

# The complexity of caring (Part 2): Moderators of detrimental health and well-being outcomes for caregivers of people with chronic wounds

Upton D, Upton P & Alexander R

## ABSTRACT

**Objective:** This review assesses the caregiving literature to understand what is known about health and well-being outcomes for informal carers in the context of caring for people living with chronic wounds. Part 1 provided background information on caregiver characteristics, as well as physical and psychological deficits related to caregiving. Part 2 looks at the positive aspects of caregiving through a number of moderating variables: social support, caregiving mastery, and subjective caregiver qualities.

**Method:** A structured literature review was carried out using the databases, CINAHL Plus, PsychARTICLES, PsychINFO, and PubMed. Keywords were: ['caregiving' or 'carer' or 'caregiver'] and ['health'] and ['well-being' or 'wellbeing'] and ['quality of life' or 'QoL']. Articles written in the English language and published in peer-reviewed journals were considered for inclusion. Relevant book chapters and web references were also assessed for inclusion. A total of 52 references were used in the review.

**Result:** The relationship between caregiving, health and well-being is a complex one. Much research indicates detrimental physical and psychological outcomes for caregivers. However, a number of moderating variables appear to 'buffer' the stress of caregiving and may even lead to positive outcomes.

**Conclusion:** Much of the caregiving literature focuses on people caring for relatives with specific health and/or mental illnesses. To date, there has been insufficient attention paid to health and well-being outcomes for carers of people living with chronic wounds. Given the predicted rise in the incidence of chronic wounds in this country over the coming decades, it is vital that we understand how to maximise health and well-being outcomes for the carers of chronic wound patients.

**Keywords:** *Caregiving, caregiver, wounds, health, well-being, public health.*

### Dominic Upton\*

PhD, FBPsS

Associate Dean, Education

University of Canberra, ACT 2601

Tel +61 (2) 6206 8709 Fax + 61 (2) 6201 5999

Email dominic.upton@canberra.edu.au

### Penney Upton

CPsychol, AFBPsS

Senior Research Fellow

Centre for Research and Action in Public Health

University of Canberra, ACT 2601

Email penney.upton@canberra.edu.au

### Rebecca Alexander

BScPsy(Hons)

Research Assistant

School of Applied Psychology

University of Canberra, ACT 2601

Email rebecca.alexander@canberra.edu.au

\* Corresponding author

## BACKGROUND

The burden of caregiving has been well researched<sup>1-4</sup>. In Part 1 of this review, we explored research showing caregivers are at risk of physical deficits (for example, poorer subjective health, increased mortality risk)<sup>4-6</sup>, as well as psychological and social risks (for example, depression, anxiety, isolation, financial strain)<sup>4,7-9</sup>. While there is a wealth of research into the health and well-being of caregivers in general, there has been little attention paid to caregivers of people with chronic wounds as a relevant sub-group<sup>10,11</sup>. With the incidence of chronic wounds set to rise in the coming decades<sup>12</sup>, it is vital we understand the impact of caring for a relative with a chronic wound. Research to date has been sparse, but reflects the wider literature reporting physical and psychosocial deficits for caregivers<sup>11,13,14</sup>.

Yet beyond these deficits, the wound care literature reviewed in Part 1 reported some positive outcomes for caregivers. In a study of people caring for relatives with a malignant fungating wound, Probst *et al.* reported caregivers felt their relationship to their loved one became closer as a result of caring<sup>13</sup>. Similarly, Marino reported an emphasis on relationship commitment and role empowerment

for carers of patients with diabetic foot ulcers<sup>14</sup>. These examples highlight the complexity of the caregiving role, with its potential for both negative and positive outcomes. Caregivers are a heterogeneous group with differing levels of vulnerability in the face of the burden of caring<sup>3</sup>. Part 2 of this review considers research into the positive outcomes of caregiving, and ways in which carer well-being is enhanced through the caregiving role.

