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Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: Development and piloting of a new survey tool

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Abstract

Background: Family caregivers play an important role in the care of patients receiving palliative care, yet little is known about the financial impact of family caregiving in this context. A lack of existing validated tools for collecting data on the costs of family caregiving in palliative care has resulted in a weak and limited evidence base. The aim of the study was to describe the development and initial piloting of a new survey tool which captures data on the costs of family caregiving in palliative care: The Costs of Family Caregiving (COFAC) questionnaire.

Methods: Development and piloting of the COFAC questionnaire involved two phases: (1) Questionnaire development based on published evidence and cognitive interviews with service users and; (2) Validity testing involving expert review and piloting with bereaved caregivers.

Results: Questionnaire content was generated from previously published research and related to work related costs, carer time costs, and out of pocket expenses. Two group cognitive interviews with 15 service users refined content of the draft questionnaire. Face validity was established through expert review with nine academics and clinicians. Piloting with eight bereaved caregivers established acceptability and feasibility of administration.

Conclusion: The COFAC tool has been shown to be valid, acceptable to bereaved caregivers and feasible to administer. The COFAC questionnaire is recommended for economic research in palliative care which seeks to capture data from a broad societal perspective which includes family caregiver costs.

BACKGROUND

Family caregivers play an important role in the care of patients approaching the end of life. Factors including demographic shifts, policy directives and a focus on home as the preferred place of death have resulted in an increasing proportion of palliative care provision shifting from inpatient facilities to community and family caregivers. [1,2] The expertise offered by family carers and wider communities is widely acknowledged, however little is known about the financial impact of family caregiving specifically within a palliative care context. The financial costs of caregiving are known to be substantial; a recent UK report estimated the economic value of the contribution made by carers is now £132 billion per year. [3] A recent systematic review on the costs of family caregiving at the end of life identified a limited evidence base but suggested costs could be significant. These costs comprised both direct financial costs but also assumed or indirect costs incurred through lost employment, caregiver time investment and lost opportunities for leisure. [4] A review of financial stress and strain in terminal cancer found that financial stress was a common consequence of terminal cancer and featured in the top three concerns of patients. [5] The effects of financial burden are notable and have been found to include increased worry, difficulties coping, family conflict, caregiver strain and an inability to function 'normally'. [6]

Despite this mounting evidence base, research on the economic impact of family caregiving in palliative care remains limited. A recent study from Canada noted the narrow viewpoint that the majority of economic analyses in palliative care have taken, highlighting that they are generally limited to the measurement of publicly financed care without consideration of the considerable costs faced by other stakeholders, including patients and their families. [7] This is despite evidence that informal care has been found to be a significant substitute for formal long-term care. [8] In the UK, the National Institute for Health and Care Excellence (NICE) does not routinely include patient and family caregiver costs as part of economic evaluations, hence this perspective generally remains unaccounted for in UK cost-effectiveness evaluations. [9] A recent systematic review explored which cost components are relevant for economic evaluations of palliative care. [10] 'Informal and family care' was identified as a key cost domain, however very few economic evaluations have included this perspective and there is limited methodological guidance which incorporates this viewpoint.

A recent review of methodological approaches which capture the financial costs of family caring in palliative care identified various data collection tools designed to capture this data. However, no single tool was identified with the sole purpose of exploring these costs. [11] All of the approaches were aimed at capturing the wider costs related to end-of-life care, rather than costs related specifically to family caregiving. As a consequence, most approaches only explored family caregiving costs in the context of a wider financial impact. For example, Guerriere et al (2011) developed the Canadian Ambulatory and Homecare Record (AHCR). [7] The AHCR is a tool which measures comprehensive costs related to end-of-life care from a broad societal perspective, however it contains only four items designed to capture costs incurred by patients and family. [7] Aside from the AHCR, most previously developed data collection tools also lack data on reliability and validity and thus the psychometric properties are unknown. [11] Given the lack of existing validated tools for collecting data on the costs of family caregiving in palliative care, the aim of this study was to describe the development and initial piloting of a new survey tool which captures the costs of informal family caregiving in palliative care: The Costs of Family Caregiving (COFAC) questionnaire.

