

Impact case study (REF3)

Institution: Edge Hill University		
Unit of Assessment: A3 - Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: The value of the Carers' Alert Thermometer (CAT) in identifying family carers' needs and supporting them in their caring role.		
Period when the underpinning research was undertaken: 2010-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Barbara Jack	Professor of Nursing	1993 - ongoing
Mary O'Brien	Professor of Palliative & Supportive Care	2003 - ongoing
Brenda Roe	Professor of Health Research	2007 - 2019 (now Emeritus)
Katherine Knighting	Senior Research Fellow	2011 - ongoing
Period when the claimed impact occurred: 2014-2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact		
<p>Working collaboratively with carers and professionals, our research developed the Carers' Alert Thermometer (CAT) for daily use in practice with family carers of those at end of life. It facilitates screening by specialist or generalist staff and highlights areas of carers' needs which require support.</p> <p>The CAT impacts both policy and practice, including addressing the issues identified in the Department of Health (DoH) (2016) consultation for evidence to inform appropriate interventions for carers' support needs. The CAT has been recommended for the assessment of carers' needs as part of the national Gold Standard Framework end of life care training programme since 2016. It was adopted by Motor Neurone Disease (MND) Associations in the UK and Western Australia as the instrument of choice for carers' screening. It has also been proposed for national adoption as part of the Quality Standards Framework (featured in the <i>National Institute for Health and Care Excellence End of Life Care, Quality Standards Consultation for the assessment of carers</i>).</p> <p>The flexibility and adaptability of the CAT has been demonstrated by successful adaptation to other carer groups including young carers and carers of stroke survivors.</p>		
2. Underpinning research		
<p>Over 6.5 million people in the UK act as unpaid carers for friends and family members, approximately 500,000 of whom are at end of life. This group of carers face mounting challenges as they are increasingly an aging population, many with their own health needs, and often lack family support due to geographic mobility and other caring responsibilities, such as childcare. Local community professionals reported an increasing number of patients admitted to hospital at the end of life when their preferred place of care was home.</p> <p>The Edge Hill team conducted research with healthcare professionals and identified that when carers could no longer cope it led to the collapse of care at home [1, 2]. This research highlighted the fundamental gap in identifying the needs of carers and provision of timely interventions. This work on carers and end-of-life care has influenced NICE guidance, <i>Supporting Adult Carers 2020</i> [3]. Prior to this work, a plethora of assessment tools existed, which in the main were lengthy and not practically suitable for clinical practice. To address this gap, the team led a 26-month NIHR-funded study to develop a short screening instrument to identify, prioritise and support carers' needs [4].</p>		

We undertook a mixed-method, multi-phased, consensus study involving 245 people (117 carers, 128 professionals) from health and social care settings across North West England (2011-2014), including an expert panel phase comprising carers and additionally professionals who held strategic roles in end of life care [5]. Drawing upon the modified early warning system (MEWS) screening instrument used in healthcare to detect clinical deterioration in patients, we developed an instrument for carers. The development was done in conjunction with a steering group of key stakeholders including carers, and staff from NHS, statutory, and third sector organisations, to ensure it would be suitable for clinical use.

The CAT is an evidence-based, free-to-use, short screening instrument for use in daily health and social care practice. It has filled a gap by providing a brief instrument for use by non-specialist staff and volunteers. It allows quick and timely screening and prioritising of the adult carer needs. Publicly launched in 2014 at a key stakeholder event, the CAT facilitates the identification, monitoring and triage of carers who are struggling, to prevent carer breakdown and hospital admissions of patients. It comprises 11 questions over two sections to identify the alert level of needs to support the carer (i) in their caring role and (ii) in their own health and well-being. Using a traffic light system to score the level of alerts, the thermometer provides a visual representation of the carer's needs. Guidance is provided on next steps for each alert e.g. signposting to local services or referral for a statutory full carer's assessment and space for an agreed interventional action plan with next review date. The CAT website provides free access to the CAT and training resources to support its implementation (www.edgehill.ac.uk/carers).

The CAT has formed the basis for an expanding portfolio of evidence-based screening instruments for carers of other patient populations in response to needs identified in practice including young carers, carers of people who have Motor Neurone Disease [6] and those who have had a stroke.

