

Title

Informal care and home-based palliative care: the health related quality of life of carers

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Abstract

Health is an important factor in the capacity of family and friends (informal carers) to continue providing care for palliative care patients at home. This study investigates associations between the health related quality of life (HRQOL) of current informal carers and characteristics of the carers and their care-giving situation, in a sample of Australian carers of palliative care patients. The cross-sectional study used the SF-36 Health Survey to measure HRQOL. It found carers to have better physical health than the general population and worse mental health. Of 178 carers, 35% reported their health to be worse than it was one year ago. Multiple regression analyses found that the HRQOL of carers whose health had deteriorated in the previous year was associated with the patient's care needs but not the carer's time input, unlike the carers reporting stable health. Clinicians caring for palliative care patients should be alert to the potential health impairments of informal carers and ensure they are adequately supported in their care-giving role and have access to appropriate treatment and preventive healthcare.

Key Words

Informal care, quality of life, palliative care

Running title

Informal carer quality of life

Introduction

While many palliative care services aim to help patients to stay at home for as long as possible, this relies on the availability and capacity of family and friends to provide care (informal carers). Health is an important factor in the capacity of informal carers to continue providing care.(1) Identifying the carers at risk of health problems would enable clinicians to provide appropriate support to prevent the development of new health problems or the exacerbation of existing conditions, and better equip them to continue their care-giving role.

There is a large literature investigating the health of carers and meta-analyses have found carers to have worse mental and physical health than non-carers.(2,3) Conversely, in a longitudinal population study of heterogeneous carers, O'Reilly et al(4) found carers to have a lower risk of mortality than non-carers after adjusting for baseline health status. There is evidence that, among older populations, healthier people are more likely to become carers,(1) but this was not found to be the case among middle aged women.(5) Edwards et al (6) found carers aged less than 65 years to have worse self-reported mental and physical health than the general population, but this was not the case for those over 65. These contradictions suggest that there might be vulnerable sub-groups of carers rather than universal health impairment associated with care-giving and that care-giving and its impacts may vary at different life stages.

Studies have found that carer health is associated with aspects of the care-giving situation. In a population sample aged over 65 years, Schulz and Beach(7) found an increased risk of mortality among carers reporting caregiver strain. Pinquart and Sorensen(8) found that psychological distress (measured as depressive symptoms and burden) had a larger negative association with caregiver physical health than socio-demographic characteristics, care-giving stressors and resources. Care-giving stressors negatively associated with caregiver health included time in the care-giving role, care recipient cognitive impairment and care recipient behaviour problems; the last was the largest of these effects. The resources associated with better carer physical health included carer education and income, and the availability of informal support. Physical health was also worse for older, co-resident and non-spousal carers.(8)

In the palliative care context, there is research suggesting impacts on mental but not physical health.(9,10) Conversely Weitzner et al(11) found that carers of cancer patients receiving curative and palliative care had similar mental health scores but that the palliative care carers had worse physical health. There is also evidence of associations with aspects of the care-giving situation for carers in the palliative care context. Brazil et al(9) found that in bereaved carers, poor physical health was associated with increasing age and with a greater disruption of usual activities by care-giving while poor mental health was associated with insufficient family support and the patient dying in an institutional setting. Schulz et al(12) found that strained carers had higher levels of depression and worse health practices than non-carers and carers reporting no strain; following bereavement, the depressive symptoms did not increase for the strained carers and their health practices improved.

Vitaliano et al (3) proposed a theoretical model for the physical health effects of care-giving as the consequence of a response to stress which may be modified by vulnerability and resources. Pinquart and Sorensen (8) suggested four potential pathways to physical health impacts of care-giving: 1) muscular strain or skeletal injury due to physical exertion, 2) negative changes in health related activities such as diet and exercise, 3) the physiological

effects of psychological distress and 4) changes in sympathetic arousal and cardio-vascular reactivity. For their meta-analysis of correlates of the physical health of carers(8) they considered variables in terms of socio-demographic characteristics, care-giver stressors, care-giver resources and psychological distress.

Much of the evidence for associations between care-giving and health comes from studies of care-giving in the aged care context. To the extent that aged care encompasses end-of-life care, there will be considerable overlap with the palliative care context. There are also likely to be differences in that the palliative care context will also include the carers of young and middle aged patients, the care-giving is expected to be of a shorter duration and the proximity to death may be a motivating factor for carers to continue providing care when it may not be in their interest to do so.

In addition to the emotional demands of care-giving in the context of anticipated death, the illness trajectory and rate of decline and functional loss of the care recipient will differ between aged care and palliative care, particularly cancer palliative care. Three main trajectories have been described for people with a terminal illness, associated mainly with a) cancer, b) organ failure and c) frailty and dementia.(13,14) In terminal cancer there is relatively little decline for most of the final year, with the major loss of function occurring in the final two to three months of life. In organ failure there is usually a prolonged period of gradual decline with intermittent episodes of more serious illness from which there is some recovery, while with frailty and dementia there is usually prolonged gradual decline. These trajectories have different implications for informal carers who are non-professionals and thus learning how to provide for the care recipient's needs. Aged care carers are likely to have a longer period of substantial 'hands on' care-giving relative to palliative care carers with time to learn and adapt to the management of the care recipient's needs, albeit with the potential for cumulative problems associated with protracted care-giving. By contrast, many palliative care carers will be faced with a steep learning curve with rapidly changing care recipient needs. These differences warrant separate investigation of carer health consequences in the palliative care context.

