoples' disabilities often arise from different *age-related diseases* such as neurodegenerative disorders, stroke, musculoskeletal disorders, cardiovascular diseases, diabetes, cancer, and disorders of the senses (Verbrugge and Jette, 1994). Most of these illnesses are chronic and tend to worsen, so that the demand for care will probably increase with time. Age-related diseases may lead to *impairments* in specific body systems which in turn lead to *functional limitations comprising* either physical ones (for example, reduced ability to ambulate, reach or climb stairs) or mental ones (for example, increasing difficulty to recognise objects or produce intelligible speech) or both. These in turn may lead to difficulties in performing *activities of daily living.* Here, one differs between *basic activities* (BADL; for example, washing oneself, eating, using the toilet), *instrumental activities* (IADL; for example, homemaking, taking care of financial and administrative issues), and *activities enabling life enrichment, personal growth, or positive development* such as cultural activities, hobbies, excursions, playing, and media usage (Lawton and Brody, 1969;

Verbrugge and Jette, 1994; Wilms et al, 1998; Lindeboom et al, 2003; Albert et al, 2009; Baltes et al, 2010). In particular, older people with dementia *often become unable to entertain normal social relationships* with their caregivers. So family carers, who are no longer recognised by their demented relative, are losing them despite their continued bodily presence (Meuser and Marwit, 2001; Holley and Mast, 2009; Losada et al, 2010; Noyes et al, 2010). Recent studies have drawn attention to the *suffering* of the older relatives (Monin and Schulz, 2009, 2010), which can be *emotional* (depression, anxiety), *physical* (for example, pain, nausea, dyspnoea) or *existential/spiritual* (loss of meaning in life, loss of religious beliefs). Perceived suffering contributes to the distressing emotions of family carers above and beyond the physical and cognitive declines of care recipients.

A final aspect of older people especially with dementia are *problematic behaviours* such as disturbances of memory and thinking activities, emotional disturbances (for example, depression), and disturbing behaviour (Teri et al, 1992; Roth et al, 2003). These contribute significantly to the subjective burden of family carers (Pinquart and Sörensen, 2003, 2005, 2007) and may motivate caregivers to institutionalise their demented relatives (Phillips and Diwan, 2003; Gaugler et al, 2005).

Caregiving tasks

The variety of potential care recipients' problems mentioned earlier corresponds to a multitude of tasks for potential family carers (Zank et al, 2006; Pakenham, 2007; Wilkins et al, 2009). Among them are skilled nursing (for example, wound care, medication management, and mechanical ventilation), in-home care management (for example, home modification, supervising home care aids), and out-of-home management such as advocacy in negotiating with the health care system (Gaugler et al, 2002; Levine et al, 2003/4; Albert,

2004).[1] Other tasks include support with carrying out the basic and instrumental activities of daily living as well as with life-enriching activities and the alleviation of their older relatives suffering.

Impact of caregiving on other life domains of family carers

Extensive family care may have an impact on various other life domains of the carers: family, job, financial situation, leisure time, and contact with persons outside the family (for example, Gottlieb, 1989; Pearlin et al, 1990; Aneshensel et al, 1995). From a developmental point of view, it makes particular sense to look at the age of family carers and, thus, at the underlying developmental tasks and roles the caregiving person is experiencing at a given time in his or her life. Different impacts can be expected depending on whether middle-aged adult children or same-age old spouses provide support to a person in need.

Caring children. Many adult children of disabled parents have a job and/or a family of their own. Besides caring for ageing parents, doing satisfactory work, maintaining close relationships, and launching children are among the widely recognised developmental tasks of middle-aged adults (McCormick et al, 2011; see also Coimbra et al, this volume). However, extensive family care for older relatives is not compatible with a full-time job and, in fact, family carers often reduce their working time by taking a part-time job or even by terminating work (for example, Covinsky et al, 2001; Black et al, 2010). For working family carers, providing support may also interfere with their job performance (Barling et al, 1994; Scharlach, 1994; Dallinger, 1996; Hepburn and Barling, 1996; Guberman and Maheu, 1999). Lack of sleep (for example, due to caregiving at night) or intrusive care-related worries at work may deteriorate job performance. This, in turn, may result in critique by superiors, career downturn and even dismissal from the job. Moreover, reduced employment usually

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[1] In extreme cases (for example, severely demented relatives), family care may include the continued monitoring of this person.

results in financial losses, not just in their active time, but – depending on pension schemes – also after retirement. Family care for older relatives may also interfere with adult children's responsibilities for the *family of their own*. If a daughter, for instance, spends much time and energy on caring for her older parents, time and energy for the relations with her partner and/or children may be lost. Partner and children may feel neglected, and this may lead to a deterioration of the relationship with them.