3. References to the research

Evidence of the Quality of the Research:

The underpinning research was published in *Journal of Advanced Nursing*, and *BMC Palliative Care*. Invited keynote presentations were given at the National Association of Hospice at Home Conference (2015) and the International Association of Nurses in Palliative Care (2018). Presentations were also given at the leading European conference for palliative care - The European Association of Palliative Care (EAPC) conference (2015), the UK Stroke Forum (2016) and the International ALS/MND Alliance Allied Professionals' Forum (2016), the MND Association Care Centre Directors, Co-ordinators and Regional Care Development Advisors Joint Study and Meeting day (2019).

Total Research Income (2009-2018) - £284,262 (peer reviewed)

2018 Liverpool Clinical Commissioning Group (CCG) National Institute for Health Research (NIHR) Research Capacity Fund. Development and evaluation of the CAT-S (Stroke). (£18,637)

2014 Liverpool Clinical Commissioning National Institute for Health Research (NIHR) Research Capacity Fund. Evaluation of the CAT. (£9,600)

2010 National Institute for Health Research (NIHR) National Institute for Health Research (Research for Patient Benefit Programme). (£248,725)

Earlier funding

2009 National Institute for Health Research (NIHR) National Institute for Health Research. Research for Patient Benefit Programme, Feasibility and sustainability funding. NHS Halton & St Helens Primary Care Trust. Carers Needs Assessment Thermometer. (£7,300)

1. Jack, B. and O'Brien, M. (2010) 'Dying at home: Community nurses' views on the impact of informal carers on cancer patients' place of death', *European Journal of Cancer Care*, 19(5), pp. 636–642. doi: 10.1111/j.1365-2354.2009.01103.x.

2. Jack, B. A. O'Brien, M.R. Scrutton, J. Baldry, C.R. and Groves, K.E. (2015) 'Supporting family carers providing end of life home care: A qualitative study on the impact of a hospice at home service', *Journal of Clinical Nursing*, 24(1–2), pp. 131–140. doi: 10.1111/jocn.12695.
3. National Institute of Health and Care Excellence (NICE) (2020) 'Supporting adult carers' (NG150) Available at: <https://www.nice.org.uk/guidance/ng150> (accessed on 01.02.21)
4. Knighting, K. O'Brien, M.R. Roe, B. Gandy, R. Lloyd-Williams, M. Nolan, M. & Jack, B.A. (2016) 'Gaining consensus on family carer needs when caring for someone dying at home to develop the Carers' Alert Thermometer (CAT): A modified Delphi study', *Journal of Advanced Nursing*, 72(1), pp. 227–239. doi: 10.1111/jan.12752.
5. Knighting, K. O'Brien, M.R. Roe, B. Gandy, R. Lloyd-Williams, M. Nolan, M. and Jack, B.A.. (2015) 'Development of the Carers' Alert Thermometer (CAT) to identify family carers struggling with caring for someone dying at home: A mixed method consensus study', *BMC Palliative Care*, 14(1), pp. 1–13. doi: 10.1186/s12904-015-0010-6.
6. O'Brien, M. R. Jack, B.A. Kinloch, K. Clabburn, O. and Knighting, K. (2019) 'The Carers' Alert Thermometer (CAT): supporting family carers of people living with motor neurone disease', *British Journal of Neuroscience Nursing*, 15(3), pp. 114–124. doi: 10.12968/bjnn.2019.15.3.114.

4. Details of the impact

The CAT is an evidence-based, free-to-use, short screening instrument for use in daily health and social care practice and addresses the issues raised in the Department of Health (DoH) (2016) consultation for evidence to support carers. It has filled a gap by providing a brief instrument that can be used by specialist and generalist staff as well as volunteers. It allows quick and timely screening and prioritising of the adult carer needs. The CAT was included by the NIHR in a themed report of research 'Better Endings' (2015) as an example of good practice [A i]. The original CAT has successfully been adapted and piloted in other long-term conditions and a portfolio of CAT instruments has been developed.