This paper aims to advance understanding of the health impacts of care-giving in the palliative care context. It reports a study which investigates associations between health and a range of care-giving context variables which represent potential stressors or resources, among current informal carers of patients receiving palliative care at home. It measures health as health related quality of life (HRQOL) and examines the associations for different HRQOL dimensions.

Methods

A cross-sectional observational study of the HRQOL of the carers of patients receiving palliative care at home was conducted in Sydney Australia in 2005-2006. It was part of a phase II study of carers' preferences for support, which has been reported elsewhere(15) as has the phase I study.(16) The study received ethical approval from the research ethics committees at the University of Technology Sydney and the research ethics committees associated with the participating palliative care services.

The nominated carers of patients newly registered with either of two community palliative care services were invited to participate. Carers were eligible if they were English-speaking, currently providing assistance to a patient receiving palliative care at home from one of the participating services and the patient and carer provided consent. The carers' health related quality of life (HRQOL) was measured with the SF-36 Health Survey (version 2),(17) administered in a face-to-face interview. The interview also asked about the help the patient needed, details of the care-giving context, the carer's time input and socio-demographic information. Details of the patient's condition were extracted from medical records.

Instruments

The SF-36 Health Survey is a 36 item questionnaire which is a generic health status measure for use in general populations as well as those with health conditions. The validity and reliability have been demonstrated for country-specific adaptations of the SF-36 in many countries including Australia.(18-20) The SF-36 (or the shorter SF-12) has been previously used in studies of palliative care caregivers.(9-11,21)

This instrument is summarised as eight domain scales: physical functioning (10 items), role-physical (4 items), bodily pain (2 items), general health (5 items), vitality (4 items), social functioning (2 items), role-emotional (3 items) and mental health (5 items).(17) All questions have categorical response scales with five options (values 1-5), except for the 10 physical functioning questions which have three response options (values 1-3). If necessary, response values are recoded so that a higher value is given to responses representing better HRQOL. The raw domain score is calculated as the sum of an individual's values for the domain questions; this is transformed as follows to produce a domain score between 0 and 100 where 100 is the best HRQOL and 0 is the worst.(17)

$$\text{Domainscore} = \frac{(\text{Rawscore} - \text{Lowestpossiblescore})}{\text{Possiblescorerange}} \times 100$$

The domain scores can be further summarised into physical (PCS) and mental (MCS) component summary scores. This is done by first transforming the domain scores into z-scores using the population mean and standard deviation for each domain. The component aggregate score is calculated by summing the weighted z-scores using factor score coefficients from the population as weights. While all domains are included in the aggregation, those most relevant to the component summary (physical or mental) will have the highest weights and therefore contribute most to the score. The aggregate component z-scores are converted to norm-based scores (NBS) as: $NBS = 50 + (z\text{-score} \times 10)$; their interpretation is then relative to a population mean of 50 and standard deviation of 10.(17)

The questionnaire to measure the help needed by the care recipient was adapted from the interview schedule used by the Victorian Carers Program, which was developed in Australia to measure the experience of informal carers in the general population.(22) Following two

pilot studies with palliative care carers, additional items relevant to the palliative care context were included (emotional support, night time assistance and three types of technical assistance). The items and response categories are listed in Table 1. Questions about the care-giving context, carer input and socio-demographic characteristics were developed for the study and tested in the phase I study.(16) The care-giving context questions included questions about the carer's relationship to the care recipient, if the carer is co-resident with the care recipient, the support received from other informal carers, the carer's employment status whether the carer's income had declined due to care-giving commitments. The carer input questions included the period for which the carer has been care-giving for this care recipient, the time spent on care-giving tasks and the time the carer needed to be with the care recipient.

Analysis

Australian population values(23) were used to convert the eight SF-36 domain scores to NBS and to calculate the PCS and MCS.(17) NBS are derived by a linear transformation (described above) of *z-scores* calculated using the population mean and standard deviation to transform the domain scores.(17) The interpretation of NBS is in relation to the population mean of 50 and standard deviation of 10. The evidence suggests that 2-3 NBS points is considered to be a minimally important difference (MID) for all domains; thus a mean score of less than 47 would be considered worse than the general population.(17, p128-131)

As the SF-36 scales differed by age and sex in the general population,(23) the mean norm-based domain and summary scores were adjusted for age and sex using indirect standardisation(24) and Australian population mean NBS for age and sex categories.(23) These are presented for comparison with the general population.

