A Review of the Factors that affect the Quality of Life of Carer-Care Recipient Dyads

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This is an internal draft paper; please do not reference without permission from the author.

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Introduction

Informal care is an integral part of the care provided to people with long term conditions. It is estimated that five million adults in England provide informal care to sick, disabled or elderly adults, of which nearly half provide care for more than twenty hours per week (Department of Health Survey of Carers in Households, 2009/10). There is evidence that caregiving has a negative impact on carers’ physical and mental wellbeing (Schulz and Beach, 1999; Sorenson et al, 2006). The negative effects of caregiving on wellbeing are conceptualised as being caused by care-related ‘stressors’, such as physical tasks and manual lifting, or the emotional impact of difficult behaviours, aggression or dealing with loss or changes in the dynamics of a relationship (Greenwood et al, 2008; Sorenson et al, 2006; Schoenmakers et al, 2010; Zegwaard et al, 2011; Madsen et al, 2011; Stenberg et al, 2010). However, care does not occur in isolation; informal care occurs within existing relationships and is a complex, dynamic interaction between the carer and the person being looked after. This literature review will evaluate the evidence for the hypothesis that the mental and physical wellbeing of carers and care recipients are linked, and identify the factors that affect their combined quality of life.

There is an increasing interest in measuring the final ‘outcome’ of social care, as a means of evaluating and improving its effectiveness and quality. The policy document Transparency in Outcomes: a framework for adult social care (2011) describes the strategic focus on the final outcome of social care (i.e. the ultimate effect on service users and carers) rather than intermediate or process outcomes (Qureshi et al, 1998) which relate to the means by which that outcome state is achieved. The ‘ultimate effect’ can be conceptualised as ‘quality of life’ or ‘wellbeing’. To realise this policy strategy, the challenge of accurately measuring the outcome state (quality of life) of service users and their carers needs to be addressed.

Quality of life (QOL) is a complex, multidimensional construct and existing measures of QOL include a broad range of domains. The Adult Social Care Outcomes Framework (ASCOF) includes the Adult Social Care Outcomes Toolkit (ASCOT), a cross-sectional, self-report measure of social care-related quality of life (SCRQoL). ASCOT includes a number of domains that comprise a quality of life outcome state associated with social care. However, these domains, for example, satisfaction with social interaction or feeling safe, may be affected by factors that are outside the direct or indirect influence of social care services\(^1\). The main question to be addressed in the ‘Identifying the Impact of Adult Social Care’ (IIASC) study is that of ‘attribution’. How can we identify the impact of social care on the overall outcome state of the carer and/or care recipient, to the exclusion of other variables?

Although the identified articles focus on the overall outcome of an individual and/or the care ‘dyad’ without discussing the impact of social care on this outcome state, an overview

\(^1\) ‘Social care services’ refer to the services provided by local authorities and the voluntary sector that support and enable individuals with physical, mental or emotional impairments to continue to live independently.
of this literature will inform the specification of a model for the analysis of the data collected in IIASC, as well as identify research questions to be addressed in the IIASC study or in future research.

Aims
The aims of this literature review are to:

1. Gain an overview of the literature on the combined outcomes for care recipients and informal carers;
2. Inform the model for Stage Two of the IIASC study;
3. Develop further research questions on the nature of the impact of social care on carer-care recipient dyads.

Method
A literature search of the electronic databases Web of Science, PubMed, Social Care Online, PsychInfo and Cochrane for the period 2002 to 2012 was conducted in March 2012. The search terms were ‘carer’ and ‘care recipient’ combined with ‘quality of life’ or ‘outcome’ and ‘dyad’ (see Appendix 1 for full details). The search was limited to articles published in English.

The titles and abstracts were reviewed to exclude reviews that:

- Only reported studies of care recipients who were aged under 18 years old
- Reported studies of pharmacological and/or psychosocial interventions
- Measured the outcome (i.e. wellbeing, quality of life, stress/strain, mental or physical health) for only the carer or the carer recipient
- Focussed on the outcomes of paid care professionals/workers
- Report research of country-specific healthcare or social care policy outside of the UK, North America or Australia
- Reports of qualitative studies
- Did not include paired carer-care recipient dyads, or where one respondent’s outcome was measured by proxy report.