Caring children and caring spouses. For both categories of family carers, *stress in the relations with other family members* may arise (for example, Pearlin et al, 1990; Semple, 1992; Bourgeois et al, 1996; Davis, 1997; Fudge et al, 1997; Scharlach et al, 2006). Quarrels may result from disagreements about the health and functional status of the care recipient, about the adequate goals, kind, amount, and location of care as well as about the recognition expected (but not received) for caregiving. Family care may also involve direct costs from buying care products or even the remodelling of the house (for example, Black et al, 2010). Family care may also interfere with *leisure time activities*. Even if caregivers had time, they might be kept from relaxing by anticipated guilt feelings about engaging in leisure time activities while their older relative is suffering (Losada et al, 2010). Family care may also interfere with maintaining *social relationships with other persons outside the family*. Even if family carers had the time and energy to invite friends or neighbours, they might feel ashamed of their dependent relative or think that they should not confront others with the appearance and behaviour of that person.

Desires and goals of family carers

From an action- and emotion-theoretical view, the multiple desires and goals of potential family carers must be considered in order to understand their actions and emotions in response to the caregiving situation. Some hypotheses on *which* desires and goals are relevant

can be derived from literature on the needs of family carers providing support to terminally ill relatives (Deeken et al, 2003) and from the literature on the motivation of family carers.

Desires regarding the fate of and relationship with the disabled relative. Literature on 'communal relationships' (for example, Mills et al, 2004) underlines that there is a general desire for the *welfare of the disabled relative*. Specific research on family members' motivation to provide care identifies several other motivating factors underlying this desire. Among them are *feelings of love and affection* (compare Silverstein et al, 1995; Merrill, 1997), the *general norm of altruism* and *parent- or spouse-related norms of responsibility* (for example, Cantor and Hirshorn, 1989; Blieszner and Hamon, 1992; Holuscha, 1992; Ikking et al, 1999; see also Coimbra et al, this volume). In addition, the *norm of reciprocity* might also be involved, demanding support provision in exchange for past support received (for example, Merrill, 1997; Ikking et al, 1999; Albert et al, 2010; see also Silverstein et al, 2002).

Such general desires and norms should lead to more specific *goals of care* in response to the particular situation of the older relative as perceived by family carers. These comprise among others: to cure the diseases, to keep health from getting worse, to preserve or prolong life, to improve or maintain mental and physical functions, to maintain independence, to provide comfort, to maintain living in the familiar environment (compare Kaldjian et al, 2009; Kaldjian et al, 2010). A general *desire to stay emotionally close* to each other should also be relevant for caregivers of older relatives, in particular for caring spouses. Love between spouses is conceived as an important binding element of marital relationships and desiring to stay close to the loved person is regarded as an essential feature of that love; this may also include physical and sexual contact even in the case of disability and cognitive decline of one partner (see Davies et al, 1998). A desire to stay emotionally close to the older

parents needing care should also be relevant and present – perhaps to a lesser extent and in a somewhat different quality – in caring children.

Desires regarding the fate of and relationship with other persons. Desires for the *well-being of other persons* beyond the older relative should also be relevant. Caring children with a family of their own usually will want to achieve the well-being of and maintain good relations with their spouse and children. Employed carers may experience responsibility for their job and desire good relations with their colleagues and superiors. Caring spouses may desire the well-being of their siblings and children. Moreover, both categories of caregivers may wish to have good relationships and regular contact with other relatives, friends and good acquaintances.

Desires regarding oneself. Caregivers strive to keep a stable, positive level of well-being, which may lead to more specific desires like to stay healthy despite the stress of caring, to receive support from other relatives or professionals, to continue their job career, to enjoy leisure time activities, to acquire new competencies and personality traits, to be a 'good' spouse or adult child. Some caregivers may even have the ambition to provide care without having to rely on help from others and to find more meaning in their life.

Caregivers' appraisals and emotions in relation to caregiving

According to action- and emotion-theoretical views, family carers' actions and emotions in response to the caregiving situation should depend on how that situation is subjectively experienced by them. However, the same objective caregiving situation can be perceived and evaluated differently by different carers. Conceptual analyses have thus emphasised the distinction between *objective* versus *subjective burden* (for example, Gottlieb, 1989; Lawton et al, 1991; Chwalisz, 1992; Chou, 2000; Zank et al, 2006; see also Masuy, this volume), which is further justified because subjective burden is more closely linked to carers' mental

health than objective burden (for example, Haley et al, 1987; Roth et al, 2003). An analogous distinction between *objective* versus *subjective gains* has not yet been explicitly drawn in the caregiving literature. In fact, positive aspects of caregiving have usually been conceived as subjective gains, but not as objective gains. The issues of subjective burden and subjective gains will be examined more closely later and remaining gaps and desiderata will be described. Possible paths for resolving them will be elaborated from developmental- and emotion-theoretical perspectives.