Ordinary least squares regression was used to investigate the association between carer HRQOL and the care-giving context, including potential stressors and resources. Potential stressors included the care recipient's care needs and the carer's care-giving input, while the resources included education, income and support from other informal carers. Other socio-demographic and contextual variables were also examined. Models of the eight domain NBS were estimated separately, with all models adjusted for age and sex. The modelling strategy was to first examine the individual effects of each covariate by adding it to the base model with age and sex. The significant covariates were then included in multiple regression analyses and retained in the final models if statistically significant. The covariates investigated included: carer socio-demographic variables (country of birth, language spoken at home, education and income), care-giving context variables (carer-patient relationship, cohabitation with patient, presence of other informal carers, carer's employment status and if the carer's household income declined because of care-giving), variables representing the carer's input (care duration, time spent daily on care-giving tasks, the daily time the carer has to be available) and variables representing the patient's care needs. The patient need variables included: activities of daily living score (mean of 7 items scored 0-3), number of instrumental activities of daily living the patient needed help with (maximum=11), the need for help on all or most nights, need for quite a bit or a lot of emotional support, need for technical nursing care, if the patient's diagnosis was cancer, if he/she died within one month of the interview and if he/she died at home.

Interpretation of the causal direction of associations is one limitation of cross-sectional observational studies. To further the interpretation of associations, the sample was divided

into two groups according to the response to the SF-36 health transition question which asks about general health compared to one year ago. Knox and King(25) found this retrospective item to be a good indicator of changed health status in a large Australian population sample. Carers were classified as “stable” if they reported their health as the same, somewhat better or much better, and “worse” if they reported their health as somewhat worse or much worse. HRQOL was analysed separately for these two groups.

Results

The 178 informal carers who participated in the study represented 21% of the eligible carers. Fifty-six percent of eligible carers were not invited by the palliative care team because: the patient was too ill (33%), the carer was too stressed or overwhelmed (13%) or the clinical staff were too busy or forgot (10%). A further 12% of carers refused and the remaining 11% did not participate because the patient died or was hospitalised before the interview. The participating carers were aged 62 years on average and 29% were male, while the care recipients were older (aged 72 years on average), 58% were male and the principal diagnosis was cancer for 89%. The most frequent cancer diagnoses were colorectal (15% of patients), lung (14%) and prostate cancer (13%). Among the 19 patients with a non-cancer diagnosis, the most frequent diagnoses were cardiac failure (4 patients, 2.3% of patients), chronic airways limitation (3 patients, 1.7%) and pulmonary fibrosis (3 patients, 1.7%). Dementia was the principal diagnosis for one patient and a co-morbid condition for five patients. All care recipients were living at home at the time of the carer interview. The care recipient's proximity to death ranged from two days to over 23 months (median 14.6 weeks) and 18% died within one month of the interview. The time to death was unknown for eight patients who were lost to follow-up due to being transferred to another service and fourteen patients who remained alive at the end of the study (between 9 and 23 months after the carer interview).

Health transition

Of 178 participants, 63 (35%) reported their health as worse than one year ago (40 somewhat worse and 23 much worse) while 115 (65%) were stable (101 the same, 7 somewhat better and 7 much better). The group of carers reporting worse health than one year ago included more spousal carers than the group reporting stable health, was older on average and spent more time on care-giving; their care recipients did not differ significantly on any measured characteristics (Table 2).

Mean norm-based domain scores

The health of the stable group was better across all domains compared with that of the group reporting worse health than one year ago (Figure 1). The age and sex standardised mean scores for the stable group were better than the general population mean of 50 on physical domains (physical functioning, role physical and bodily pain) and general health perceptions, but worse for mental domains (mental health, role emotional and vitality) and social functioning. For the group reporting worse health than one year ago, all age and sex standardised mean domain scores were lower than the population mean of 50; physical functioning was the only domain score within three NBS points of the population mean (47.1) and therefore the difference is not considered important. For both groups, there was a substantial difference in mental health compared to the population mean; mean mental health scores were eight NBS points below the population mean for the stable group and 17 NBS points below for the group with worse health than one year ago (Figure 1).

Socio-demographic characteristics and HRQOL

Age and sex were included in all models and showed associations with physical domains but not mental domains. For both health transition groups, age was associated with physical functioning, role physical and bodily pain, while sex was associated with physical

functioning and role physical in the group with stable health. These domain scores were worse with increasing age and were better for men than for women.

The proportion of the variance in each HRQOL domain that was explained by the statistically significant individual covariates is reported in Table 3. No other socio-demographic characteristics were associated with HRQOL in the group with stable health, while country of birth (COB) and language spoken at home (LAH) were associated with HRQOL in the group whose health was worse than one year ago. For this group, Australian born carers reported better physical functioning than those born overseas (explaining 5% of the variance) and English speakers reported better mental health and role emotional scores than those speaking another language at home (explaining 14% and 6% of the variance respectively). These associations persisted when the significant care context, carer input and patient need variables were included (see Table 4).

Care-giving context and HRQOL

The only care-giving context variables to be associated with HRQOL were the carer's employment status and if the carer's income had declined through care-giving. In the group whose health was worse than one year ago, working carers reported worse bodily pain (explaining 9% of the variance) and carers with lower income through care-giving reported better social functioning (explaining 12% of the variance). These associations persisted when the other significant covariates were included (see Table 4). There were no care-giving context variables associated with HRQOL in the group with stable health.

