

The complexity of caring (Part 1): Detrimental health and well-being outcomes for caregivers of people with chronic wounds

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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. The first part of this review provides background information on caregiver characteristics, and physical and psychological deficits related to caregiving. The second part explores 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']. Only those 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 of those with wounds. However, a number of moderating variables appear to 'buffer' the stress of caregiving and may even lead to positive outcomes.

Conclusion: To date, there has been insufficient attention paid in the research literature to the health and well-being outcomes of carers of people living with chronic wounds. Given the predicted rise in the incidence of chronic wounds in Australia over the coming decades, it is vital that we understand how to maximise health and well-being outcomes for the carers of patients with chronic wounds.

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

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BACKGROUND

Wound care is a rising burden on the Australian health care system, with more than 400,000 Australians living with a chronic wound at any time¹. Chronic and non-healing wounds account for 69–77% of all wounds, and are most prevalent in the elderly². More than 60,000 elderly Australians currently live with a chronic wound and this number is predicted to rise to over 120,000 over the coming 25 years². The important role that family caregivers play in providing support for relatives living with chronic wounds cannot be underestimated. Yet, the health and well-being of these caregivers is currently under-researched. Understanding the factors that impact on health and well-being outcomes for these caregivers is vital if we are to support sustained informal caregiving in wound care to the benefit of care recipients and the community.

HEALTH AND WELL-BEING OF CAREGIVERS

Caregivers have been identified as a "population at risk"³. There are an estimated 2.7 million carers in Australia, of which approximately 770,000 have been identified as primary caregivers⁴. Family caregivers are providing unpaid support and assistance to elders, as well as family members with a disability or chronic illness⁵. In 2010, the estimated economic value of informal caregiving in Australia

was in excess of \$40 billion per annum⁶. This type of informal carer relationship is likely to become increasingly prevalent, given Australia's forecasted ageing demographic over the next 25 years⁷. Informal caregivers provide a valuable service to the community, and to the recipients of their care.

International research indicates similar trends. The National Alliance for Family Caregiving in the United States estimated approximately 65.7 million Americans (or 29% of the adult US population) provided care for ill or disabled family members⁸. Caregivers are reported as providing an average of 20 hours unpaid care per week, predominantly to relatives (86%), most often to parents (36%). It has been estimated that carers provide an estimated \$375 billion annual economic value to the US, providing long-term care in the home to people with chronic illness or disabilities⁹. Similarly, in the UK there are an estimated 6.5 million carers (that is, one in eight adults), providing £119 billion pounds of unpaid care to loved ones a year¹⁰. As in Australia, a projected ageing of the population in the US and UK over the coming three decades will place strain on the public health system and intensify the need for informal caregiving^{11,12}.

Carers clearly provide a valuable service to loved ones and to the wider community. Yet, research indicates that informal caregiving can take a toll on the health and well-being of carers¹³⁻¹⁵. This toll may directly impact on the quality of care provided and the carer's capacity to provide support¹⁶. In Australia, primary carers are significantly more likely to have a disability themselves than are non-carers⁴. The 2012 Australian Census reported around one-third of primary carers living with a disability (37%), compared to 16% of non-carers. Beyond disability, the physical and emotional toll of caring for a loved one can also impact on a carer's general physical and psychological health⁵.

This review aims to assess what is currently known about health and well-being outcomes for informal caregivers, with the intention of placing this information into the context of caring for patients with chronic wounds. The first part of this review presents information on the characteristics of caregivers and reviews the detrimental health and well-being outcomes for family caregivers. The second part of this review discusses a number of moderating factors which impact on physical and psychological health outcomes for carers, and investigates positive outcomes which enhance caregiver well-being.

Method. A literature review was undertaken in February 2015 using the databases, CINAHL Plus, PsychArticles, PsychInfo, and PubMed. A number of keywords were included in the search, such as ['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 across the past 20 years were considered for inclusion. The literature search extended to relevant book chapters and web references from professional or government bodies, which were also assessed for inclusion. A total of 52 articles were ultimately found to be relevant to this, or the second, review.