Negative appraisals and emotions: subjective burden

Prior caregiving literature has treated subjective burden as a composite construct including at least two different kinds of psychological variables, namely, *negative appraisals* and *negative emotions* in relation to one's caregiving situation (Gottlieb, 1989; Lawton et al, 1991; Chou, 2000). This composite nature is also reflected in widely used measures like the *Zarit Burden Interview* (*ZBI*; Zarit et al, 1980), the *Caregiver Strain Index* (*CSI*; Robinson, 1983), the *Measurement of Subjective Burden* (*MSB*; Montgomery et al, 1985) and others which combine ratings of such appraisals and emotions into one sum score of *global* subjective burden. However, dimension analyses urge for differentiation: several negative appraisal factors emerged consistently in connection with one negative emotion factor. Here the different appraisal factors were defined by different aspects of caregiving as objects of appraisal (for example, social burden, physical burden, impact on schedule, impact on finances). The *emotional burden* factor was consistently defined by sets of negative emotions such as feeling embarrassed, ashamed, resentful, frustrated, and angry in relation to caregiving (Novak and Guest, 1989; Cousins et al, 2002; Ankri et al, 2005). However, aggregating different negative emotions into one global emotional burden score diminishes heuristic chances for a deeper understanding of how people react and adapt to caregiving,

because each emotion type is linked to different conditions and consequences. Unfortunately, in-depth examinations of single care-related emotions are still very rare, with one notable exception. In their study examining guilt, Losada et al (2010) provided factor analytic evidence that there are different types of guilt arising from different aspects of the caregiving situation (for example, doing wrong to the care recipient, failing to meet the challenges of caregivers, caring for oneself, neglecting other relatives, negative feelings towards other people). Such a differentiated analysis can be taken, to some extent, as a model for the effective examination of other relevant care-related emotions. An action- and emotion-theoretical view can provide a good foundation for the broader and deeper analysis of specific emotions in response to caregiving. Before we elaborate this point, however, we will consider the positive aspects of caregiving as experienced by caregivers.

Positive appraisals and emotions: subjective gains

Research interest in positive aspects of family caregiving has greatly increased in the last two decades (early overview: see Kramer, 1997). These aspects have been labelled differently (for example, satisfactions, gains, benefits, pleasures, rewards, enjoyments, growth), and we will use *subjective gains* as the generic term to describe these here. Subjective gains are frequently conceived as a composite construct consisting of *factual beliefs, positive evaluative beliefs,* and sometimes also *positive emotions* (for example, joy, happiness and pleasure) regarding one's caregiving. This is reflected in major subjective gain measures like the *Caregiver Satisfaction Scale* (CSS; Lawton et al, 1989), the *Carers' Assessment of Satisfaction Index* (CASI; for example, Ekwall and Hallberg, 2007) and the *Caregiver Strain Index positive* (CSI+; Al-Janabi et al, 2010). These instruments allow combining the ratings of *factual beliefs, positive evaluative beliefs* and *positive emotions* into sum scores of domain-specific or of global subjective gain. As yet, only a few empirical dimension analyses of

subjective gain have been performed. A factor analysis by Ekwall and Halberg (2007) found several belief-related factors distinguished by their respective content, that is, either referring to accomplishments for the care recipient (for example, promoting care recipient's welfare) or for the caregiver (for example, widening horizon and personal growth of caregiver). Findings from qualitative studies (for example, Netto et al, 2009; Peacock et al, 2010) as well as an inspection of the item content of the various relevant scales have revealed that subjective gains refer to a broad range of caregiving facets which can be sorted into five major domains (see also Nolan et al, 1996; Kramer, 1997; Dupuis et al, 2004; Carbonneau et al, 2010):

(1) *Benefits for care receiver:* Provision of effective help for and to have prevented deterioration of an older relative and thus his or her institutionalisation; seeing that the care receiver is happy

(2) *Benefits for caregiver:* Thanks and recognition from care recipient and from others; acquisition of new skills, personal growth, and increased maturity through caregiving

(3) *Positive relationships between caregivers and care receivers:* Companionship, remained or increased closeness, feeling loved by the care receiver, mutual affection within the caregiving dyad due to caregiving

(4) *Positive relationships between caregivers and other family members:* Increased cohesion and cooperation among family members with respect to caregiving (for example, adult children supporting their mother who cares for their father, siblings who cooperate in providing care for their parents)

(5) *Increased meaning in caregivers' lives:* Having fulfilled an important duty, having adopted the caregiver role as a new goal in life; being in line with religious or ethical principles (for example, love thy neighbour, honour your parents, be grateful for what you have received).

A separate *emotional gain* factor has yet to emerge, probably due to the very small number of emotion items contained in the relevant questionnaires. Although there is an interesting analysis on fading and renewed hope in dementia caregivers (Duggleby et al, 2009), systematic analyses of other positive emotions in relation to family caregiving (for example, admiration, gratitude, joy, pride) are missing.