Carer input and HRQOL

Carer input was not associated with HRQOL in the group whose health was worse than one year ago. In the stable group, the time the carer spent on care-giving tasks each day was negatively associated with physical functioning, bodily pain and vitality but the proportion of variance explained was small (Table 3). These associations persisted after the addition of other significant covariates (see Table 4); this was the only covariate associated with vitality.

Patient need and HRQOL

Several indicators of patient need were associated with HRQOL in the group of carers whose health was worse than one year ago. For this group, the patient's need for technical nursing was associated with worse physical functioning and bodily pain (explaining 8% and 16% of the variance respectively), the patient's need for help at night was associated with worse general health perceptions and mental health (explaining 10% and 8% of the variance respectively), and the patients need for a lot of emotional support was associated with worse social functioning (explaining 9% of the variance). These associations persisted after the addition of other significant covariates, with the exception of that between the patient's need for help at night and the carer's mental health (see Table 4).

Only two patient variables were associated with HRQOL in the group of carers whose health was stable relative to one year ago; the patient's diagnosis and if the patient died at home. A patient diagnosis of cancer was associated with worse role physical and social functioning scores in this group of carers (explaining 4% and 8% of the variance respectively) and the patient's death at home was associated with better physical functioning, general health perceptions and mental health in these carers (explaining 5%, 5% and 4% of the variance

respectively). These associations persisted after the addition of other significant covariates (see Table 4).

HRQOL domains

For both health transition groups, after adjusting for age and sex, the care-giving and patient need variables explained very little variance in role physical, role emotional and vitality (4-6%); thus the models are not shown. For the group with stable health compared to one year ago, care-giving and patient need variables explained very little variance in the remaining domains (less than 10%), after adjusting for age and sex. For the group with worse health compared to one year ago, care-giving and patient need variables explained further variance in physical functioning, bodily pain, general health perceptions and social functioning (10% to 22%) and carer country of birth and language explained further variance in physical functioning and mental health respectively, after adjusting for age and sex. The estimates for all statistically significant effects were greater than the MID of 3 NBS points (see Table 4). The impact of the significant effects on mean scores for different sub-groups is illustrated in Table 5.

Discussion

This study investigated the care-giving characteristics associated with different domains of HRQOL in the carers of palliative care patients, using the SF-36 health transition question to identify carers with worse health relative to one year ago. If there were negative health impacts related to palliative care care-giving, we would expect to see them in this group. The mean HRQOL scores for this group were worse than those for the group reporting stable (or improved) health on all domains and worse than those for the general population on all domains except physical functioning. The group with stable health had worse mean scores than the general population for the mental and social domains but had similar or better scores for the physical domains, which is consistent with the studies by Grov et al(10) and Brazil et al.(9)

Different stressors were associated with carer health in the two health transition groups; the care recipient's needs were associated with several HRQOL domains in the group with worse health relative to one year ago, while the carer's input (time spent care-giving) was associated with physical domains in the group with stable health. In our group with worse health, we found specific care recipient needs (need for technical nursing and need for help at night) rather than general impairment (measured by ADL or IADL scores) associated with carer health which differs somewhat from the meta-analysis by Pinquart and Sorenson.(8) Care-giving resources (education, income and support from other informal carers) were not associated with HRQOL in either group, also counter to Pinquart and Sorensen.(8) The differences may reflect the different carer samples as the studies included in their meta-analysis were predominantly aged care and dementia carer studies. The majority of our palliative care carers were helping patients with terminal cancer and may have had access to more formal support than many aged care carers.

Among the group with stable health, some of the associations may have been the effect of the carer's health on their care-giving rather than the other way around. In this group, the carer's physical functioning and bodily pain worsened as the hours spent on care-giving tasks increased and the carers of patients who died at home reported better physical functioning, general health perceptions and mental health relative to carers of patients who died in an institution (also found by Brazil et al(9)). Causality may have been in either direction for these associations, and it is likely that the carer's mental and physical health were determinants of his/her capacity to care for the patient at home until death.

Among the group with worse health relative to one year ago, the patient's need for technical nursing care such as injections or dressings was associated with worse physical functioning and bodily pain. This association may be related to the stress experienced by non-professional carers when providing technical care tasks or the need for technical nursing may simply be an indicator of severity or other aspects of the patient's condition associated with strain on the carer. Also in this group, the carers of patients needing help at night reported worse general health perceptions than carers of patients not requiring night-time help while the carers of patients needing a lot of emotional support reported worse social functioning than those caring for patients with relatively low emotional support needs. The causal direction for these associations would appear to be the impact of care-giving on the carer's HRQOL through stress, fatigue and time constraints as it is unlikely that the carer's health would influence the patient's care needs. In addition to patient needs, the carer's employment status was also a factor where working carers reported worse bodily pain relative to non-working carers, which may also be related to fatigue and time constraints.