The reviews were considered relevant if they reported the outcome for paired carer-care recipient dyads. Where uncertainty regarding the relevance of the article arose, the full text was obtained and read. Although the articles were not evaluated separately, all of the articles included in the review were published in peer-review journals. This was taken as a measure of quality of the research.

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2 Dyads are units of interpersonal interaction, for example, the interaction between a husband and wife. Dyads may be set within a wider network of interpersonal relationships, or may be members of other dyads, but this concept is widely used by social scientists in the analysis and interpretation of data collected from non-independent pairs (Kenney et al, 2006).
Results

A total of 293 articles were identified in the literature search (see Appendix 1 for full details of the search methods). The search results were saved in an Endnote file, and the abstracts were reviewed based on the inclusion/exclusion criteria. Of the 283 articles, 260 articles were excluded. Eight (8) further studies were identified from an associated literature search of the effect of the quality of the relationship with the care recipient on the carers’ quality of life. In total, 31 articles are considered in the discussion.

Table 1. Study Selection Process.

<table>
<thead>
<tr>
<th>Total citations: 283</th>
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<tbody>
<tr>
<td>Removed 8 duplicates</td>
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<tr>
<td>Number of articles: 283</td>
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<tr>
<td>Exclusion criteria:</td>
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<tr>
<td>46 reported outcomes for the carer or care recipient, rather than outcomes for both</td>
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<td>17 reported proxy measures of outcome for the care recipient</td>
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<td>55 reported studies of interventions</td>
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<td>2 reported studies where the care recipient is aged under 18 years</td>
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<td>1 reported a study where different outcome measures were used for the carer and care recipient</td>
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<td>5 Qualitative Studies</td>
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<td>4 Theoretical/Clinical Guidance Papers</td>
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<tr>
<td>2 not published in peer-review journals</td>
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<td>4 reported the development of outcome measures</td>
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<td>41 removed as they were not relevant to the research question</td>
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<td>75 removed in the manual filter of PsychInfo references (i.e. not relevant to the research question)</td>
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<td>Number of identified articles: 31</td>
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Discussion

Although the literature on the impact of informal care on ‘quality of life’ tends to focus on outcome of the informal carer, there is evidence that the outcomes of carers and care recipients are associated. Significant positive correlations have been found between the outcomes of carers and care recipients on measures of mental and physical health (SF-12 or 36) (Evangelista et al, 2002; Myaskovsky et al, 2005), distress (Kim et al, 2008), stress (Ostwold et al, 2009) and depression (Siminoff et al, 2010; Vangel et al, 2011; Schrag et al, 2006). Among care recipients with cancer and their informal carers, studies found an association between the carer and care recipient scores of distress (Matthews et al, 2003; Ko et al, 2005) and fear of disease recurrence (Hodges et al, 2009).

However, there is also evidence that the outcomes of carers and care recipients, as measured using SF-36 (Sarna et al, 2006; Northouse et al, 2002) and depression or general
health (Lyons et al, 2002), are not correlated. This seems to be due to underlying differences in carers’ compared to care recipients’ quality of life. For example, care recipients with heart failure report a significantly poorer quality of life in terms of emotional wellbeing than their caregivers (Evangelista et al, 2002); carers report lower quality of life than care recipients with dementia (Hurt et al, 2008) and lung cancer (Sarna et al, 2006); and, carers of care recipients with cancer in remission report significantly higher levels of concern about disease recurrence (Hodges et al, 2009), distress (Matthews et al, 2003) and anxiety (Price et al, 2008) than care recipients. These significant differences between carer and care recipient QOL are mediated by condition-specific factors that independently impact the carer or care recipient. Northouse et al (2007) found that care recipients with advanced cancer had significantly lower physical health, but significantly higher mental health, than carers. In contrast, there was no significant difference between carers’ and care recipients’ mental health quality of life at early or mid-progression stages of the disease. The progression of the disease has different, independent effects on the carer and care recipient.