Caregivers' appraisals and emotions: developmental and emotion-theoretical perspectives

As indicated earlier, care-related emotions have not yet been analysed comprehensively. This is surprising, because emotions probably play an important role in focusing family carers' attention to specific aspects of the caregiving situation and in determining how they will act in response to it. Importing concepts from both life-span developmental psychology and psychology of emotion into caregiving research will help to narrow this gap. According to an elaborated action-theoretical model of human development (for example, Brandtstädter, 2001, 2011) as well as cognitive theories of emotion (for example, Weiner, 1985; Ortony et al, 1988; Lazarus, 1991; Reisenzein, 2009), the kind of emotional response to a situation does not depend on the situation per se, but on how this situation is appraised by the individual. More specifically, individuals' comparisons between what is believed and what is desired to be the case give rise to emotions. If a situation is evaluated as actually or potentially diverging from what is desired, negative emotions will result (for example, sadness, worry). If, however, the situation, as it is perceived, actually or potentially fulfils one's desires, positive emotions will result (for example, happiness, hope). More complex emotions (for example, pity, guilt, pride, gratitude) will emerge from comparisons involving more elaborated beliefs and desires. With respect to multi-faceted situations (such as caregiving), a broad spectrum of emotion types can be expected to emerge which may refer to various

aspects of that complex situation. This will be elaborated a bit more by formulating some hypotheses about conditions of specific emotions in relation to caregiving.

Given a *carer's desire for the welfare of their older relative,* the perception of the relative's bad fate should give rise to *pity or empathetic sadness for the relative;* if the carer anticipates a bad fate of the relative in the future, *worry about the relative* may arise. If family carers hold a moral norm that they should serve their older relatives' welfare, but believe that they have not done so, even though they could, *guilt feelings* should emerge. If family carers desire that other family members should have done more for the older relative, but believe that they have not even though they could, *anger about other family members* should result. If family carers believe that they are unable to do anything for the older relative's welfare, *helplessness* should be evoked.

The desires for the welfare of the older relative may also be fulfilled. If carers believe that the older relative's situation has improved, this should elicit *empathetic happiness,* and an anticipation that the situation could improve in the future should evoke *hope for the older relative*. If family carers have a more specific ambition to improve their older relative's welfare without the help of others and believe that they have succeeded in doing so, *pride* should arise. If family carers believe that professional personnel did more for the welfare of an older relative than they were obliged to do, *gratitude* should emerge.

However, family carers may also desire their own welfare in various respects. If they believe that they experience job- and leisure time related losses, *sadness* may result. If a caregiver anticipates further losses in the future, *worry about oneself* should arise. If one believes that one should not have taken on so much caregiving responsibilities with a negative impact on one's own welfare, *anger about oneself* should arise. If family carers desire that the older relatives care more for themselves to alleviate the carer's workload and they believe that the care recipient does not do so even though he or she could, *anger about*

the older relative should be the response. If family carers believe that they do not have sufficient means to avoid such losses, *helplessness* should emerge.

The carers' desires for their own welfare may also be fulfilled. If, for instance, carers have a specific desire for recognition of their efforts, *joy* or *happiness* about appreciation of care efforts may result. If carers have the specific desire to acquire new competencies through caregiving and believe that they have succeeded in this, *pride* should be the response. If carers can imagine some future possibility of how the negative impact of caregiving on other highly valued life domains might be reduced, *hope* for better times should emerge. If family carers notice that other family members are taking over a larger share of care than is their duty, *gratitude* towards other family members should be elicited.

Action- and emotion-theoretical approaches further assume that different emotions are closely linked to different *action tendencies* (for example, Frijda, 1996; Reisenzein, 1996; Brandtstädter, 2011), negative ones in particular to tendencies towards a reduction of the discrepancy between what is believed and what is desired. In relation to caregiving, *pity* should be linked to a tendency to restore the welfare of the older relative, whereas *worry* about that person should be linked to actions preventing damage to the welfare of him or her. Moreover, *guilt feelings* go along with a desire to get rid of one's guilt, for instance, by apologizing, by restorative actions, or by abstaining from leisure time gratifications. *Anger about the older relative* should be linked to an aggressive tendency against what the carer is angry about. In contrast, carers' *helplessness* should inhibit tendencies to promote the older relative's and/or even one's own welfare. Some positive emotions are also assumed to be linked to action tendencies. For example, family carers' *gratitude* towards other supporting family members should go along with a tendency to thank them, whereas carers' *pride* should be associated with a tendency to let others know what one is proud of. However, such action tendencies do not necessarily result in overt action. That should depend on boundary

conditions like opportunities for the respective actions and beliefs about effective means of expressing the respective action tendency.

Goal pursuit: action possibilities and resources of family carers

Family carers usually have several care-related desires (for example, welfare of older relative, own welfare, welfare of other persons) against which they evaluate the actual caregiving situation. If there are actual or anticipated discrepancies, carers are motivated to reduce them by actively changing the actual situation in the desired direction. According to action theories, apparently only those actions are chosen which are believed to be effective means for reducing or avoiding these discrepancies. In the case of family care, carers are challenged by possible conflicts and discrepancies between the 'is' and the 'ought' with respect to various desires. For instance, serving the welfare of the older relative might interfere with the carers' own welfare and vice versa. So the issue of balancing the desires through the carefully considered choice of action paths arises. Three basic possibilities of acting exist here: providing care themselves, use of informal support by relatives, friends, and others, and use of formal support by institutional care providers.