METHODS

The purpose of the questionnaire was to capture comprehensive data on the financial costs associated with family caregiving in palliative care. The intention was to capture all cost data for the

one-month period prior to completion, with options for monthly repeat administration for six months or until the patients death. 'Cost data' comprises all financial and economic costs incurred by family caregivers as a result of caring for a patient receiving palliative care. Family caregivers are defined as *'carers, who may nor may not be family members, who are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management'*. [12] Key features of the questionnaire were that it should take account of the sensitivity of the subject, be easy to use and comprehend (including for older people and those with disabilities) and be valid and reliable. Development and piloting of the COFAC questionnaire occurred in two distinct phases: (1) Questionnaire development and; (2) Validity testing and piloting. The process of questionnaire development is outlined in figure 1.

Phase 1: Questionnaire development

Questionnaire development involved four stages: systematic review; qualitative research; adaptation of an existing tool and; cognitive interviews with service users.

Generic content of the questionnaire was informed by two previously published systematic reviews which aimed to identify literature on the financial costs of caring for family members receiving palliative/end of life care [4] and identify previously developed approaches which capture these costs. [11] Specific questionnaire content was further informed by a previously published qualitative interview study with 30 bereaved caregivers who had provided care for a patient receiving palliative care. [6,13] Caregivers in this study reported on financial costs in relation to both day-to-day care and emergency situations, other people involved in caring, related costs and whether financial assistance had been received from elsewhere. [6]

Additional content was then added to the draft questionnaire through adaptation of items from an existing tool from the ALS-CarE study. ALS-CarE is an on-going study which aims to map and compare services for patients with Amyotrophic Lateral Sclerosis (ALS) across Europe, funded by the EU Joint Programme – Neurodegenerative Disease Research. [14] The ALS-CarE survey tool aims to capture data on costs related to caring for a patient with ALS. Patients with ALS tend to require high levels of support and care in response to their complex needs [15], therefore the comprehensive nature of the ALS-CarE tool made it useful in identifying additional areas of cost.

Following the development of a draft questionnaire cognitive interviewing techniques were used to refine content. Cognitive interviewing was used to identify and analyse sources of response error in the questionnaire, by focusing on the cognitive processes respondents use to answer questions. Specifically, the purpose of the method was to examine whether subjects understood the questions, both consistently across subjects and in the way intended by the researcher. [16] The draft questionnaire was tested during group cognitive interviews with service users. Service users were recruited using convenience sampling methods from two existing service user groups attached to UK university research groups, comprising patients and bereaved carers with experience of cancer and/or palliative care services. Concurrent and retrospective verbal protocols were used [16; 17] in which the respondents were asked to "think aloud" as they considered each question. The concurrent protocol was used to collect data during the task, whilst the retrospective protocol gathered data after the task as the participant walked back through the steps they had taken previously. Participants also responded to prompts from the interviewer regarding clarity, comprehension and sensitivity of the questions. All service users provided verbal consent.

Phase 2: Validity testing and piloting

The aim of this phase was to test the validity of the draft COFAC questionnaire and pilot it for acceptability and feasibility. Reliability was not assessed as part of this study but will be addressed in future work. As there are no existing validated instruments for measuring family caregiver costs in palliative care, we developed a multidimensional approach to validating the COFAC questionnaire. This involved two stages: expert review and piloting with bereaved caregivers.

Expert review was undertaken to establish face and content validity. [18] This phase involved consultation with a range of international experts recruited using convenience sampling methods, from existing academic and clinical networks known to the authors. Consultation took place using an e-mail protocol which asked experts to give their opinion about whether questions measured the construct under study. Questions were then ranked as *appropriate, needs revision*, or *should be removed*. Where more than two experts identified questions as 'needing revision' or 'should be removed' consensus was reached by discussion between experts and CG. Experts also examined the questionnaire for potential problems, recommended possible remedies (rewording, reordering), and noted any additional areas for questioning. Comments and advice from experts were incorporated into a final revised version of the questionnaire.

Following expert review, piloting was undertaken to establish feasibility and acceptability. Bereaved family caregivers were recruited using convenience sampling methods from the two service user groups described in phase 1. We chose to pilot with bereaved caregivers as they were able to comment on financial outgoings throughout the whole illness trajectory and into bereavement. Participants provided written consent and were asked to select their preferred method of completion for the pilot, either face to face or over the telephone. The draft COFAC questionnaire was then completed with a researcher as a structured interview. Piloting sought to assess acceptability and feasibility by establishing: average completion time; determining frequency of non-response of items; assessing method of administration and; assessing data management issues such as coding and data entry. [19] All aspects of questionnaire development and piloting took place between Jan – May 2016.

