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Providing comprehensive, person-centred assessment and support for family carers towards the end of life

10 recommendations for achieving organisational change

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"Unless we support the carers, the carers aren't going to support the patients, then we're all going to be struggling."

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Introduction

This is a summary report of a project examining organisational structures and procedures needed to identify, assess and support carers during end of life care. The project was led by Professor Gunn Grande, Division of Nursing, Midwifery and Social Work, University of Manchester and Dr Gail Ewing, Centre for Family Research, University of Cambridge.

There are clear and positive policy ambitions to achieve comprehensive, person-centred assessment and support for carers, but so far these take the form of aspirations. The proposed recommendations in this report are key building blocks to enable these aspirations to be implemented in practice.

This work will be followed by a national survey of hospice providers to establish what is currently in place to assess and support carers, compared against these recommendations.

Intended audience

This report is highly relevant in health and social care settings (hospice, hospital, primary and community care) where carers (family/friends) often play a pivotal role at the end of life. It is particularly aimed at organisational leads, commissioners and policy makers because it provides evidence-based recommendations for the system changes required to enable practitioners to deliver comprehensive, person-centred carer assessment and support in everyday practice.

We for instance hope that this report may be used by organisations to develop practice standards to begin to benchmark the support they provide for carers against evidence-based recommendations for comprehensive, person-centred carer assessment and support.

Definitions

'End of life care': we use NHS England's definition of end of life care as the care that is provided in the last year of life.

'Carers': we use the NICE[1] definition: "Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management."

Forewords

I became a carer one day when my husband was diagnosed with late stage pancreatic cancer. One day I was his wife; the next day I was his carer. In reality nothing had changed but everything had changed; I was his wife, I was his carer but most of all I was the person who was dealing with the most heart wrenching news. I was dealing with the fact that my husband was going to die and I needed help to navigate a world of palliative and end of life care.

Like me, carers often do not see themselves as carers. Often their needs go unnoticed, unsupported and unfulfilled at a time when that support is essential. The work undertaken in this project will bring focus to the carer as a person and using person-centred approaches will ensure two-way communication and active listening. This will be supported by systems and processes that focus on the needs of the person/people who are caring with their needs at the centre of all actions.

This work and its recommendations will bring a clarity, focus and emphasis that will provide the holistic approach to help meet those identified needs and support carers in their vital and unique role.

Lesley Goodburn

Ensuring that informal and family carers are seen as vital members of the care team that surrounds the dying person, whilst recognising the support they need as people facing personal loss and grief, has been an underpinning philosophy of palliative care from the beginning. National policy supports this position: 'Involving, supporting and caring for those important to the dying person' is one of the eight foundation blocks of the Ambitions for Palliative and End of Life Care (2015-2020) which sets out our collective system-wide national aspiration. Supporting dying people to involve those important to them (to the extent that they wish) is also one of the Government's six point commitment to increase choice and control for people who are facing the last year of their life, that was published in 2016.

The research recommendations published here have been rigorously investigated by a team who have a deep and long-standing appreciation of issues affecting carers. The voices of carers, support teams, social workers and care managers have all been heard as part of the research and their direct quotes richly illustrate the report. I encourage all caring organisations to read this carefully, as it will help them to consider how they can promote a more systematic proactive approach to identifying, assessing and supporting carers. Not only is this an important part of being a humane, compassionate society, it is also going to become ever more important as the number of people needing care towards the end of their lives increases in the coming years. No matter how willingly and lovingly care is provided, we must not underestimate the challenge this poses to individuals, nor the extent to which we can help carers increase their own capability, resilience and sense of achievement by giving them the right level of support at the right time and acknowledging their critically important role.

Professor Bee Wee, National Clinical Director for End of Life Care, NHS England

Executive summary and background

Purpose of document

Comprehensive, person-centred support for family carers during end of life care requires whole-systems change within healthcare organisations. This document outlines the structures and processes that need to be in place to deliver such change in the form of 10 recommendations. Recommendations have been developed from review of a programme of research on supporting carers (family members/friends) conducted at the Universities of Manchester and Cambridge and extensive consultation with key stakeholder groups for this specific project.