Personal care provision and the development of caregiver skills

Family carers will provide care personally if they believe that providing care by themselves is the best means to serve the welfare of their older relative (without sacrificing their own welfare and that of others)[2]. Which kind of care is provided should depend on the specific caregiving demands as perceived by family carers: support with basic and instrumental activities of daily living, with life-enriching activities, with alleviating the suffering of their older relatives (Gaugler et al, 2002; Levine et al, 2003/4; Albert, 2004). If family carers find

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[2] This does not exclude other motives for providing care such as the necessity to deal with reduced financial resources.

it difficult to promote the welfare of the older relative, they could increase their efforts. If that should not suffice, they may start to acquire new competencies.

A first group of competencies is particularly relevant for the welfare of older relatives by dealing effectively with their diseases, functional declines, disabilities and problem behaviours. Among them are nursing skills, abilities to respond in a flexible and emotionally accepting manner to cognitive declines, knowing how to preserve the strengths of care recipients, ability to correctly identify the amount or kind of support needed and attuning support provision to that information, creativeness in providing basic and instrumental care, understanding the causes and communicative meaning of problem behaviours, and responding to them flexibly and repeatedly with a broad spectrum of interventions (compare Farran et al, 2003). A second group of competencies is particularly relevant for carers' own welfare and that of other persons and for balancing the various desires. Among them are abilities to communicate openly with the parties involved in or affected by caregiving and to flexibly coordinate caregiving with other familial or occupational duties. Moreover, abilities to balance the duties of providing care for older relatives with caregivers' self-care needs such as finding and using informal and formal support, and knowing how to live in a health-conscious manner constitute further competencies here (compare Farran et al, 2004).

A general action-theoretical perspective predicts that the willingness and the way family members actually provide care to their older relative do not just depend on the competencies that potential family carers actually have, but also on their *beliefs to have* such competencies and to be able to apply them to the caregiving situations at hand. In other words: caregiver's perceived self-efficacy is assumed to play an important role (compare Steffen et al, 2002).

Use of informal support from relatives, friends, and others

If principal caregivers come to believe that they are unable to provide the care as they would like to, a desire to receive some informal support (for example, by other family members) may arise, which may be more or less specified regarding the amount, kind and style of the expected help (for example, Clipp and George, 1990). In some cases, other family members (for example, children) will offer their assistance or may participate in caregiving without being asked for their help by the principal caregiver. This could be motivated differently, for instance, by their desire for the welfare of the older relative or by their desire for the welfare of the principle caregiver or both. In other cases, principle caregivers may actively *mobilise support* either indirectly by communicating about the older relative's state and by complaining about caregiver burden or directly by explicitly asking for help. The actual receipt of informal support depends, of course, on the principle caregivers' social networks, that is, the number and closeness of persons who could help. The likely support providers vary somewhat depending on who the primary caregiver is. Caring spouses are predominantly supported by their children, less frequently also by the grandchildren or siblings of the care recipient (see also Albert & Ferring, this volume). Caring children are most often supported by their spouses, their siblings, or their children and to some extent from persons outside the family. Three major types of assistance may be provided (see Wills, 1991): *informational support,* that is, giving information and advice which helps the primary caregiver in performing the various tasks, *instrumental support* as assistance with performing nursing and household tasks, the handling of problem behaviour, and the alleviation of suffering, and e*motional support* aiming at an improvement of primary caregivers' emotional states, for instance, by showing empathy or by providing recognition and appreciation.

The effects of informal support on principle caregivers depend on their evaluations of the received in relation to the desired support. Thus, the amount of support can be appraised as too little, as sufficient, or as too much and the kind and style of support can be appraised as

helpful vs. overprotecting, as ensuring vs. restricting freedom of action, or as implying that the principle caregiver is competent vs. incompetent. As a result, caregivers can be satisfied or dissatisfied with specific aspects of informal support and/or with informal support in general. Satisfaction with informal support is consistently related to increased well-being of caregivers as indicated by less depression and better physical health in older (for example, Fiore et al, 1986; George and Gwyther, 1986; Stuckey and Smyth, 1997) and more recent studies (for example, Roth et al, 2005; Clay et al, 2008).

Use of formal support: professional home care services, day care units and nursing homes

A progressive decline of the older relative's condition may raise caregiving demands to a level which may exceed the power and/or competencies of both caregivers and their informal supporters. This development may be exacerbated by decreasing health of family carers due to caregiving and in particular to age-related decline of caring spouses and/or by a lack of informal support. This process may result in increased burden not just from the caregiving itself, but also from negative effects on other life domains (for example, job, leisure time, social relationships). Approaching their limits, caregivers may search for additional means to serve the welfare of their older relative without sacrificing their own welfare and that of the other relevant persons involved. Which further options will be chosen should depend on family carers' knowledge about such possibilities and on what they believe about their effectiveness in meeting the various care-related desires.

In many cases a *professional home care service* is the first option considered, because it provides additional competence in caregiving (for example, medical care) and some burden relief for primary and secondary family carers, while permitting family carers to continue their responsibilities and enabling older relatives to stay in their usual private environment.