REVIEW

Carers of people living with chronic wounds

While much research has been conducted into the impact of caregiving in general, there has been little research attention paid to the particular experiences of carers of people living with chronic wounds^{17,18}. The studies that have been undertaken to date have largely been phenomenological in nature, with small samples of caregivers. These studies provide initial observations on the lived experiences of caregivers providing assistance to people with chronic wounds. A number of similar themes have arisen from these studies — for example, the intensity and distress of caring for a loved one with a chronic wound. Alexander¹⁷ interviewed a number of patients living with malignant fungating wounds, along with nurses and a single caregiver (a wife who had cared for her husband at home). Both the professional nursing staff and the one informal caregiver reported the negative physiological and psychological impact of wound malodour, along with vivid memories of the wound, which remained with the caregiver long after the patient had passed away.

Similarly, Probst and colleagues²⁰ explored the experiences of seven caregivers of patients living with malignant fungating wounds. As in Alexander's study, Probst and colleagues identified the experience of caring for this type of wound as intense and distressing, again referencing the constant management of exudate and malodour as particularly stressful. Indeed, Alexander surmised that living with and providing care for someone with a malignant fungating wound was an intense and unforgettable experience, with the potential to be more traumatic for the carer than the patient¹⁷.

In-depth interviews with caregivers of people living with diabetic foot ulcers also prompted Marino to identify the intensity and distress of caring for a person with a chronic wound¹⁹. Eleven themes emerged from this study to indicate the emotional impact of caregiving for a patient with a wound: loss of intimacy, relationship commitment, isolation, role empowerment, building frustration, perceived barriers, self-neglect, guilt, co-dependence, unanticipated burdens, and fear of the future. The emphasis on negative emotions led the researcher to conclude that structured support would benefit these caregivers.

Despite the strains of caregiving, each of the three studies reported here also referenced changes in self-concept and relationship with the loved one as a consequence of caring. Alexander reported the one informal caregiver in her study needed to adapt to a "new mode-of-being" in the world and resulting changes in self-identity and relationship to her husband. Despite the intensity of caring, the caregiver reported a sustained hope for a "good death" for her loved one. Echoing the complexity of caring for a patient with a chronic wound, Probst and colleagues highlighted caregivers felt an increased closeness of relationship with their care recipients²⁰. The intensity of the caregiving experience brought them closer to their loved one. Similarly, Marino noted caregivers' relationship commitment to their care recipient and caregiving role empowerment, suggesting some positive outcomes for carers¹⁹.

While each of these studies provides valuable insight into the lived experience of family carers of those with chronic wounds, it is important to note that the sample sizes for each study were relatively small. In the case of the Alexander study, the phenomenological data focused principally on the experience of *formal* caregivers, as opposed to *informal* caregivers. Further and more structured investigation is necessary before specific conclusions can be reached about the health and well-being outcomes for this population. In order to better understand caregivers of patients with chronic wounds, much can be learned from the broad research into caregivers in general.

CHARACTERISTICS OF INFORMAL CAREGIVERS

There have been a number of studies aimed at identifying the profile of people most likely to provide care to a relative and most vulnerable in this role⁵. A nationwide survey of home-based caregivers in the US found that “vulnerable caregivers” were more likely to be over 65 years of age, female, married, and have less than 12 years’ education²¹. Vulnerable caregivers are more likely to be providing higher intensity care (that is, more than 20 hours of care per week; and assisting with a higher number of activities of daily living [ADL] or instrumental activities of daily living [IADL]). They are more likely to report poorer physical health as a result of providing care, to experience difficulties providing care, and to have unmet needs in providing care. Despite their vulnerability, these carers were no more likely to receive paid care assistance, and were less likely to be employed than non-vulnerable caregivers. Innovative programs and services are needed to help alleviate the burden of vulnerable caregivers, noting that those most in need of support are least likely to receive it²¹.

The results of the former study were supported by another US report, which identified an estimated 16 million informal caregivers across the country¹⁴. Data indicated that women aged between 50 and 64 were most likely to be carers; that caregivers were less likely to be employed than non-caregivers, and where they were employed, they were more likely to miss days of work. Caregivers were also more likely to experience financial hardship and, as a consequence, less likely to be insured and consequently to have more difficulties in meeting medical costs. Caregivers reported anxiety about their capacity to access quality care for their relatives and themselves in the future. The financial difficulties inherent to unpaid informal caregiving, combined with the psychological profile of carers, may lead to a particularly stressful experience for many people providing care for a loved one¹⁴.