Differences in QOL between carer and care recipient may also be mediated by personal characteristics that differ between the carer and care recipient. Kim et al (2008) found that there was a significant association between the quality of life of male care recipients with prostate cancer and their female spousal carers. In contrast, the association between self-report of QOL by carers and care recipients did not reach significance for female care recipients with breast cancer and their male spousal carers. These results may be interpreted in two ways. This difference may be due to the differences in symptoms and impairment caused by prostate compared to breast cancer, or due to the gender difference of the carer/care recipient between the two groups. The study provides some support for the latter interpretation; being in a dyad with dissimilarity of distress levels between carer and care recipient was associated with poorer mental health outcomes for females only. In contrast, psychological distress in women (either carers or care recipients) is negatively associated with the man’s physical health. These findings suggest that there may be an interaction of gender with the mediating factor of emotional distress on the outcomes of individuals within the dyad and the dyad outcome.

The association between carer-burden and the concordance or discordance between carer and care recipient self-ratings of QOL has been investigated in a Swedish study of stroke survivor and carer dyads (Bergstrom et al, 2011). Dyads with a high combined QOL were associated with lower carer burden and dyads with lower combined QOL were associated with higher carer burden. Among the discordant dyads, there were more dyads with the carer rating their own quality of life as lower than the care recipient’s self-report of quality of life, than the reverse. These carers also reported significantly higher carer burden compared to carers in congruent, satisfied dyads. Satisfied carers in discordant dyads also reported higher carer burden than carers in congruent, satisfied dyads but this trend did not reach significance. This study suggests that there may be an association between the dyad’s
joint QOL outcome and carer burden, and that the discordance of QOL ratings between the carer and care recipient is associated with increased carer burden.

In summary, the identified literature highlights some key principles to understanding the combined outcome of carers and care recipients (see figure 1):

- **Carer and care recipient outcomes may be associated (i.e. they are ‘interdependent’). This could be due to:**
  - External factors in the social, relational or physical environment shared by the carer and care recipient which independently influence the outcome of the carer and the care recipient; or, alternatively,
  - There may be a direct impact of the carer or care recipients’ mental/physical health or behaviour that influences the outcome of the other partner through interpersonal interactions or relationship.
- **In addition, there may be factors (for example, perceived burden, health or gender) that directly and independently affect one individual in the dyad; this will lead to divergence in the reported outcomes of the carer and care recipient.**
- **The outcomes of care recipients and their carers may be ‘discordant’ or mismatched;**
  - due to independent external factors on the carer and care recipient; or,
  - due to factors that impact both carer and care recipient, but in different ways. The outcome of one individual may improve to the detriment of the partner’s outcome.
- **Understanding the nature of this ‘discord’ may be important in interpreting joint outcomes.**
The literature identified a number of different factors by which the combined outcome of carers and care recipients are influenced.

1. The nature of the physical, mental or emotional impairment experienced by the dyad (for example, condition-related symptoms, impairment or disability experienced by the care recipient and/or the carer, and the services or professional care provided to mitigate them);
2. Relationship factors (for example, relationship quality and mutuality, indirect effects of one partner's mental health on the other, and shared coping strategies and support); and
3. Other factors (for example, age and financial worries) that may directly and independently contribute to the outcome of the carer or care recipient.