Why comprehensive, person-centred carer assessment and support is important

Family carers play a crucial role in supporting patients at the end of life, enabling care at home, and preventing hospital (re)admission. Government policy promotes comprehensive, holistic carer assessment and support and a person-centred approach for carers as well as patients [2-4], though provides little clarity about how this is to be achieved in routine practice. Carers' needs differ from those of patients and should be assessed separately. Carers require support within two broad areas:

1. as 'co-workers' in supporting patients, to ensure carers have the information, skills and equipment for this role
2. as 'clients' in their own right to preserve their own wellbeing and health[5].

In this context of holistic person-centred care, 'health' is considered in its widest sense, encompassing physical, emotional, practical, social and spiritual dimensions to enable carers to retain their own wellbeing, identities and personhood. Carers will differ in what they find helpful, and what they need is often very different to what practitioners expect. In order to achieve truly comprehensive carer support in end of life care, many carers need input from healthcare professionals in addition to any support provided through statutory assessments by the Local Authority.

Findings from the review and consultation

This project has brought together research evidence and practice experiences to consider how well we are meeting policy aims of supporting carers in end of life care. It has revealed:

(a) a lack of coherence between what research evidence tells us about the impact of taking on a caregiving role and carers' need for support and the realities of the practice context when working with carers at the end of life

(b) key gaps that need to be addressed if comprehensive, person-centred assessment and support is to be achieved consistently for carers in end of life care.

Our review of research and stakeholder experiences, even within hospice care, revealed that carers are not routinely identified. Data are not always gathered on who carers are, their support needs or how they are supported, in part because record systems are set up for patients. Carer assessment and support is ad-hoc depending on workforce capacity, and is professionally-led rather than person-centred. Facilitative leadership and champions for carers are not commonplace, but where they are in place we know they can have a key role in communication, training and monitoring to drive forward carer assessment and support. Most telling is that little, if any, of the above issues are addressed in a policy context which is about aspirations rather than being grounded in the realities of practice delivery.

To achieve comprehensive, person-centred carer support at end of life requires a change in current practice and a cultural shift both at practitioner and organisational level.

Ten recommendations for achieving organisational change

A set of 10 recommendations were identified for key structures and processes required to achieve whole-systems change, all of which were considered important and not consistently met by current provision:

1. **Consistent identification of carers within the care setting.**
2. **Demographic and contextual data on who the carer is and their situation.**
3. **A protocol for assessing carers and responding to the assessment.**
4. **A recording system for carer information, separate from patient data.**
5. **A process for training practitioners about carer assessment and support.**
6. **Available time/workload capacity for carer assessment and support.**
7. **Support from senior managers for carer assessment and support.**
8. **Role models/champions for carer assessment and support.**
9. **Pathways for communication about carer assessment and support.**
10. **Procedures for monitoring/auditing processes and outcomes of carer assessment and support.**

While much of the reviewed research was based on hospice organisations, the findings and recommendations apply to all care settings. The 10 recommendations outline the necessary building blocks to achieve the change to comprehensive, person-centred assessment and support for carers towards the end of life, which can be translated into measurable standards by individual organisations.

Implications

Achieving comprehensive, person-centred assessment and support for carers requires change management and targeting of several levels within organisations. However, successful take-up of these recommendations depends on addressing the underlying question of where carers truly 'fit' within health service provision, i.e. what status do carers have within different healthcare organisations providing palliative and end of life care.

Since its beginnings, palliative and end of life care has had an ethos of services being there for the carer and family, not just the patient. While this is a strong philosophy, its translation into practice to ensure carers are identified, assessed and supported consistently at the end of life, hinges on establishing whether or not they are to be viewed as true clients of services (and therefore their assessment and support can become legitimised).