There were also socio-demographic characteristics (apart from age and sex) associated with HRQOL in the group with worse health relative to one year ago. In this group, Australian born carers reported better physical functioning than those born overseas and English speakers reported better mental health. While all of the carers in the study were able to speak English, it is possible that carers from culturally and linguistically diverse (CaLD) backgrounds were unable to access the same level of formal and informal support as other carers or there may have been cultural differences in responses to the interview questions. Unlike Pinquart and Sorensen's(8) meta-analysis of physical health in the carers of older adults, we found no association between health and duration of care-giving, spousal status, or co-residence. While our group reporting worse health relative to one year ago included a higher proportion of spousal carers than the stable group, spousal status was not associated with any of the HRQOL domains in either group.

Our study has some limitations. It is a cross-sectional study which weakens the capacity to draw causal inference from associations. However, regardless of the causal direction, the associations indicate sub-groups with health impairment and, in the case of mental health this impairment is substantial. It is also possible that the carer's mental state may have influenced his/her assessment of other self-reported measures including physical HRQOL domains and explanatory variables, resulting in associations. For example the carer's assessment of the time taken to provide care might be affected by mental state, but this is not likely to be the case for patient needs such as injections and night-time assistance.

The study participants may not be representative of all palliative care carers, as our recruitment rate was low, our sample was English-speaking and recruited through a specialist palliative care service operating in a metropolitan area. While 8% of carers were ineligible because of language, the study did include sufficient numbers of carers from CaLD backgrounds to identify effects among the group with worse health relative to one year ago. Further, while it is likely that many of the carers who were not recruited were having difficulty coping and may have been in worse health, this does not weaken the associations identified between care-giving and HRQOL.

The care-giving variables explained a relatively small portion of the variance in HRQOL. This is ostensibly a non-diseased sample and the care-giving predictors might be expected to impact on many of the health domains only indirectly. It is therefore not surprising that, when compared to the effects of treatments in diseased populations (where direct health impacts are expected), the variance explained by the care-giving related variables is relatively small. While it is not surprising that care-giving variables do not explain most of the variation between carers in HRQOL, it is nonetheless important that for some carers there do appear to be health consequences from care-giving. More conclusive results might be achieved through longitudinal research which would enable the observation of changes over time with changing care-giving demands.

The HRQOL of carers whose health had deteriorated in the previous year was associated with the patient's needs but not the carer's time input, unlike the carers with stable health. This study provides important information about informal carers of palliative care patients who are at risk of health problems and the aspects of health which are impaired. While further research is needed to more precisely identify the carers most at risk, it is essential that clinicians caring for palliative care patients are alert to the potential health impairment in their carers and ensure they are adequately supported in their care-giving role and have access

to appropriate treatment and preventive healthcare. This is important both for the carers' health outcomes and their capacity to continue providing care.

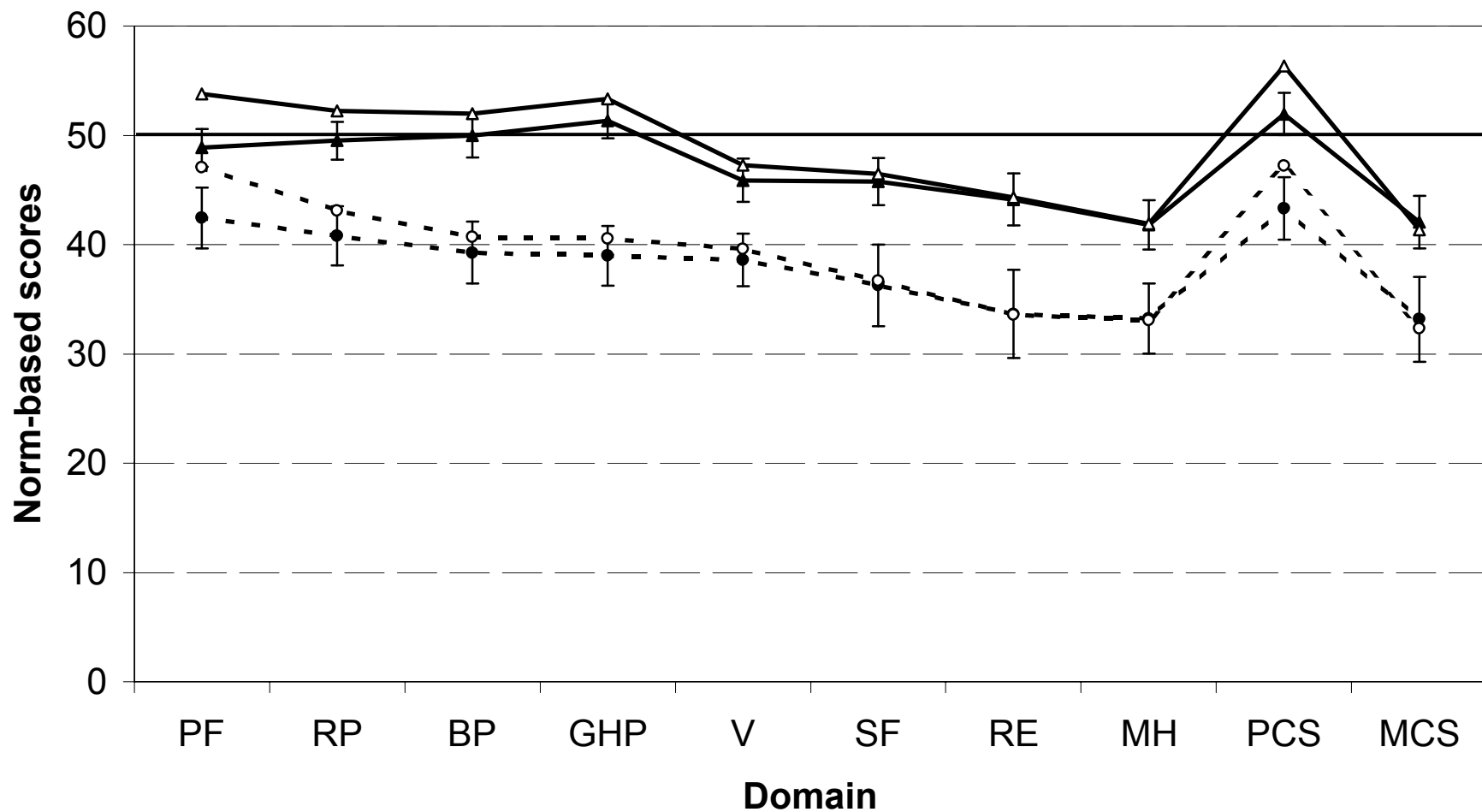
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Figure legends