1. Care Recipient’s Health Condition and Symptoms
The combined outcome of the carer and care recipient has been found to be associated with severity of disease (Hooley et al, 2008; Northouse et al, 2007), the impact of the care recipient’s condition on everyday life (Bergstrom et al, 2011) and the care recipients’ functional capacity and cognitive ability (Ready et al, 2008). The care recipient’s (or indeed carers’) mental and physical health may directly influence their own quality of life (Ostwold
et al, 2009). In addition, there may also be indirect psychological or emotional consequences for the individual or their partner that affect quality of life. For example, carers’ concerns about cancer-related symptoms have been shown to be a significant predictor of carer distress (Le et al, 2004; Hodges et al, 2009) with a similar within-individuals effect for care recipients (Hodges et al, 2009). A study by Northouse et al (2002) investigated the relationship between emotional distress, quality of life and care recipient symptom severity and found no significant, direct pathway (association) between the self-report of symptoms by care recipients with cancer and the quality of life of carer or care recipient. However, the care recipients’ report of symptoms was significantly associated with the care recipients’ feelings of hopelessness and uncertainty, and the carers’ negative appraisal of caring. These in turn were significantly associated with the care recipients’ and carers’ outcome. This suggests that there is an indirect link between care recipient symptoms and the quality of life of care recipient and carer mediated by the emotional reactions of the care recipient and carer respectively.

This indirect effect of disease symptoms via the emotional response of carer/care recipient on their quality of life may also be influenced by the quality of the carer-care recipient relationship. Morgan et al (2011) found that self-reports of higher relationship quality was associated with reduced report of pain by care recipients with cancer. Furthermore, the self-report of pain by care recipients with cancer was significantly associated with the care recipients’ quality of life, although there was no direct relationship with the partners’ quality of life. A tentative interpretation of these results is that relationship quality indirectly impacts care recipient, and thus dyad, outcomes by acting as a ‘protective factor’ in the care recipients’ appraisal of the symptoms of disease.

In contrast to the wider literature on the impact of the behavioural and physical symptoms on carers’ outcomes, the literature search reported here identified only one study of outcomes for care recipients with dementia and their carers (Hurt et al, 2008). This is due to the inclusion/exclusion criteria of the search which ensures that only studies where quality of life measures from both the carer and care recipient by self-report are reported are included. Despite the inherent challenge of obtaining quality of life measures directly from care recipients with dementia, one study of care recipients with dementia was included although the self-report measure was obtained from only 25% of the sample (Hurt et al, 2008). The study found that the behavioural and physical symptoms of dementia (BPSD) were associated with the quality of life of both care recipients and carers. However, different aspects of BPSD had an impact on care recipients compared to carers. Carers’ QOL was inversely related to depression and irritability in the care recipient, whereas the care recipients’ QOL was associated with delusions and apathy. As quality of life (in 75% of cases) and the BPSD were measured by carer report, the findings of this study should be interpreted with caution in the context of this review. However, they contribute an insight into the impact of BPSD on the joint outcome of care recipients with dementia and their carers.
Overall, the literature shows that care recipients’ symptoms directly affect their own quality of life; physical health and mental health are key domains in the concept of ‘quality of life’. There may be a weaker indirect association between care recipients’ symptoms and carers’ quality of life and this may be mediated by social and/or emotional factors, such as relationship quality, appraisal of the caring role and carer burden.

2. Relationship Quality

The nature of informal care means that there is a close relationship between the carer and care recipient. This often occurs within the context of an existing relationship. The relationship between the carer and care recipient can be conceptualised as a shared ‘relational environment’, the experience of which may have an effect on outcome. The experience of support and encouragement, or indeed criticism or conflict, may act to enhance or be detrimental to an individual’s quality of life.

Relationship mutuality, a measure of the reciprocity and equity within a relationship, is a significant predictor of life satisfaction for both stroke survivors and their spousal carers (Ostwold, 2009). Care recipients’ report of relationship mutuality with their carer was a significant predictor of care recipient self-report of stress. In contrast, carers’ report of mutuality was not associated with carer stress; other factors, such as gender, social support, coping and preparedness for the carer role were significant predictors (Ostwold et al, 2009). Self-report of relationship strain (a negative aspect of relationship quality, as opposed to mutuality which is seen as a positive, desirable aspect of a relationship) was associated with carer depression. Dyads whose caregivers perceived high relationship strain were more likely to report more caregiving difficulties and experience a greater discrepancy between carer and care receiver rating of the difficulties of caring (Lyons et al, 2002). This suggests that there is an interaction between the quality of the carer-care recipient relationship, the appraisal of caring by the carer and care recipient, health status, and the individual and joint outcomes of carer and care recipient.