The relationship between caregiving, and physical and mental health has often been portrayed as negative for the caregiver<sup>4-9</sup>. However, it is important to note that a direct causal relationship between caregiving and negative health outcomes cannot be assumed<sup>15</sup>. Vitaliano *et al.*<sup>16</sup> conducted a meta-analytic review of the caregiving literature from across a 38-year period, and were unable to determine that caregiving was directly linked to negative health consequences. Caregivers showed a slightly higher likelihood of negative physical health consequences than did non-caregivers (for example, especially higher stress hormones and lower immune responses). Yet they noted the relationship between caregiving and health outcomes was clearly moderated by a number of factors. They concluded that searching for a direct relationship between caregiving and health outcomes was likely too simplistic. The heterogeneity inherent to caregivers as a group, and the multidimensionality of the caregiving role, suggests a more complex relationship than direct comparisons allow<sup>16</sup>. In fact, a number of moderating factors have been identified as impacting health and well-being outcomes for carers<sup>17-19</sup>. However, there is emerging support to conceptualise positive and negative effects of caregiver as distinct concepts and not opposing ends of a spectrum. One can experience benefits (depending on how these are operationalised) whilst also experiencing negatives, and they are moderated by other variables such as the type of relationship or hours of care provided. Similarly, there are theoretical moderating factors including social support, caregiving mastery, and subjective caregiver characteristics.

It is important to note that there are a number of theories and moderating/mediating factors that can impact on the experience of caregiving, but this review will simply focus on these three buffers.

## SOCIAL SUPPORT AS A MODERATOR

The relevance of social support as a moderator of the stress of caregiving has been well researched<sup>15,20-22</sup>. However, consensus has yet to be reached about how social support impacts health and well-being outcomes for carers<sup>23</sup>. Phenomenological data from the wound care literature certainly indicates that social isolation can be an issue for carers<sup>13,14</sup>, but the role of social support in bolstering informal carers' experience is yet to be established.

Social support for caregivers has been broadly categorised as instrumental (that is, practical, for example "respite care"), emotional (for example, "counselling services"), and informational (for example, "health education")<sup>23</sup>. An early study by Franks *et al.*<sup>20</sup> investigated caregiving, social support and well-being in

adult daughters caring for a parent. The study focused specifically on support source (in this case, husbands); support type (that is, defined as emotional or instrumental support); and the relevance of the support provided (that is respondents reflected on a specific, recent, challenging incident and the support provided at this time). The study found that higher emotional and instrumental support from husbands was associated with greater marital satisfaction. More instrumental support from the husband also buffered the relationship between caregiving stress and caregivers' physical health. Unusually, the more support a caregiver received from her husband at high levels of stress, the *lower* her positive affect was. The authors concluded that women place high value on their caring role, and may feel guilty if someone else assists them, as they perceive they have been unable to meet their care responsibilities<sup>20</sup>. The complex nature of social support as a moderator is clearly in evidence here.

Broadly, however, good social support has been linked to positive outcomes for caregivers, such as lower levels of depression<sup>24</sup> and greater life satisfaction<sup>22</sup>. Han *et al.* found that higher levels of affectionate support (defined as emotional support from close loved ones) and positive social interaction relieved psychological burden in caregivers. Similarly, instrumental support helped alleviate non-psychological burden (that is, associated with daily care activities)<sup>21</sup>. Bademli and Duman<sup>25</sup> considered the psychological health of people caring for relatives with a mental illness. They found improvements in well-being outcomes for those attending a family social support program compared with a control group of carers. Following the program, and again at three and six months post-intervention, the program showed a reduction in depressive and anxiety-based symptoms, as well as improvements in self-confidence, optimism and social support-seeking behaviours<sup>25</sup>.

Yet, the 'more is better' approach to social support has been challenged by research showing that poor quality social interactions can have a powerfully negative impact on caregiver emotional well-being<sup>24,26</sup>. Wittenberg-Lyles *et al.*<sup>23</sup> found that caregiver burden in hospice family caregivers was associated with perceived relational barriers between friends and family, and the carer's need to maintain control in their caregiver role, recognition that the care recipient was no longer able to act as a source of social support or guidance in decision making, general family dynamics, and decreased availability of emotional support from the care recipient. As well as the type and source of support, the quality and the nature of social support are also important moderating aspects to the relationship between caregiving, health and well-being outcomes<sup>23</sup>.

## CAREGIVING MASTERY

Caregiving mastery is also a recognised moderator of the relationship between caring, health and well-being outcomes. Within the wound care literature, Marino noted the emphasis carers placed on "role empowerment" as a source of personal satisfaction

in their caregiving role, and this is something that needs further exploration<sup>14</sup>. A similar construct, “caregiving mastery” is described as an individual’s understanding of their ability to control the forces affecting their life<sup>27,28</sup>. “Mastery” is conceived of as multidimensional and dynamic (that is, an individual’s control of factors will shift and change depending on the context across time)<sup>28</sup>. Kim and Kim<sup>19</sup> investigated the impact of caring for stroke patients on caregivers’ psychological well-being. They found that caregivers’ caregiving mastery, subjective health, the number of activities of daily living (ADLs) a carer assisted with, and caregiving duration all influenced psychological well-being. In particular, the relationships between well-being and both ADL assistance and caregiving duration were moderated by caregiving mastery. It appeared that carers with a greater sense of mastery in their role were buffered from the stress of high ADL assistance and longer periods of time in a caring role<sup>19</sup>. It would be of interest in future research to investigate the moderating influence of caregiving mastery in relation to the intensity of care required from a caregiver (that is, if a higher level of care is needed than a caregiver has the “mastery” to provide, does “mastery” maintain the same moderating effect on psychological well-being?).