Figure 1: SF-36v2 composite and norm-based domain scores for informal carers by health transition status: unstandardised mean with 95% confidence interval and age and sex standardised mean (population mean=50 sd=10)



—▲— Health stable - unstandardised —△— Health stable - standardised
 -●- Health worse - unstandardised -○- Health worse - standardised

Table 1: Help needed by care recipients (n=178) –number (%)

Type of assistance	None	A little	Quite a bit	A lot
Personal activities of daily living				
Bathing or showering	70 (39)	35 (20)	29 (16)	44 (25)
Dressing	69 (39)	49 (27)	23 (13)	37 (21)
Eating	135 (76)	19 (10)	12 (7)	12 (7)
Using the toilet	128 (72)	21(12)	3 (2)	26 (14)
Incontinence problems	132 (74)	29 (16)	5 (3)	12 (7)
Going out	25 (14)	29 (16)	27 (15)	97 (55)
Moving about within the home	94 (53)	39 (22)	15 (8)	30 (17)
Getting in or out of a bed/chair	83 (47)	51 (29)	17 (9)	27 (15)
Instrumental activities of daily living				
Communication with others	139 (78)	16 (9)	12 (7)	11 (6)
Managing money	57 (32)	16 (9)	8 (4)	97 (55)
Organizing appointments/services	42 (24)	29 (16)	21 (12)	86 (48)
Paying for things required	143 (80)	7 (4)	5 (3)	23 (13)
Household tasks				
Cooking or preparing meals	11(6)	12 (7)	24 (13)	131 (74)
Washing and ironing	13 (7)	11 (6)	21 (12)	133 (175)
General housework	4 (2)	12 (7)	23 (13)	139 (78)
Repairs around the home	4 (2)	7 (4)	3 (2)	164 (92)
Shopping	6 (3)	12 (7)	18 (10)	142 (80)
Technical tasks				
Taking medication	64 (36)	43 (24)	12 (7)	59 (33)
Injections or suppositories	144 (81)	5 (3)	2 (1)	27 (15)
Changing dressings	141 (79)	7 (4)	4 (2)	26 (15)
Catheters or colostomy bags	163 (92)	4 (2)	1 (1)	10 (6)
Emotional support, listening and reassurance				
Night-time assistance				
Wakes during the night and needs help	Never 77 (43)	Some nights 45 (25)	Most nights 28 (16)	Every night 28 (16)

Table 2: Characteristics of the informal carers and the care recipients by carer health transition status –number of carers (%) unless otherwise stated