Figure 1 about here

RESULTS

Phase 1: Questionnaire development

Initial questionnaire content was generated from two previously published systematic reviews [4,11] which identified costs in three key domains: work related costs, carer time costs, out of pocket expenses. These three domains provided the initial structure for the questionnaire. The domain 'work related costs' contained four questions and related to changes in the caregivers employment which occurred as a result of caregiving, and the associated costs of this. The domain 'carer time costs' contained five questions related to the time dedicated to caregiving, which can subsequently be assigned a monetary value using the human capital approach. The domain 'out-of-pocket expenses' contained ten questions related to direct outlays of money by caregivers e.g. travel costs, over the counter medications. [20] Each domain was populated with individual questions. Where appropriate questions were adapted from the ALS-CarE questionnaire [14] or from studies included in the systematic reviews. [4,11] New questions were also generated from our previous qualitative interview study with 30 bereaved caregivers. [6,13] Data from these studies identified a range of

direct and incurred costs; new questions were developed based on these constructs and were added to the draft questionnaire.

Fourteen questions on demographic and socio-economic status were added to provide general context. A number of standardised measures of socio-economic status (SES) were used to develop SES content. Postcode was included in order to be indexed to the Indices of Multiple Deprivation 2015 [21], which provides statistics on relative deprivation in small areas in England. Participants employment status and most recent occupation were also included in order to identify National Statistics Socio Economic Classification (NS-SEC), using the ONS Occupational Coding Tool [22] which codes occupations according to the ONS Standard Occupational Classification (SOC) Hierarchy. [23] Further questions on age, gender and ethnic group were included in order to provide general demographic content.

Two group cognitive interviews were held with a total of 15 patient (n = 7) and carer (n = 8) service users to refine content of the draft questionnaire and analyse potential sources of response error. Feedback from cognitive interviews related to: improved clarity around wording; identification of additional areas of cost to be included; removal or rewording of questions deemed sensitive; and the inclusion of appropriate introductory information. Following cognitive interviews a final draft questionnaire was produced for piloting (see 'on-line only supplementary material' for the full version of the questionnaire).

Phase 2: Validity testing and piloting

Nine individuals provided expert review. Five were academic researchers in palliative care; two were health economists; one a member of hospice staff and one a researcher in socio-economic deprivation. In order to establish face validity questions were ranked by experts as 'appropriate', 'needs revision', or 'should be removed'.. Following expert review no questions were removed but nine were revised. Experts also recommended the inclusion of additional or modified response options on a number of items, to enhance validity and reliability.

Sixteen bereaved caregivers were invited to be involved in the piloting phase, of these eight consented to participate. The mean age of the pilot participants was 66 years and five (63%) were female. Four participants (50%) completed the questionnaire face to face and four (50%) completed it over the telephone. Mean completion time for the COFAC questionnaire was 37 minutes (range: 19 - 60 minutes). Completion times for face to face and telephone methods of administration were comparable. . Frequency of non-response of items on the questionnaire was zero due to the questionnaire being researcher administered. Both methods of administration were acceptable to participants and were feasible to administer. However, it should be noted that as pilot participants were able to choose their preferred method of administration, this will have aided acceptability. Data from completed questionnaires were entered into SPSS Statistics 21 and no issues were identified with data management or coding.

DISCUSSION

This study describes the development and piloting of a new questionnaire to measure the costs of family caregiving in palliative care. We have demonstrated the validity of the COFAC questionnaire, established its acceptability for participants and demonstrated feasibility of administration. The COFAC tool is, to the best of our knowledge, the first questionnaire which seeks to capture

comprehensive and detailed information on the costs of family caregiving in palliative care. Economic research in palliative care has been criticised for failing to account for costs to patient and family [7] yet until now there have been no tools available to accurately capture these costs. The development of the COFAC questionnaire may allow economic evaluations in palliative care to consider a wider perspective and to include a societal viewpoint where appropriate.