Next stages

The work of this project is on-going. The next phase is a national survey of carer assessment and support within UK hospices. The purpose of the survey is to understand the current provision for carers in organisations which focus on palliative and end of life care, highlight examples of best practice and identify gaps in service delivery. Results of the survey will be published towards the end of 2018.

Methods to create recommendations

Research review and stakeholder consultation

Stage 1: Secondary analysis of practitioner experiences of implementation of carer assessment and support

Purpose: Initial identification of organisational structures and processes that facilitate or hinder implementation of comprehensive, person-centred carer assessment and support in end of life care.

We re-analysed data from qualitative research into practitioners' experiences of implementing carer assessment and support in 36 services (mainly hospices, but also some hospital and generalist community teams)[6,7]. This involved interviews with practitioners at two time-points during implementation, and end-point focus groups with practitioners and managers. Thirty-eight people took part. An initial framework of key structures and processes for implementation was developed from the re-analysis.

Stage 2: Focus groups with managers and lead practitioners

Purpose: To present the initial framework from Stage 1 to service leads for further expansion, refinement and validation and to develop draft recommendations.

We invited 67 managers and lead practitioners, purposively sampled to represent a broad range of services that had participated in the above implementation study and a trial of a carer assessment and support intervention. Nineteen participants took part in two face-to-face and one virtual focus group. We explored participants' experiences of implementation in their services in general and their views on the framework in particular. From the analysis, draft recommendations were developed for structures and processes required to support comprehensive, person-centred carer assessment and support.

Stage 3: Stakeholder consultation

Purpose: To validate draft recommendations, assess their importance and identify challenges for uptake in practice with a wider stakeholder group.

(a) Workshops with representatives from palliative care provider organisations (e.g. Marie Curie, Macmillan, Sue Ryder), generalist care (e.g. RCGP carer champions), CCGs, policy and academia.

Personalised invitations were sent out to 89 individuals identified by Hospice UK, the research team or by key organisations approached. Twenty-three participants took part in two workshops, commenting on the relative importance of each recommendation and factors affecting their delivery in practice.