In addition to ‘mutuality’ or ‘relationship strain’, the quality of adult relationships can be conceptualised using attachment theory (Bowlby, 1969). The nature of the attachment of an individual to another person can be summarised as ‘anxious’ (characterised by a fear of getting too close), ‘avoidant’ (characterised by withdrawal, often as a protective mechanism) or ‘secure’ (characterised by an accepting and feeling comfortable with the ‘give and take’ nature of a relationship). In a study of care recipients with cancer and their carers, it was found that care recipients who did not feel comfortable being close to their caregivers (high attachment avoidance) reported poorer mental health. In contrast, their carers reported better physical health than the carers of care recipients with secure or anxious attachment. Anxious attachment in carers was associated with poorer mental health outcomes for both carer and care recipient (Hall et al, 2012).

In a study of the impact of cohesiveness, conflict and emotional expression within a family on carer/care recipient outcomes, Siminoff et al (2010) found that the self-reported ‘family
environment’ was associated with depression in both care recipients with lung cancer and their carers. Carer depression was significantly associated with lower reports of familial expressiveness. In multivariate analysis of the data, it was found that blaming the care recipient (either self-blame by the care recipient or blame by the carer) was significantly associated with higher levels of self-reported depression in both care recipients and their carers. The study also found that a higher care recipient report of conflict was associated with higher caregiver depression scores. In a study by Ostwold (2009), it was found that carers’, but not care recipients’, outcomes were significantly associated with the reported availability of social support from people outside of the carer-care recipient dyad. This evidence suggests that the wider social and relational environment in which the carer and care recipient interact may have an impact on outcomes, particularly those of the carer.

In the literature on carer quality of life, coping has been found to be associated with carer outcome (Rand and Fox, 2012). ‘Coping’ refers to psychological strategies adopted to limit the impact of a traumatic or difficult situation on an individual’s internal mental state. Although coping is intended to play a ‘protective’ function, some coping strategies appear to be less effective than others among informal carers (Gottlieb and Wolfe, 2002; del-Pino Casado et al, 2011). In multivariate analysis of measures of QOL and coping, care recipients’ and caregivers’ coping strategies were more consistently related to their own QOL than to each other’s (Myaskovsky et al, 2005; Kershaw et al, 2004), however, different coping styles were associated with better quality of life outcomes for carers compared to care recipients. Active coping and ‘acceptance’ were related to higher quality of life scores on vitality in care recipients, but support seeking and avoidance were associated with higher quality of life in carers (Myaskovsky et al, 2005).

In addition to the within-individual impact of coping strategy on quality of life, there is also some tentative evidence for an across-individual impact of coping on quality of life. It would logically follow that if one (or both) individual(s) in the dyad copes ineffectively, this will impact the other member of the dyad. This effect could be direct (e.g. shared support or coping, or lack thereof) or indirect (e.g. through an increase in experienced psychological distress, which may adversely affect relationship quality, the personal and emotional resources available to support the other individual and ultimately the other person’s quality of life). Myaskovsky et al (2005) found that, although carer coping strategy did not significantly predict care recipient quality of life, the care recipients’ coping strategy was associated with carer quality of life. Specifically, the use of self-blame by care recipients predicted poorer outcomes for their carers; active coping, acceptance and support seeking were positively correlated to higher carer quality of life scores. Kershaw et al (2005) also found that carer coping was not significantly associated with care recipient quality of life but found a significant interaction between carer avoidant coping, care recipient distress and care recipient quality of life. For care recipients who reported higher levels of distress, the use of avoidant coping by their carer was significantly associated with poorer care recipient quality of life. There was a similar interaction between carer avoidant coping, care recipient
distress and carer quality of life. The negative correlation between carer avoidant coping and carer QOL is weaker in dyads where the care recipients’ reported distress is lower. Although these studies do not support an association between carer coping and care recipient quality of life, Ko et al (2004) found that carer social problem-solving (which can be conceptualised as a specific form of coping and also a factor that influences the quality of interaction between carer and care recipient) can influence the care recipients’ positive/negative mental state. Dysfunctional social problem-solving in spousal carers was found to be indirectly (via an association with increased spousal carer distress) associated with increased care recipient distress. Constructive problem solving was directly associated with reduced care recipient distress (Ko et al, 2004).