The alternatives to this are day care units as well as nursing homes as the last solution available requiring a move from the home to a completely new environment.

Support by adult day care centres represents an out-of-home option, and different possibilities exist across Europe, varying in availability (open days, opening hours) and in services offered. The spectrum ranges from medical care, personal assistance, meals, social services, to activities. If the older relative's condition becomes even worse, the strength and/or competencies of family carers, informal supporters, and the professional home care services might be exceeded. Then, caregivers may come to believe that a *permanent institutionalisation* is the only means that can serve the welfare of their older relative, their own welfare and that of the other persons involved. The institutionalisation usually releases family carers from very difficult and/or burdensome kinds of care (for example, skilled nursing, bodily care, care at night). Yet other kinds of family care will be continued at least sometimes (for example, help with eating, help with some IADL). However, new stressors may emerge such as family carers' conflicts with nursing home staff. Longitudinal studies provide inconsistent findings since some convey that stress levels of carers may stay the same or increase (Matsuda et al, 1997), whereas others indicate considerable reductions in burden (for example, Gaugler et al, 2009). This may be due to several factors including different methodological approaches, but it underlines as well that 'objective factors' such as institutionalisation are transformed into subjective reality and depending on the way these are perceived and evaluated, different profiles of strain will result. By no means, however, does this imply that individual strain is always a unique function of subjective perception. Objective conditions may be so inadequate that they do not leave much room for different interpretations and thus appear to have a 'direct' negative effect on individual well-being. Especially, the high costs of institutionalisation add to this, and there are different models of supporting additional formal care within the context of informal care across Europe (see

Mestheneos and Triantafillou, 2005; Rodrigues and Schmidt, 2010). Depending on the national solutions that are found, different models of financing these services come into play (see also Kutsar and Kasearu, this volume). In the worst case, a person in need of additional support may not receive this, because such a service will be too expensive. All these objective conditions will add significantly to the strain of the informal carer.

Goal adjustments and other accommodative processes

If family carers' increased effort and even an additional mobilisation of external support could not sufficiently change the actual caregiving situation in the desired direction, they may come to believe that neither they nor others can do anything to reduce the discrepancy. In that case, the discrepancy between what is desired and what is believed might be reduced in a fundamentally different way, that is, by adjusting the care-related desires to the constraints of the actual caregiving situation. Such accommodative processes have been described in general (not in relation to caregiving) in an action-theoretical model of human development by Brandtstädter and colleagues (for example, Brandtstädter and Rothermund, 2002) and a corresponding generalised interindividual difference variable ('Flexible Goal Adjustment') has been conceptualised and measured (Brandtstädter and Renner, 1990).

The role of goal adjustment has only rarely been examined in relation to caregiving. As a notable exception, Leipold (2004) has provided evidence that the generalised flexible goal adjustment disposition had a buffering effect on the relation between care-related stressors and well-being of family carers of demented relatives. More recently, Wrosch and Heckhausen (2011) found that related generalised dispositions ('goal disengagement', 'goal reengagement') buffered association between caregiver burden and depression of family caregivers for mentally ill relatives. One should note that the aforementioned dispositions and their measures refer to goals in general and not to specific goals. Future research will have to

examine the accommodative dispositions and processes specifically for care-related goals. In what follows we will provide hypotheses about how the disengagement from old care-related goals and reengagement in new care-relevant goals might be conceived.

Several goals may be distinguished here in a first step. There are goals related to the welfare of older relatives as well as those related to one's own welfare. Concerning the first class of goals, the carer may have, for instance, to shift from the idea of curing diseases to keeping the health from getting worse, from prolongation of life to maintaining life quality, from keeping health status to alleviating suffering – just to give three examples here. Goals related to the carer's own welfare may concern the shift from working full time to working part time, from frequent to rare leisure time activities, from frequent and longer to rare and shorter contact with other family members or friends. Related to this is also the fundamental decision to share the caregiving with professionals.

Accommodative processes also involve a change in central care-related concepts and representations by redefining those concepts. To be a 'good carer' may thus shift from the carer who exclusively considers desires of the recipient to being a carer who considers both needs of the recipient and needs of the carer. The definition of 'good care' may be changed from a conception focusing on the prolongation of life to a conception focusing more on 'enabling life quality'. As a last example one may describe here the shift from the view of 'being demented is no life worth living' to the personal evaluation that 'dementia is a life worth living'. It is evident that these accommodative endeavours will take time and they take place as a process of continuous adaptation to a changed life situation. Accommodation as redefinition of concepts may be supplemented by emphasising positive meanings of the caregiving situation. The carer may thus focus the chances that caregiving provides for him or her such as having the chance of repaying for benefits, of expressing gratitude and affection,

of expressing one's religious and moral values (for example, love thy neighbour, honour your parents).

Accommodation comprises several other manoeuvres that cannot all be listed here (for example, selective social comparisons). We like to highlight, as a general principle, that people will not easily engage in redefining their world by changing their concepts, and this represents a step-by-step process as we have described elsewhere as 'processing bad news under threat' (see Ferring and Filipp, 2000).