In a UK-based survey of caregivers, data collected from the British Household Panel Survey (BHPS) was used to consider factors that influence psychological distress in caregivers¹³. The study found that unique subsets of caregivers were more vulnerable to distress in the caregiving role. ‘Distress’ was measured using the General Health Questionnaire (GHQ)²² to assess symptoms of anxiety, depression, social dysfunction and loss of confidence and self-esteem. Results

showed that women reported more distress than men; people providing more than 20 hours of care who were co-resident with the care recipient reported greater distress; and women about to transition into 20 hours or more of care were more distressed. It would appear that certain individual and contextual factors lend themselves to greater vulnerability in the caregiving role.

It is important to contextualise the ‘typical’ caregiver profile in light of ‘who’ in a family is most likely to take on the caregiving role. Research shows that the majority of caregivers are female, many of whom are mothers or daughters caring for children or elderly parents^{13,14,21,23-25}. In these contexts, the nature of the relationship with the care recipient appears to be a primary motivator, with women perceiving their caregiving role as a “duty”²⁵. These women often balance their caregiving responsibilities with other family duties and paid employment, potentially leaving them vulnerable to high levels of burden and stress.

Alternatively, it has been noted that the caregiving role may be designated to a member of the family who is unemployed and does not have ties to the labour market, leaving them free to take on the caregiving role^{13,14}. Sometimes a family member with prior mental or physical health difficulties themselves may take the opportunity to leave employment to take on the caring role¹³. Again, it may be that individuals who take on the caring in a family are already vulnerable and at risk of distress prior to commencing an informal caring role.

HEALTH OUTCOMES FOR CAREGIVERS

Caregivers are a heterogeneous group and health outcomes reflect differences in individual carer vulnerability¹⁵. The caregiving role is multidimensional and the literature reports both negative and positive outcomes for caregivers²⁶. Broadly, however, research into the health of caregivers has showed a number of physical and psychological health detriments for this group^{15,23,24,27-29}. Internationally much attention has been called to public health policy interventions aimed at providing “relief from the relentless work of family caregiving and its debilitating effects”³⁰. These recommendations have been based on evidence that informal caregivers are at risk of physical and psychological impairment as a consequence of active caregiving³¹. However, as noted above, some caregivers may come to their role already at risk of strain and more vulnerable to the rigours of caregiving than others.

CAREGIVERS EXPERIENCE PHYSICAL AND PSYCHOLOGICAL DEFICITS

The evidence shows that caregivers are vulnerable to a number of negative physical and psychological outcomes. For example, compared to non-caregivers, caregivers are more likely to report worse subjective health, to access medical care more frequently, and to take psychotropic medication³²⁻³⁴. Two studies investigating people caring for relatives with either cardiovascular disease²⁹ or coronary heart disease²⁸ reported higher mortality rates for caregivers than for non-caregivers. In a recent study of people providing care for elderly relatives, del-Pino-Casado *et al.*²⁴ found

that the number of stressors a carer experienced (that is, psychiatric/psychological symptoms and amount of ADL assistance), a tendency towards emotion-focused coping and dysfunctional coping, and the level of subjective carer burden, were all predictive of greater anxiety amongst caregivers. Evidence from such studies indicates clear physical and psychological risks for caregivers²⁴.

CAREGIVER BURDEN, PHYSICAL AND PSYCHIATRIC MORBIDITY

Caregiver “burden” has been a much studied construct and is associated with high physical and psychiatric morbidity for carers³⁵. Caregiver burden incorporates factors from three domains: care recipient characteristics, carer characteristics, and care context^{32,36}. The more perceived stress in each domain, the higher the caregiver burden. Paradise and colleagues³⁵ considered factors influencing burden in people caring for relatives with mild cognitive impairment (MCI). The study found that 36% of MCI-caregivers reported clinically significant levels of burden, twice that of a control group. Care recipient behavioural problems contributed most to level of burden, with caregiver depression and cognitive functioning also implicated³⁵. Here the interplay of factors making up the care recipient/caregiver relationship, as well as the caregiving context all combine to create a subjective sense of burden for the carer.