In a study of ‘sense making’, Pakenham (2008) found that shared sense making may affect the joint outcome of carer and care recipient. ‘Sense making’ can be conceptualised as a form of coping in the face of a traumatic event or difficult situation and involves both comprehension of the situation and seeking to find benefit and meaning in the situation. These processes play an important role in adjustment to caregiving and may reduce distress experienced by the carer and care recipient. The study of 220 dyads of care recipients with Multiple Sclerosis (MS) and their carer found that self-reports of sense making by carers was associated with sense making by care recipients, which can interpreted as ‘shared sense making’ as a single social unit. Carer sense-making was associated with higher life satisfaction in both carer and care recipient. Care recipient sense-making was associated with their life satisfaction, but the association with carer life satisfaction did not reach significance. In a study by Kim et al (2011) it was found that the ability to find meaning and peace in a situation was a strong correlate of an individual’s (carer or care recipient) mental health outcome. The spiritual wellbeing (SWB), a measure of the ability to find peace, meaning or faith, of one partner in the dyad was positively related to his or her partner’s physical health. The study also found across individual associations between characteristics of one individual in the dyad and the outcome of their partner; the SWB of one individual in the dyad was associated with their partner’s outcome.

Coping could be conceptualised not only as a form of protection of self from the adverse psychological impact of trauma, but also as protection of significant others. In an extension of this approach, ‘buffering’ is where an individual hides or suppresses negative thoughts in order to protect someone else. A study by Langer et al (2009) investigated the links between ‘buffering’, relationship quality and quality of life in transplant care recipients and their carers both before and after the transplant operation and found that carers used buffering strategies more than care recipients. A negative association between the use of buffering by carers and care recipients and their self-reported relationship satisfaction and mental health was found. This suggests that ‘buffering’ can be costly both in terms of relationship satisfaction and outcomes.
Self-report of relationship satisfaction is associated with the carer and care recipient motivation for buffering. An altruistic motive (i.e. to protect their partner) in care recipients is associated with an increase in their own, but a decrease in their carers’, self-report of relationship satisfaction. In contrast, carers who were motivated to protect their partner reported a decrease in relationship satisfaction over time. This suggests that a self-oriented motivation for using buffering by carers may protect against dissatisfaction with the relationship with the care recipient (Langer et al, 2009). Overall, these findings indicate that the motivation for use of buffering can have an effect on their own and their partner’s outcomes in terms of satisfaction with their relationship.

3. Other Factors
The literature on the factors that affect carers’ quality of life has established that a wide range of physical, social and psychological environmental factors, as well as demographic characteristics and resource inputs, are associated with the outcome of informal carers (Rand and Fox, 2012). The literature identified in this review provides evidence that some of these factors also affect the outcomes of the care recipient and thus the care dyad. Financial worries are associated with poorer quality of life for both carers and care recipients (Morgan et al, 2011). Higher self-reported levels of informational and emotional support are associated with better mental health outcomes for care recipients through a direct effect on their own mental health. In addition, there was an effect of the care recipients’ report of social support on the outcomes of their carers, but not vice versa (Thomson et al, 2012).

Limitations
Due to time constraints, a single researcher reviewed and selected the articles for inclusion/exclusion. In addition, the articles were not screened or assessed for quality, apart from the inclusion criteria of publication in a peer-review journal.