Outcomes for family caregivers

Mental and physical health outcomes

Most older and more recent research has focused on possible negative effects on mental and physical health of family carers which deserve attention for several reasons (Pinquart and Sörensen, 2007). First, such effects are detrimental to and straining for family carers. Second, illness-induced absenteeism of family carers increases costs for businesses and public organisations alike, and medical treatment of family carers increases costs for them and for health insurance organisations and their contributors. Third, poor mental and physical health may reduce the quality and quantity of care provided by family carers to their older relatives and may finally increase the risk of an earlier institutionalisation of older family members in nursing homes. So providers and recipients of family care as well as the economy and society at large should be interested in maintaining caregivers' health.

Physical health of carers

In order to better understand that caregiving can have detrimental health effects, one should notice that the first important group of family carers, namely, caring spouses, are usually quite old and so many of them already manifest some health risks and may even suffer from

age-related diseases. The second important group of carers of older persons are middle-aged adult children which often face conflicting responsibilities from their own family and from their jobs (Vitaliano et al, 2004). For many of them, having to care for an older relative further increases the total demand load and may constitute a risk for the health of adult children (Pinquart and Sörensen, 2007). For instance, providing bodily care may cause joint and spinal injury. Moreover, extensive care may interfere with relaxing and other health preserving activities. In addition, psychological stress may suppress the immune system and thus increase caregivers' risk for infections. Finally, stress may lead to a hyperactivation of the autonomous nervous system (in particular, the sympathetic nervous system) which may increase the risk for cardiovascular diseases.

The best available studies compare the physical health status of family carers with that of a control group of non-carers of similar age and sex. Physical health indicators were: (1) Self-reports of family carers (for example, global ratings on scales from 'bad' to 'excellent'; frequency estimates of perceived symptoms), (2) objective measures (for example, number of physical diseases, number of stays in hospitals), (3) physiological risk factors for various diseases (for example, stress hormones in the blood, hypertension, immunological reactions).

Meta-analyses have found that family carers are characterised by a poorer health as compared to non-carers, and this particularly with respect to global health self-ratings (Pinquart and Sörensen, 2003; Vitaliano et al, 2003). Prospective longitudinal studies also found that poor health in family carers and that larger amounts of or more strenuous caregiving were linked to worse health and even higher death rates of family carers (Shaw et al, 1997; Schulz and Beach, 1999; Vitaliano et al, 2002). Another meta-analytic finding is that physical health of family carers of demented relatives was worse compared to that of family carers of non-demented relatives; moreover, the health of caring spouses (which

themselves are rather old) is worse compared to that of caring adult children (Pinquart and Sörensen, 2003, 2011).

That only a moderate, but significant difference emerged between carers and non-carers may be due to subjective gains of caregiving and also due to the resources of family carers, namely, caregiver skills, and informal and formal support. Moreover, it is important to note that physical health is influenced by several other factors beyond the provision of family care (for example, genes, socio-economic state, health promoting and health deteriorating behaviours; Pinquart and Sörensen, 2003).

Mental health of carers

Several studies also compared the mental health of family carers with that of comparable non-carers (controlled for age and sex). Indicators of mental health were: (1) Perceived stress (for example, negative affect, lower controllability beliefs regarding burdening situations), (2) depression (self-reports or estimates by medical staff), (3) subjective well-being (global life-satisfaction, positive affect), and (4) self-efficacy.

Meta-analyses found that mental health of family carers was worse (for example, more stress and depression, lower psychological well-being, lower self-efficacy) than that of comparable non-carers (Pinquart and Sörensen, 2003, 2005). Differences regarding mental health were larger than differences regarding physical health. Similar to findings regarding physical health, the mental health of family carers of demented relatives was worse (for example, more stress, lower subjective well-being, lower self-efficacy) than that of family carers of non-demented relatives. Similar to physical health, the mental health of caring spouses was worse (for example, more stress and depression, lower psychological well-being) than that of caring adult children (Pinquart and Sörensen, 2003, 2011).

Recently, Vitaliano et al (2011) compared 96 caregivers of spouses with Alzheimer's disease (AD) with 95 similar non-caregiver spouses, and they report a small but significant cognitive decline in the carers' sample which they relate to psychophysiological mediators. If one considers cognitive functioning as a prerequisite to effective adaptation and regulation of one's mental health, this finding – which certainly has to be confirmed in other studies – underlines the high risk of caregiving for the regulation of mental health.

Developmental changes in goals, competencies and personality attributes

As we have already described earlier, caregiving involves a developmental process of continuous adaptation. Adapting to the strains of caring is perhaps best described by the dichotomy of 'changing the world' and 'changing the self' introduced by Rothbaum et al (1982). According to this model, one can either change circumstances or bring them into line with one's desires and needs, that is, change the world, or one can change one's beliefs, lower one's aspirations or replace unattainable goals, that is change the self. Active attempts to change the world are, in several models, referred to as 'problem-focused coping', 'primary control', or 'assimilative coping' and these may be an adaptive response to many stressful situations experienced in life. Such processes may result in more permanent developmental changes such as the actual acquisition of new competencies and corresponding self-efficacy and control beliefs and may also induce a change in personality characteristics. Past research on subjective gains from caregiving has shown that family carers *believe* that they have developed new competences and have grown personally. But future research will have to demonstrate that *actual* competence development and personality change has taken place in response to being a family carer.