When a caregiver’s physical and psychological health is negatively impacted in the caregiving role, there is a very real risk to the care recipient. The caregiving relationship is reciprocal⁵. Just as the level of cognitive, behavioural and functional impairment of the care recipient impacts the carer; so too, the health and capacity of the carer influences outcomes for the care recipient^{5,16}. Potentially harmful caregiver behaviour (for example, screaming and yelling, insulting, swearing, withholding food, threatening with nursing home placement, hitting or slapping, handling roughly in other ways), are considered abuse. In a study of carers and their care recipients, Beach and colleagues¹⁶ found the following variables were predictive of these risk behaviours: higher levels of care recipient needs for help, a spousal caregiving situation (as opposed to non-spousal), higher levels of caregiver cognitive impairment, poor caregiver physical health, and higher levels of caregiver depression. These results are indicative of the potential risks to informal caregiving if the health and support needs of caregivers are unmet¹⁶.

THE COMPLEXITY OF THE CAREGIVING ROLE

Despite the strong evidence for negative health and well-being outcomes for carers, it is increasingly recognised that the caregiving role is a complex one and a number of positive outcomes have also been reported. A longitudinal study of caregiver health effects by Beach and colleagues considered a sample of elderly people caring for a spouse in early stages of disability²⁶. They reported that caregivers reported physical and mental health *benefits* from their caregiving role. It appeared that the intensity of caregiving impacted the caregiver’s appraisal of their role, and with positive appraisal came the capacity for positive outcomes²⁶.

The importance of “time away” from the caregiving role and perceived social support from others was investigated in a study considering negative and positive outcomes for family caregivers of patients with heart failure²⁷. In this study, the health status of caregivers was comparable to population norms. Yet despite this, carers still self-reported poorer health as a consequence of their caregiving role. The study found the greatest negative impact for caregivers was on their daily schedules, suggesting carers who do not have sufficient time away from their caring duties are at risk of diminished social engagement, greater social isolation and, consequently, less social support²⁸.

These studies begin to paint a more complex picture of the caregiving role, demonstrating both negative and positive health and well-being outcomes for carers. It would appear that a number of mitigating factors play in to the strain of caregiving and how an individual carer manages this. Factors such as caregiver *appraisal* of the situation; availability of social support; and amount of time away from the caregiving role have all been shown to impact on health and well-being in caregivers. The complexity of caregiving appears to reflect the heterogeneity of caregivers as a group. The second part of this review builds on the complexity of caregiving and explores research into positive health and well-being outcomes for caregivers. This data will inform future research efforts focused on outcomes for carers of people with chronic wounds.

SUMMARY

The prevalence of people living with chronic wounds is set to rise with Australia’s ageing demographic². These predictions are mirrored in other first-world nations, such as the US and UK^{11,12}. The valuable role that informal caregivers provide to people living with chronic wounds has been vastly under-researched¹⁷. The wider caregiving literature has documented physical deficits (for example, poorer perceived health, higher mortality rates)^{26,28,29} as well as negative psychological impact (for example, depression and anxiety symptoms)^{24,35} and significant social issues (for example, social isolation, financial burden) for caregivers^{14,21}. Some of these issues have been reflected in the phenomenological wound care literature, which reported significant strain, distress, and negative impact for the caregivers of people with malignant fungating wounds^{17,20}. In light of this evidence, caregivers are clearly a “population at risk”²³, with caregivers of people living with chronic wounds amongst this vulnerable group.

Despite evidence of physical and psychosocial deficits, caregiving is increasingly understood as a complex interplay of stressors and moderating factors. As research attention is turned to the construct of ‘well-being’, some of the positive outcomes for caregivers are now being investigated.

Part 2 of this review considers research into the positive, enhancing aspects of caregiving through the lens of a number of moderating factors (that is, social support, caregiving mastery, and subjective caregiver characteristics).

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