Pioli found both global and caregiving mastery moderated the impact of subjective and objective stressors on depression and anxiety in a sample of caregivers of people with Alzheimer’s<sup>29</sup>. Specifically, higher levels of caregiving mastery appeared to buffer the effects of role overload and role captivity, leading to lower levels of carer depression and anxiety<sup>29</sup>. These findings are encouraging and suggest that personal psychosocial resources have a role to play in protecting caregivers from the stresses of their role and potentially harmful health outcomes.

## MODERATOR VARIABLES

Specific characteristics of the carer and the carer/recipient relationship have also been identified as moderating factors between caregiving, health and well-being outcomes. The importance of carer–recipient relationship has been reflected in the wound care literature. Caregivers have indicated that their caring role helped them to come closer to their loved one, and that they valued this closeness<sup>13,14</sup>. To date, however, there are no studies in the wound care literature that specifically investigate the role of caregiver characteristics in moderating carer health and well-being outcomes.

Within the broader caregiving literature, the moderating influence of gender has been well established; with women being more susceptible to negative health and well-being consequences in the caregiving role than men<sup>3,16,20</sup>. López *et al.*<sup>18</sup> went beyond basic demographic factors to consider other moderating characteristics of caregivers of elderly relatives. Contrary to expectations, they found a number of positive emotional outcomes for carers, as measured by the Caregiver Satisfaction Scale (CSS)<sup>30</sup>. These positive emotional experiences included: enjoying being with the patient, delighting

in patient pleasure, feeling closer to the patient, increased meaning to caregiver’s life, boosting caregiver self-esteem, and general satisfaction in the caregiver role. More positive emotional outcomes were associated with having had a close affectionate relationship with the care recipient pre-caregiving; with the caregiver taking on their role as a personal initiative (rather than by default); with not working outside the home; with maintaining the same amount of leisure time as prior to caregiving; and with less use of venting as a coping strategy. The authors surmised that these factors were all characteristics of the *caregiver*, rather than of the care recipient. It appears that subjective inter- and intra-personal caregiver characteristics not only buffer the effects of stress in the caregiving role, they may also lead to positive emotional outcomes and a greater sense of well-being<sup>18</sup>.

Marshall *et al.* provided further evidence that caregiver characteristics are implicated in well-being<sup>31</sup>. In an Australian study of people caring for relatives with psychosis, the study found caregivers with relationship partners and those without a history of mental illness themselves experienced greater well-being and hopefulness. In addition, positive caregiving experiences predicted caregiver well-being; while caregivers’ perceptions of their relative’s psychotic experiences and less frequent contact with the affected relative predicted hopefulness. Again, it appears that subjective characteristics of the carer and aspects of the carer/recipient relationship are associated with improved carer well-being and hopefulness for the future<sup>31</sup>.

The relationship between caregiving, health and well-being outcomes is clearly a complex one. As well as potentially buffering carers from the stresses inherent to caring for a loved one, factors such as social support, mastery, and subjective characteristics of the caregiver may also interact to deliver positive health and well-being outcomes. O’Reilly *et al.* were interested in better understanding the impact of positive, well-being-related outcomes for carers<sup>17</sup>. They used data collected from the 2001 Northern Ireland Census to assess whether caregivers were at risk of increased mortality. In previously reviewed studies of (1) people with cardiovascular disease<sup>5</sup> and (2) coronary heart disease<sup>6</sup>, caregiver mortality rates were reported as higher than those of non-carers. However, O’Reilly *et al.* highlighted the limitations to these prior studies, which were both relatively small in scale and rather restricted in nature<sup>17</sup>. In contrast, their census-wide data provided evidence for *reduced* mortality risk to caregivers, and improved longevity. The authors suggested greater research attention needs to be paid to the well-being-related aspects of caregiving (for example, life purpose, meaning, spirituality, and emotional connection)<sup>17</sup>.