	Health compared to 1 year ago			p ^a
	Total N=178	Stable N=115	Worse N=63	
<u>Carer characteristics</u>				
Age – mean (sd)	61.7 (13.5)	54.4 (12.1)	66.7 (12.1)	<0.0001 ^b
Sex male	51 (29)	31 (27)	20 (32)	0.49 ^c
Born in Australia	124 (70)	85 (74)	39 (62)	0.12 ^c
Speak English at home	136 (76)	91 (79)	45 (71)	0.27 ^c
Education degree	31 (17)	22 (19)	9 (14)	0.54 ^c
Gross household income				
Missing data	40 (22)	27 (23)	13 (21)	0.67
<\$A37,000 per annum	59 (33)	37 (32)	22 (35)	(χ^2 1.5 df=3)
\$A37-77,999 per annum	44 (25)	26 (23)	18 (29)	
>=\$A78,000 per annum	35 (20)	25 (22)	10 (16)	
<u>Care-giving context</u>				
Relationship to care recipient				
Spouse	109 (59)	59 (51)	46 (73)	0.02
Child/grandchild/in-law	51 (29)	39 (34)	12 (19)	(χ^2 7.9 df=2)
Other	22 (12)	17 (15)	5 (8)	
Cohabiting	150 (84)	94 (82)	56 (89)	0.28 ^c
Other informal carers helping	126 (71)	82 (71)	44 (70)	0.86 ^c
Carer works (fulltime/part-time/casual)	52 (29)	37 (32)	15 (24)	0.30 ^c
Carer's household income declined	56 (31)	33 (29)	23 (37)	0.31 ^c
<u>Carer input</u>				
Care-giving duration (years) – mean (sd)	2.2 (3.0)	2.1 (3.0)	2.3 (3.0)	0.77 ^b
Care-giving tasks (hours/day) – mean (sd)	8.5 (5.7)	7.7 (5.3)	9.8 (6.2)	0.03 ^b
Have to be there (hours/day) – mean (sd)	19.6 (6.7)	19.6 (6.9)	19.7 (6.5)	0.94 ^b
<u>Patient characteristics and care needs</u>				
Age – mean (sd)	72.4 (13.4)	73.0 (13.3)	71.3 (13.8)	0.49 ^b
Sex male	104 (58)	64 (56)	40 (63)	0.34 ^c
Diagnosis cancer	159 (89)	104 (90)	55 (87)	0.61 ^c
Weeks to death - median (range)	14.6 (0.3-97.9)	14.6 (0.3-76)	13.6 (0.3-97.9)	0.59 ^d
Died within 1 month	32 (18)	23 (20)	9 (14)	0.42 ^c
Died at home	45 (25)	25 (22)	20 (32)	0.15 ^c
Needs emotional support (quite a bit/a lot)	109 (61)	72 (63)	37 (59)	0.63 ^c
Needs technical nursing care ^e	67 (38)	41 (36)	26 (41)	0.52 ^c
Needs help at night (most/every night)	57 (32)	34 (30)	23 (37)	0.40 ^c
ADL score ^f – mean (sd)	0.8 (0.9)	0.8 (0.9)	0.9 (0.9)	0.32 ^b
IADL number ^g – mean (sd)	8.2 (1.9)	8.1 (1.9)	8.3 (1.8)	0.36 ^b

Abbreviations: ADL activities of daily living; IADL instrumental activities of daily living.

a P value for the test of the difference between stable and worse.

b 2-sample *t* test.

c Fisher's Exact test.

d Log-rank test

e Injections, suppositories, dressings, catheter or stoma care.

f Mean of 7 items scored 0-3 (0=needs no help, 3=needs a lot of help).

g Number of IADL activities needs help with (0 to 11).

Table 3: Variance in SF-36 domain scores explained by statistically significant individual covariates for those with stable or worse health compared to one year ago

Health compared to 1 year ago	Stable (n=115)			Worse (n=63)		
	Model R ²	Variance explained ^d	p ^e	Model R ²	Variance explained ^d	p ^e
<u>Physical functioning</u>						
Base model ^a	0.15			0.28		
Base + country of birth				0.33	5%	0.05
Base + care-giving time ^b	0.18	3%	0.03			
Base + patient needs technical nursing ^c				0.36	8%	0.01
Base + patient died at home	0.20	5%	0.01			
<u>Role physical</u>						
Base model ^a	0.07			0.15		
Base + patient diagnosis cancer	0.11	4%	0.03			
<u>Bodily pain</u>						
Base model ^a	0.09			0.07		
Base + carer works				0.16	9%	0.02
Base + care-giving time ^b	0.13	4%	0.03			
Base + patient needs technical nursing ^c				0.23	16%	0.001
<u>General health perceptions</u>						
Base model ^a	0.01			0.02		
Base + patient needs help at night				0.12	10%	0.01
Base + patient died at home	0.06	5%	0.01			
<u>Vitality</u>						
Base model ^a	0.04			0.03		
Base + care-giving time ^b	0.08	4%	0.03			
<u>Social functioning</u>						
Base model ^a	0.02			0.01		
Base + income declined				0.13	12%	0.005
Base + patient needs emotional support				0.10	9%	0.01
Base + patient diagnosis cancer	0.10	8%	0.002			
<u>Role emotional</u>						
Base model ^a	0.02			0.01		
Base + language at home				0.07	6%	0.05
<u>Mental health</u>						
Base model ^a	0.04			0.02		
Base + language at home				0.16	14%	0.002
Base + patient needs help at night				0.10	8%	0.02
Base + patient died at home	0.08	4%	0.04			

a Includes age and sex as independent variables.

b Hours per day spent on care-giving tasks.

c Injections, suppositories, dressings, catheter or stoma care.

d Additional variance explained by variable

e p value for *t* test that parameter=0

Table 4: Multiple regression models for five SF-36 domain norm-based scores (population mean=50, Standard Deviation=10) by health transition status: coefficients and 95% CIs