The COFAC questionnaire considers costs in three key domains: work related costs; caregiver time costs and; out of pocket expenses. These key domains capture both direct and indirect financial costs. Direct costs are those which represent direct outlays of money and are the more visible costs associated with caregiving e.g. transport, aids and appliances, prescriptions or over the counter medications. Indirect costs are those which are incurred or assumed and include caregiver time and costs related to changes in employment. Whilst it is acknowledged that both direct and indirect costs are important, attributing a monetary value to indirect costs is potentially complex. We recommend the use of the Human Capital Approach for calculating the cost of time lost from employment, [20] this approach applies current average wages by age and sex categories to lost labour market time. Although this method reflects inequities in wage rates [24] there is general support for its use. [25] Alternatives include the friction method based on the value of production lost rather than wages per se, but this method has been criticised for its lack of theoretical underpinnings and for treating leisure time as having no value. [26] There is also some debate over how caregiver time lost from other household or leisure activities is valued. Attaching what is called a *shadow price* to this time allows the carer's time to be valued using what the individual could be earning (the opportunity cost of time lost). [24] Alternatively, a replacement cost approach might be used whereby the unit cost of replacement care is applied, in line with official estimates of the actual cost per hour of providing homecare. [27,24] Both methods are currently used and no consensus exists on which is favoured. Overall estimates of time lost from employment, household and leisure activities are highly dependent on the method used. [4]

In addition to the financial costs to family caregivers, patients themselves can incur considerable costs when receiving palliative care. [28] Complex family relationships and evolving family roles mean that older people in particular can be left living alone and isolated at the end of life, without the presence of a family caregiver. [29] In cases such as these patients may be facing considerable financial burden as a result of their ill health. The COFAC questionnaire has been specifically developed for family caregivers, however further research should explore the feasibility of adapting this tool for patients in order that data can also be captured from those living alone without a family caregiver.

The COFAC questionnaire has been developed in the UK in the context of a comprehensive health care funding environment. In the UK the National Health Service (NHS) provides comprehensive health care free at the point of delivery for all citizens, therefore the COFAC questionnaire does not capture data on the costs of healthcare delivery. Whilst this is appropriate for the UK and other countries with universal health coverage such as Belgium, Canada, Denmark and Finland [30] it is unlikely to be suitable for research in countries with voluntary insurance based healthcare systems or those which lack comprehensive healthcare coverage. In these countries costs incurred by family caregivers are likely to be much greater. A study exploring costs at the end of life and economic burden in the USA reported that for patients with moderate/high care needs, up to 10% of their household income was spent on direct healthcare costs. [31] In contexts such as this, data collection tools such as the COFAC questionnaire would require further adaptation to account for the increased range of costs which are likely to be incurred. A recent systematic review proposed a framework which outlined the range of cost components relevant for economic evaluations in

palliative care. [10] This included the full range of costs that could be incurred by family caregivers in different healthcare funding environments. This framework could be used in the adaptation of COFAC for different countries and funding contexts.

Poor recruitment of participants and high levels of attrition are challenges often encountered in palliative care research. [32] Given these challenges it is important to provide flexibility and adaptability wherever possible to enhance recruitment and retention of participants. The COFAC questionnaire has been piloted for both face to face and telephone methods of administration, and no differences were observed between these different administration options. We recommend that researchers offer both face to face and telephone options to potential participants to enhance recruitment and retention. The researcher administered interview technique is important due to the sensitivity of the content and in order to clarify potential issues and minimise missing data and non-response of items. As such we do not consider the questionnaire is suitable for self-complete administration options.

Limitations

Some limitations must be acknowledged with this study. Development of the questionnaire was partly based on previous research and literature from outside of the UK, therefore transferability may have been affected. Cognitive interviewing in a group setting may mean participants have less opportunity to express negative or contradictory opinions. Further work is required to establish reliability and other aspects of validity.

CONCLUSION

This study describes the development and initial validation of a questionnaire tool to measure the costs of family caregiving in palliative care. The CCOFAC questionnaire is recommended for economic research in palliative care which seeks to capture data from a broad societal perspective which includes family caregiver costs. The COFAC tool has been shown to be valid and is acceptable to bereaved caregivers. Feasibility of administration has also been established. Further research is required to establish reliability and other aspects of validity, and to adapt the COFAC questionnaire for patients who live alone without a family carer. Further adaptation would also be required for use in countries without comprehensive healthcare coverage, to ensure costs of health care services are captured.

Contributorship: CG collected data and wrote the first draft, CM and CH revised subsequent drafts

Competing interests: None declared

Ethical approval: Ethical approval was granted by the University of Sheffield School of Nursing & Midwifery ethical review committee.