(b) Online survey

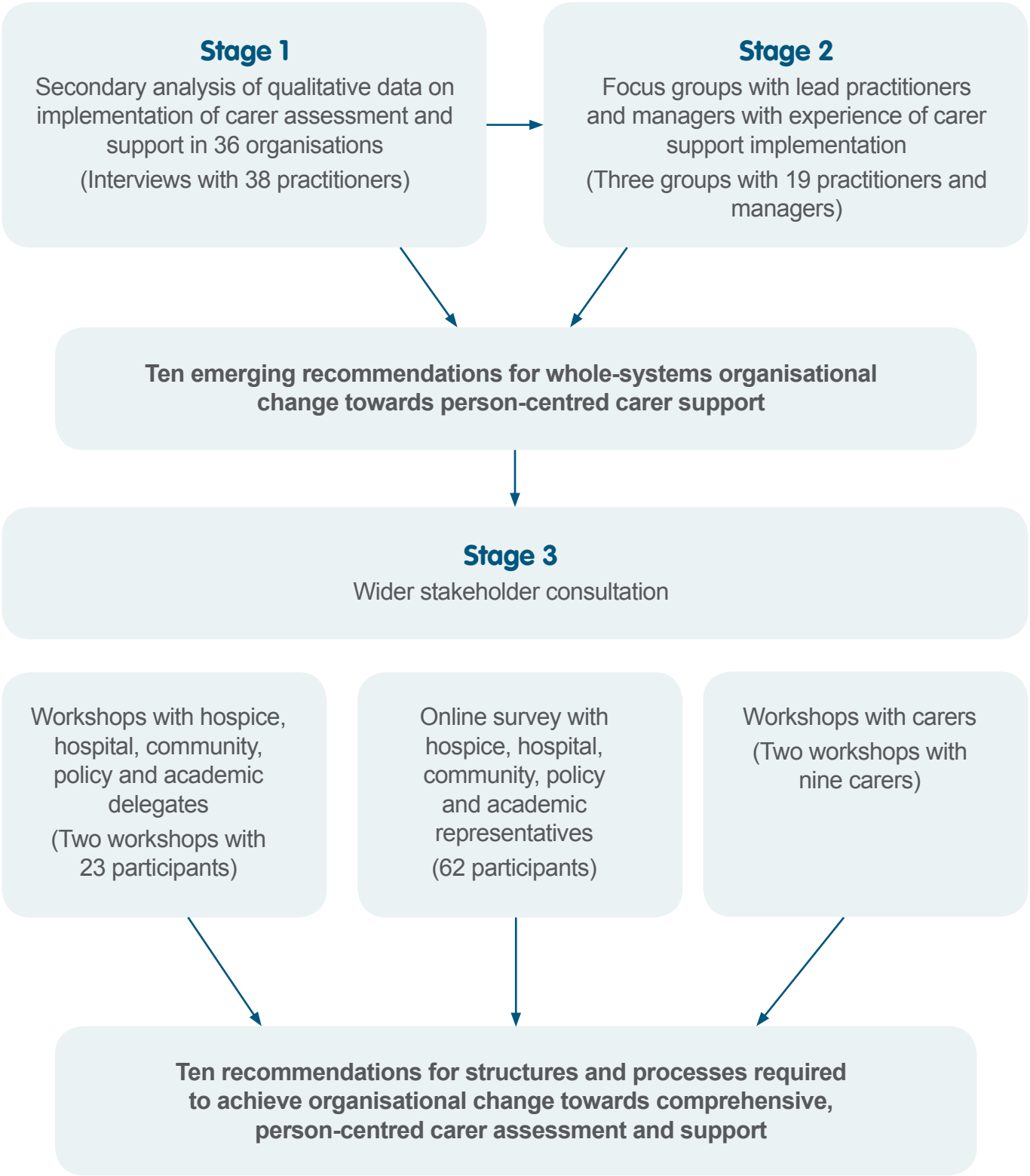
The survey was directly emailed to 75 individuals who had been invited to Stage 2 or Stage 3a and in some cases cascaded by the invitees to members of their organisation (e.g. all GP Carer Champions). Sixty-two individuals took part. Survey content was based on the outputs of the workshops and asked participants to rate the importance and challenges related to each recommendation.

(c) Workshop with family carers

Members of two local carer support groups were invited to participate in carer workshops. Nine carers took part. Workshops explored carers' views of the draft recommendations with an emphasis on areas where carers would have more personal experience.

All qualitative data were transcribed. At each step, two researchers were involved in the analysis process and the results reviewed within the wider research team. An overview of the process of review and consultation is provided in Figure 1 on page 7.

Figure 1: Research review and stakeholder consultation



Recommendation

1

Consistent identification of carers within the care setting

... to ensure services know who patients' main carer(s) are in the first place

Identifying who the carers are and recording this information is the essential first step in assessing and supporting carers.

What stakeholders told us:

- Carer identification should be a **systematic and consistent process** to ensure equity for all carers.

  "... the key word is consistent because I think at the moment carer identification is quite kind of ad hoc, down to sort of goodwill, good practice, and if it's consistent, that suggests every carer will get identified, so it kind of formalises the process, it puts carers on an equal setting with the patient, which is what the legislation says nowadays." (W1b)

- Practitioners should take a proactive approach, as carers told us that they were very unlikely to identify themselves to healthcare professionals.

  "I was looking after my wife and it never occurred to me to go and ask the doctor about myself. I was constantly looking after my wife, and that was it, my needs were second and I never approached them and say: 'Look, I'm struggling here'. I would just dismiss it and carry on." (Carer Workshop1)

- It is important that carers are recognised as carers so they can be supported in this role, while also maintaining their relationship identities as husband/wife, son/daughter etc.