Health compared to 1 year ago	Stable (N=115)			Worse (N=63)		
	Estimate	95% CI	p	Estimate	95% CI	p
Physical Functioning						
Intercept	49.35	46.20, 52.50	<0.0001	41.13	36.87, 45.40	<0.0001
<i>Carer variables</i>						
Age (mean centred ^a)	-0.18	-0.30, -0.06	0.004	-0.39	-0.55, -0.24	<0.0001
Sex male	4.24	0.67, 7.82	0.020	3.33	-1.47, 8.12	0.170
Born in Australia				4.77	0.19, 9.36	0.042
Care-giving time ^b	-0.39	-0.70, -0.09	0.011			
<i>Patient variables</i>						
Died at home	5.67	1.88, 9.45	0.004			
Needs technical nursing ^c				-5.97	-10.49, -1.45	0.011
R ²	0.24			0.40		
Bodily Pain						
Intercept	51.89	48.09, 55.69	<0.0001	43.89	39.86, 47.93	<0.0001
<i>Carer variables</i>						
Age (mean centred ^a)	-0.16	-0.31, -0.01	0.035	-0.31	-0.53, -0.10	0.005
Sex male	3.97	-0.41, 8.35	0.075	3.25	-2.13, 8.63	0.232
Works FT/PT/casual				-8.21	-15.38, -1.04	0.025
Care-giving time ^b	-0.40	-0.77, -0.03	0.032			
<i>Patient variables</i>						
Needs technical nursing ^c				-8.50	-13.56, -3.44	0.001
R ²	0.13			0.29		
General Health						
Intercept	49.95	47.90, 52.00	<0.0001	41.65	37.81, 45.50	<0.0001
<i>Carer variables</i>						
Age (mean centred ^a)	0.04	-0.08, 0.17	0.498	-0.13	-0.32, 0.05	0.155
Sex male	1.32	-2.28, 4.92	0.469	-0.04	-5.68, 5.60	0.989
<i>Patient variables</i>						
Died at home	4.99	1.13, 8.85	0.012			
Needs help at night ^d				-7.07	-12.53, -1.60	0.012
R ²	0.06			0.12		
Social Functioning						
Intercept	55.28	48.42, 62.15	<0.0001	35.55	28.42, 42.69	<0.0001
<i>Carer variables</i>						
Age (mean centred ^a)	0.08	-0.08, 0.24	0.313	0.21	-0.07, 0.50	0.134
Sex male	2.61	-2.10, 7.33	0.2743	4.04	-3.65, 11.72	0.297
Income declined ^e				11.01	2.65, 19.36	0.011
<i>Patient variables</i>						
Diagnosis cancer	-11.22	-18.32, -4.12	0.002			
Emotional support ^f				-8.02	-15.29, -0.75	0.031
R ²	0.10			0.20		
Mental Health						
Intercept	39.44	36.61, 42.27	<0.0001	25.74	19.64, 31.84	<0.0001
<i>Carer variables</i>						
Age (mean centred ^a)	0.15	-0.02, 0.32	0.086	0.06	-0.15, 0.28	0.553
Sex male	4.70	-0.27, 9.66	0.063	-0.85	-7.39, 5.68	0.795
Speaks English at home				10.82	4.02, 17.62	0.002
<i>Patient variables</i>						
Died at home	5.62	0.30, 10.94	0.039			
R ²	0.08			0.16		

Abbreviations: CI Confidence intervals.

a Mean age = 62 years.

b Hours per day spent on care-giving tasks.

c Injections, suppositories, dressings, catheter or stoma care.

d Patient needs help most nights/every night.

e Carer's household income declined because of care-giving.

f Patient needs quite a bit/a lot of emotional support.

Table 5: Adjusted^a mean norm-based SF-36 domain scores for carers by significant covariates in multiple regression analysis (population mean=50 sd=10).

Health compared to 1 year ago		Stable (N=115)	Worse (N=63)
Physical Functioning			
Age	52 years	50.5	47.1
	62 years	48.7	43.2
	72 years	46.9	39.2
Sex	Male	51.7	
	Female	47.4	
Born in Australia	Yes		44.6
	No		39.8
Care-giving time ^b	0 hours	52.0	
	8.5 hours	48.7	
Patient died at home	Yes	52.9	
	No	47.2	
Technical nursing ^c	Needed		39.5
	Not needed		45.4
Bodily Pain			
Age	52 years	51.2	42.3
	62 years	49.6	39.2
	72 years	48.0	36.1
Carer works	Yes		33.4
	No		41.6
Care-giving time ^b	0 hours	53.0	
	8.5 hours	49.6	
Technical nursing ^c	Needed		34.0
	Not needed		42.5
General Health			
Patient died at home	Yes	55.3	
	No	50.3	
Help at night ^d	Needed		34.6
	Not needed		41.6
Social Functioning			
Income declined ^e	Yes		42.8
	No		31.8
Patient diagnosis cancer	Yes	44.8	
	No ^e	56.0	
Emotional support ^f	Needed		32.1
	Not needed		40.1
Mental Health			
Speaks English at home	Yes		36.3
	No		25.5
Patient died at home	Yes	46.4	
	No	40.8	

a Adjusted for level of independent variables as per multiple regression models in Table 4 using total sample covariate levels (mean/proportion).

b Hours/day doing care-giving tasks (8.5=overall sample mean).

c Patient needs help with injections, suppositories, dressings, catheter or stoma care.

d Patient needs help most nights/every night.

e Carer's household income declined because of care-giving.

f Patient needs quite a bit/a lot of emotional support.