Conclusions
This rapid review of the literature has identified associations between the following factors and the outcomes of care recipients and their carers:

- Disease symptoms/severity via psychological impact (anxiety, depression) on carer and care recipient;
- Relationship quality (mutuality/reciprocity, attachment);
- Family environment/conflict;
- Social support;
- Coping, ‘shared sense making’ and ‘buffering’;
- Other shared factors (e.g. financial worries).

In studies that employed structural equation modelling, it was found that the outcomes of the individuals in the dyad are most strongly influenced by factors that impact directly upon
them. The associations between individuals in the dyad were generally weaker or did not reach significance. This would suggest that although the outcomes of carers and their care recipients are linked, there are also independent factors that influence the outcomes of each individual independently of their partner (carer or care recipient).

The literature review has identified a number of research questions that have yet to be considered in the literature on the outcomes/quality of life of carer-care recipient dyads and which may be addressed by either using the IIASC dataset or through future research in the Quality and Outcomes of Person Centred Care Research Unit (QORU):

- How do services designed to help the service user influence carers’ outcome and/or the joint service user/carer outcomes?
- What is the impact of carer services on joint outcomes? (I.e. do carer services have an impact on the service user via their effect on the carers’ mental or physical wellbeing?)
- Are there any ‘trade-offs’ in outcome? (I.e. are some social care services or patterns of service provision associated with improved service user outcome to the detriment of the carer? Or vice versa?)
- What is the pattern of discord between carers’ and service users’ self-report of quality of life? Is discord in QOL ratings associated with the impact (‘gain’ or ‘value added’) of social care services?
Bibliography

* Included in the Literature Review.


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Ostwald SK, Bernal MP, Cron SG, Godwin KM (2009) Stress Experienced by Stroke Survivors and Spousal Caregivers During the First Year after Discharge from Incare recipient Rehabilitation, *Topics in Stroke Rehabilitation, 16*, 2, 93-104. *


Weaver KE, Rowland JH, Augustson E, Atienza AA (2011) Smoking Concordance in Lung and Colorectal Cancer Care recipient-Caregiver Dyads and Quality of Life, *Cancer Epidemiology Biomarkers & Prevention*, 20, 2, 239-48. *


Appendix 1 – Search Terms

PubMed (NLM)
((("Caregivers"[Majr]) AND (care recipient OR "care taker" OR "care recipient" OR "care receiver") AND (outcome OR "quality of life" OR “well being”)) AND (joint OR combined OR dyad OR dyadic)) Limits: English, All Adult: 19+ years, published in the last 10 years

67 results

Cochrane (Wiley)
#1 MeSH descriptor Caregivers explode all trees
#2 care recipient OR "care recipient" OR "care taker" OR "care receiver"
#3 outcome or "quality of life" or "well being"
#4 joint or dyad or dyadic or combined
#5 (#1 AND #2 AND #3 AND #4), from 2002 to 2012

26 results

Web of Science (Thomson Reuters)
#1 Topic=(carer* or caregiver*) NOT Topic=(intervention* or child*)
AND
#2 Topic=(care recipient or "care recipient" or "care taker" or "care receiver") NOT Topic=(intervention* or child*)
AND
#3 Topic=(outcome* or "quality of life" or "well being") NOT Topic=(intervention* or child*)
AND
#4 Topic=(dyad or dyadic or joint or combined) NOT Topic=(intervention* or child*)
Refined by: Countries/Territories=( USA OR SCOTLAND OR CANADA OR ENGLAND OR AUSTRALIA OR UK )
Timespan=2002-2012

80 results
Psychinfo
As above
2002-2012
Adults 18+

99 results

* Of which 24 were exported into Endnote; the remaining 75 articles were excluded based on a review of the titles/abstracts.

Social Care Online
(topic="carers") and (freetext="care recipient" or freetext="care recipient" or freetext="care taker") and (freetext="dyad" or freetext="dyadic" or freetext="joint" or freetext="combined") and (freetext="outcome*" or freetext="quality of life" or freetext="well being") and (publicationdate>2002)

11 results