These findings were supported by Brown *et al.* in a study of elderly married couples, where one partner provided care for their spouse<sup>32</sup>. The authors found that providing more than 14 hours of care a week was predictive of increased longevity (that is, decreased mortality) independent of the degree of behavioural and cognitive impairment

of the care recipient and individual demographic factors. Brown *et al.* concluded that active caregiving could be beneficial to caregivers' health and well-being, though the specific factors at play were yet to be accurately identified and measured<sup>32</sup>.

Research has pointed towards a subtle interplay of moderating factors that impact health and well-being outcomes for carers<sup>3,18</sup>. Increased focus on well-being-related outcomes for carers is vital if adequate support programs and initiatives for this potentially vulnerable group of people is to be provided<sup>1,3</sup>. This is particularly so for the carers of people living with chronic wounds; a population which is on the rise in Australia and at risk of experiencing the stress and related detrimental effects of caregiving. The key element to such research is the potential to move beyond merely protecting carers against the stresses of caring. Future research into the carers of patients with wounds may also assist in developing programs and supports that will enhance the well-being of these carers and care recipients, assisting them in building close interpersonal relationships<sup>11,14</sup>.

However, to date, there has been virtually no research that considers health and well-being outcomes for this caregiving group<sup>10</sup>. Much of the caregiving literature takes a broad approach to the definition of "carer", focusing on outcomes for people providing care to elderly relatives<sup>18,32</sup>. This may include carers of people living with a chronic wound, but does not attend specifically to this caregiving category. Alternatively, caregiving research has also considered outcomes for carers of people living with specific medical or neurological/mental illnesses, such as cardiovascular disease<sup>4-6</sup>, stroke<sup>33</sup>, dementia<sup>21,34,35</sup>, mild cognitive disorder<sup>8</sup>, and mental illness (for example, schizophrenia, psychosis)<sup>25,31</sup>. It is likely that many of the findings from such studies will apply broadly to the carers of patients with wounds. However, this is a unique caregiving group with its own challenges and related stresses<sup>11</sup>; as such, the well-being of carers of patients with wounds deserves specific research attention.

## CONCLUDING REMARKS

Research into the health and well-being of caregivers shows a complex set of interwoven relationships. Much previous research has emphasised the deleterious effects of providing active, informal care, including risk of increased mortality<sup>5,6</sup>, poorer subjective health and quality of life<sup>4,9</sup>, as well as a higher likelihood of depression and anxiety symptoms<sup>4,7,24,34</sup>. These deficits are correlated with specific characteristics of caregivers, such as demographic factors (gender, age), amount and intensity of care provided, and the impact this has on a caregivers' daily routines and self-care practices<sup>1-3</sup>. When caregivers are compromised there is a real risk that care recipients will experience poor quality care, and an associated risk of abuse<sup>36</sup>. It is vital that public health policy focuses on providing relief and support for caregivers, in order to underpin the valuable service they offer to care recipients and the community<sup>3,37</sup>.

While caregivers remain vulnerable to stress, recent research into caregiving indicates a more complex relationship between caring, health and well-being<sup>16</sup>. A number of moderating factors appear to act as a "buffer" against the stresses of providing informal care; such as high quality, well-timed instrumental and emotional support<sup>21-23</sup>, caregiving mastery<sup>19,29</sup>, and specific caregiver characteristics (for example, caring as a personal initiative, close relationship with the care recipient, sufficient leisure time)<sup>18,31</sup>. Such moderators have been associated with decreased depression and anxiety symptoms, enhanced subjective health, and even improved longevity in caregivers<sup>17,32</sup>. Researchers have called for more attention to be paid to the positive outcomes of caregiving, especially well-being-related aspects such as personal meaning, spirituality, hope and close interpersonal relationship<sup>17,31,32,38</sup>.

Despite the wealth of research into caregiving, there has been limited attention paid to the carers of people living with chronic wounds<sup>10,11</sup>. Australia's ageing population is set to rise, as it is across first-world nations<sup>39,40</sup> and this will be accompanied by an increase in the incidence of chronic wounds<sup>12,41</sup>, which particularly affect the elderly<sup>42</sup>. Given the value of informal, home-based caregiving, it will be vital to understand how the health and well-being of caregivers of patients with wounds is impacted by their caregiving role. Beyond merely understanding, the capacity to influence and increase positive health and well-being outcomes for these carers will be an asset to those living with chronic wounds and to the wider community.

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