Benefits of CAT

There are several key reported benefits of the portfolio of CAT instruments that have resulted in adoption in a variety of settings demonstrating its reach and significance for supporting carers. It can be successfully administered by generalist staff and volunteers providing flexibility of its use and the workforce composition. The CAT has received positive feedback from carers, volunteers and professionals [C i-ii, E ii-iii]. Using the portfolio of CAT instruments allows for carers' needs to be identified and the provision of targeted support which enables them to continue caring [1-6, A i, B v, E ii]. Carers have provided positive feedback on the impact of the CAT, one family carer made the following comment, "*I felt my needs were acknowledged/listened to; felt my MND Adviser's responses were appropriate; not telling me what to do but using a coaching style (rather than directing); acknowledged what I said*" [B v]. Using the CAT has reportedly also has a positive impact on the person being cared for alongside other family members, "One carer remarked that using the CAT actually helped them reflect and they identified that they were relying too heavily on wider family support (their children). This enabled them to seek support elsewhere" [B v]. Additionally, the use of the CAT supports attainment of national and international policy recommendations for carer assessment. It also provides management information for service development; for example, data from use of the CAT has led to the expansion of carer support services including the development of new posts nationally and internationally [B iv-B v, E vi].

Adoption of the CAT

The CAT has been adopted in a number of settings both nationally and internationally. The CAT provides a structured approach for organisations to engage meaningfully with family carers, for example adoption for use with people living with motor neurone disease (MND). Following an exploratory study where it was used by volunteers with carers of people living with MND, use of

the CAT was included in training received by Association Visitors (volunteers) which enabled carers' needs to be identified and discussed [B iv]. It is part of a toolkit of support resources used by the Motor Neurone Disease Association's (MND) Area Support Coordinators and Association Visitors with family carers of people living with MND [B i-iii]. Comments have been received from an Area Support Coordinator highlighting the positive impact using CAT has by providing an opportunity to focus on the needs of the carers: "*This helps carers to continue in their caring role which ultimately has a positive impact on the people they care for*" [B i]. Furthermore, the CAT was included as a resource in the MND response to the DoH call for evidence on improving support for carers [B iii]. The document stated the importance of focusing on carer support and highlighted that carers should not have to reach crisis point before their needs and capability for caring are considered. The CAT was listed as an instrument to use to prevent carer crisis [pg14]. Evidence gathered during use of the CAT across Scotland by volunteers from MND Scotland led to a number of benefits; "*We were able to identify the wishes of carers to be supported by MND Scotland, and as a direct result of that we have developed our Keeping-in-Touch Service... This has been particularly important since the outbreak of the Covid 19 pandemic*" [B iv]. In this new service, MND Scotland makes individual contact with everyone in Scotland currently living with MND and their carers to determine how they are coping, and if there is anything MND Scotland can do to assist them.

Internationally the CAT has been used by the MND Association of Western Australia (MNDAWA) in Perth to support carers of people living with MND. As a result of the positive feedback they received from these carers regarding the CAT, the MNDAWA has decided to include a focus on family carers in the job description of all MND advisors. Furthermore, adoption of the CAT has enabled them to collect more data on carers that is now stored alongside the patient data [B v]. Additional international reach of the research is shown through development of CAT as an electronic screening tool in the Princess Margaret Cancer Centre in Toronto (Canada). Colleagues there have secured funding for two posts to pilot the electronic CAT for caregivers of patients who are attending the outpatient palliative care setting [E iii].

The adaptability of the CAT for use across long-term conditions has been evidenced by the successful pilot and implementation of the CAT-S by the Stroke Association [C i]. More recently, the Stroke Association found that "*utilising the CAT-S was beneficial to carers as it helped them to recognise their own needs and seek support; supported staff to prioritise the needs for support and identify carers most at risk; and facilitated discussions on difficult or sensitive topics*" [C ii]. The Stroke Association implemented the CAT-S for carers of service users across the Liverpool region [K]. Following successful piloting and further adaption for use with young carers the CAT-YC has been embedded as part of the developing well-being pathfinder programme to be delivered in primary and secondary schools to facilitate the assessment and support of young carers led by Barnardo's Action with Young Carers Liverpool Service. Planned roll out was delayed due to the pandemic [D i].