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FIGURE LEGENDS

Figure 1: Process of COFAC questionnaire development

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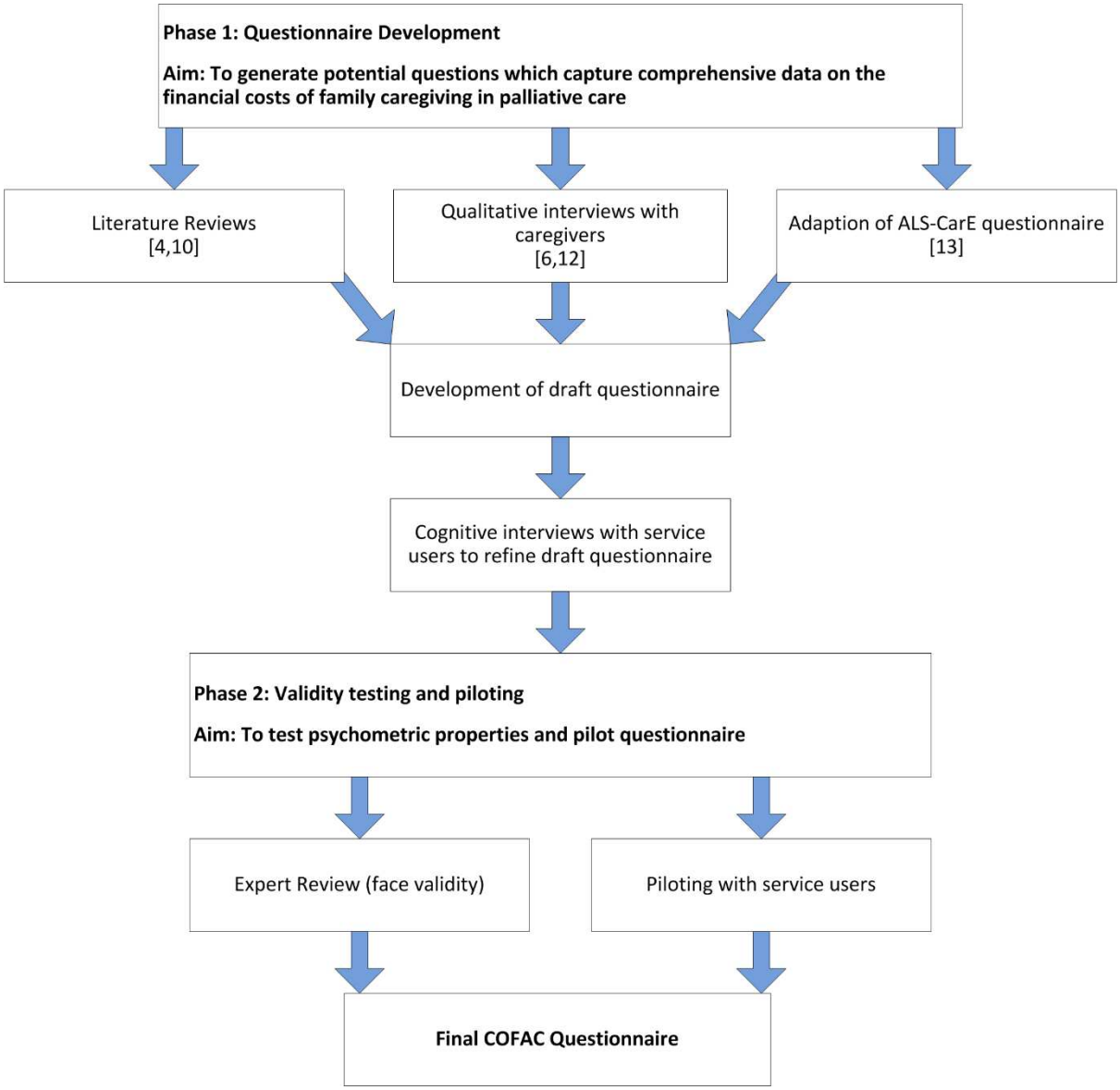
Phase 1: Questionnaire Development
Aim: To generate potential questions which capture comprehensive data on the financial costs of family caregiving in palliative care
Literature Reviews [4,10]
Qualitative interviews with caregivers [6,12]
Adaption of ALS-CarE questionnaire [13]
Development of draft questionnaire
Cognitive interviews with service users to refine draft questionnaire
Phase 2: Validity testing and piloting
Aim: To test psychometric properties and pilot questionnaire
Expert Review (face validity)
Piloting with service users
Final COFAC Questionnaire