Of course, assimilative coping and related processes are of limited use if a person has to come to terms with a situation that cannot be altered and that does only allow for little, if

any, control as in the case of caring for a family member in the situation of dependency. As we have outlined earlier, here one has to change aspirations, goals and personal beliefs as well as to disengage from unattainable goals. These attempts have been referred to in specific models as 'emotion-focused coping', 'secondary control', or 'accommodative coping' (Lazarus and Folkman, 1984; Brandtstädter and Greve, 1994; Heckhausen and Schulz, 1995). There are good reasons to believe that these processes will also result in permanent developmental changes in the belief and goal systems of family carers, but this should be further examined in future research. If one considers subjective gains and losses within the context of caring as well as the objective burden one meets here, accommodative processes – in the sense of changing the self – will allow explaining interindividual differences in the psycho-social situation of caregivers. Care providers in objectively comparable situations may – depending on their regulative efforts – develop different evaluations that will be followed by different actions. Evaluations themselves depend largely on the personal needs that are central in a given situation and – depending on the predominant motives – different constructions of a given situation may occur. In general, one can assume that the person is motivated to balance negative and positive emotions in order to maintain one's capacity to act; this can be considered as a basic motive underlying most individual actions.

Changing goals, competencies and personality attributes can be considered as an inherent and central part of the adaptation process serving this motive. Changes in the behaviour of the later care recipient are usually not directly visible or interpretable as indicators of an initial impairment. Thus, it is evident that one already has to recognise a change in the life situation before any overt or covert action can take place. Even if one finally perceives significant changes in the behaviour of a loved one – such as in the case of early dementia – one may have alternative explanations ready (for example, as indicating depression) that may not be as threatening as the image of a neurodegenerative disease. If

changes are perceived, persons will start interpreting those changes and again they will do this in relation to their predominant needs and motives. Being a family mother and having to care for an ageing parent at the same time will have an impact on many needs and motives, and the person will have to start rearranging these and associated goals. He or she will also need to acquire new competencies to deal with the critical life situation and to search for various (or various alternative) forms of support. All this may contribute to changes in personality attributes and a changed self-perception. In this perspective, caring may also contribute to the perception of gains and positive personality changes as we have already described earlier.

Conclusion

Caring is a complex situation and it unquestionably represents a socially relevant problem field like violence, poverty and disease. This social relevance will increase in response to the current demographic change: due to a continuously ageing population, the need for informal and formal care will rise in the near future in most European countries. In general, socially relevant problem fields are open to interdisciplinary research and discourse, since they require answers on several levels of the socio-ecological context. Here, we put emphasis on a psychological analysis of the caring situation that was dedicated to life-span developmental psychology in general and to an action- and emotion-theoretical background conceptualising personal adaptation to the changed life situation in particular.

Our analyses mentioned earlier have focused strongly on family carers as individuals and on their immediate environment. But in line with the basic tenets of life-span developmental psychology (for example, historical embeddedness, contextualism) we are well aware of the constraints and the options that cultural and macro-social factors provide for the individual development in the context of caregiving. For instance, the sustainability of

public resources and, linked to this, the financing of health and care services set the frame and the conditions in which the individual has to adapt. A society that cannot or will not support family carers will evidently set up conditions that may have a direct impact on the individual level, increasing the burden of all involved persons. Moreover, and as a second example, developments of assisting technologies (for example, service robots) that are promoted at the macro-level will have to find their way into individual life in order to have the expected positive impact on the quality of life of carers as well as the quality of care. There are several further examples of how macro-social factors will or have to be *translated* into individual life that cannot be elaborated here in detail.

What is the advantage of the analysis proposed here? By putting the emphasis on subjective appraisals of objective life situations, by focusing on goals involved in the care situation and by highlighting processes of cognitive adaptation, such as accommodative efforts, we underline that 'reality' is mostly 'reality as it is perceived' (see Zittoun et al, 2013). Such a constructivist position is apparently nothing new, but it certainly helps to explain the *interindividual* differences one observes between persons in comparable care situations. It also helps to explain that caring is a process where one has to continuously adapt to changes of the life situation which results in *intraindividual* differences as indicated by changes in goals, competencies and even personality attributes. Finally, a life-span developmental analysis of the care situation underlines that one has to consider both caregiver as well as recipient within the context of their individual biographies and their socio-cultural environment in order to develop a profound understanding of their life situation. All this is a significant prerequisite if one wants to build up services and support for the carer as well as for the care recipient that will help to deal with the complex situation. Last but not least, all this is also a prerequisite for developing an understanding at the socio-

political level to further promote and foster intergenerational relations and solidarity between

generations in general.

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