The value of the CAT is further demonstrated through its recommendation by a variety of key figures including authors of the International Palliative Care Family Carer Research Collaboration (IPCFRC). It was recommended for use with carers of patients with respiratory disease and highlighted for having an advantage over other instruments due to the specificity of its design for clinical practice [F i]. It was also recommended as a resource for use with carers in Australia by the palliative care knowledge network [F ii]. It was also recommended in a professional journal for end of life care [F iii] and reported in a palliative care textbook [F iv].

Embedding of the CAT in training as part of the Gold Standards Framework

Since Autumn 2016 the National Gold Standards Framework (GSF) [E i] (recognised by Care Quality Commission (CQC) and professional bodies) have promoted and recommended the CAT for the assessment of carers' needs. The GSF formalises best practice and impacts on the care of half a million people each year across all care settings in the final year of life. A key element of the GSF in all training programmes is the support for carers. In partnership with Hospice UK, the GSF Centre is the leading training provider in the UK for front line staff caring for people in their last year of life. They train over 500 health and social care teams each year. The GSF team have

made the following comment about the CAT, “*We think [it is] a valuable resource for health and social care staff needing a short screening assessment of carers. This [CAT] would enable carers’ needs to be identified and the provision of targeted support, which enables them to continue caring and reduce avoidable hospitalisation*”. Currently, as part of the Quality Standards Framework review, the GSF/Hospice UK team have also proposed the CAT for national implementation in the ongoing 2020/21 (NICE) End of Life Care Quality Standards Consultation [E ii].

5. Sources to corroborate the impact

A. Examples of sources recommending CAT as good practice.

- i. National Institute for Health Research (NIHR) Themed review. 2015 <https://evidence.nihr.ac.uk/themedreview/better-endings-right-care-right-place-right-time/> (Accessed 04.02.21)

B. Sources to corroborate impact of MND iteration of CAT.

- i. Testimonial statement from Area Support Coordinator, Motor Neurone Disease Association
- ii. MND Association carer survey 2019 infographic.
- iii. MND Association 2016 Response to the Department of Health call for evidence on improving support for carers.
- iv. Testimonial statement from Information Officer for MND Scotland.
- v. Testimonial statement from Professor of Palliative Care Research at the Perron Institute for Neurological and Translational Science, and the Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Australia.

C. Sources to corroborate impact of the CAT-S (stroke).

- i. Jack, B. O’Brien, M. Knighting, K. Malewezi, E. Poole, C. & Kirton, JA. (2020) Pilot and evaluation of the Carers’ Alert Thermometer adapted for carers of stroke survivors (CAT-S) and development of a bid to conduct a trial of CAT across long-term and progressive conditions. A commissioned report for Liverpool Clinical Commissioning Group. <https://www.edgehill.ac.uk/carers/> (Accessed 03.02.21)
- ii. Testimonial statement from Director of Stroke support services for the North of England Stroke Association.

D. Sources to corroborate impact of the CAT-YC (young carers)

- i. Testimonial statement from Development Worker for [Barnardo’s Action with Young Carers Liverpool Service](#).

E. Sources to corroborate impact of CAT for end of life care.

- i. <https://www.goldstandardsframework.org.uk/training-programmes> (accessed 02.02.21)
- ii. Testimonial statement from Hospice UK/GSF training lead.

F. Sources to corroborate impact of CAT for use in toolkits.

- i. Farquhar, M (2017) Assessing carer needs in chronic obstructive pulmonary disease. *Chronic Respiratory Disease* 15(1): 26–35 DOI: <https://doi.org/10.1177/1479972317719086>
- ii. The CARESEARCH palliative care knowledge network website in Australia as a resource for palliative care nurses. <https://www.caresearch.com.au/Caresearch/tabid/1447/Default.aspx> (Accessed 04.02.21)
- iii. Hardy B (2018) Meeting the needs of carers of people at the end of life. *Nursing Standard*. doi: 10.7748/ns.2018.e11128
- iv. Grande G., Ewing G. (2019) Informal/Family Caregivers. In: MacLeod R., Van den Block L. (eds) *Textbook of Palliative Care*. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_52-1