- Asking the patient *"Who is the person who gives you the most help and support (who is not a healthcare professional)"* (W2a) can help identify the main carer so they can be supported, even if they may not yet see themselves as a 'carer'.

Without an effective process for identification, organisations are hindered in delivering consistent carer support.

Recommendation

2

Demographic and contextual data on who the carer is and their situation

... to aid communication with carers and awareness of their circumstances

Documentation about carers is necessary to underpin processes of assessment and support.

Carers told us important information they felt should be recorded about their situation. This included who is 'next of kin'; who is the main carer; if the carer has other caring responsibilities; whether the carer is working; and the health of the carer. Information needs to be updated when circumstances change.

Across all settings there is a lack of documentation about carers. Even in hospices, which have an ethos to support carers, information is not always recorded – even basic data on number of carers can be missing:

> *"Well, it's interesting, because I'm always asked how many carers are we supporting, and everyone always knows how many patients were referred last year. But we have no data on exactly how many carers we are supporting."* (FG1a)

Systems need to be put in place across settings to ensure basic data is recorded about carers.

> *"But I think my issue is we don't highlight all the carers and we're not capturing all the carers, so we're not assessing them because we don't know about them."* (FG1a)

In secondary care, where the primary focus tends to be on the patient, this may require set up of basic systems to begin to identify and record who the carers are first of all.

Regardless of setting, organisations need to take the lead on collecting data. Carers told us that most would not think about volunteering information about themselves.

Recommendation

3

A protocol for assessing carers and responding to the assessment

... to ensure consistent, comprehensive assessment of carers' support needs and relevant response

Current practice needs to move away from an informal, practitioner-led approach to a carer-centred approach.

Stakeholders told us current processes were:

- inconsistent: many carers were missed because they were not identified or known to services
- narrow in focus and ad hoc – because of absence of a more comprehensive assessment process.

> *"So, we get lots of phrases like 'so and so's struggling, not coping, not managing', but the specifics: What is it that they're struggling with? What is it that they're not managing? What it is they are not coping with? They don't get explored. We just get this top level and it's like the old iceberg, what you see is what you get at the top but what we don't get is that deeper assessment."* (FG3)

What carers wanted was for practitioners to:

- take the initiative in asking carers about **their needs as carers** because they rarely thought to ask for support for themselves
- take time to enable carers themselves to identify their needs and express what is important to them before putting in place any support.

Stakeholders also identified that because the situation of the carer is always going to change over time:

- responsibility for carer assessment and support cannot lie with a single sector
- palliative care teams have an important role but only a small percentage of patients and carers will have input from specialist services
- there are key points along the pathway where primary care can be involved, including members of primary care teams other than GPs.

A more consistent, comprehensive process of assessment and support puts carers on a similar footing to patients and values their role in end of life care.

Recommendation

4

A recording system for carer information, separate from patient data

... to ensure that information on carers is recorded in a defined location for record keeping and future reference

Separate recording of carer information for easy reference, access and retrieval is a necessary change in practice for carers to be consistently identified and systematic carer assessment and support to be put in place.

> *"... predominantly the carer information tends to slip into the patient record under family support or whatever. Whereas perhaps we need to be much more upfront about having these records sitting side-by-side with their own title and very much develop carer records."* (FG1a)

Different challenges to recording carer data need to be addressed:

- **Current record systems are patient-oriented**.
  - » Organisations will need to examine the capacity of current record systems to develop a separate recording process for carers.
- **Flexibility to incorporate a separate carer record will vary across settings**.
  - » In the acute hospital: separate recording for carers is particularly challenging as current inpatient record systems leave no scope for accommodating carer details, and systems change is needed.
  - » In primary care: stakeholders told us that although patient and carers have separate records, problems exist with linking them, even within the same GP practice.

In all settings it is important to plan for ample set-up time as stakeholders noted that creation of a carer record requires considerable advance planning.

Where carer records have been created, carer details still need to be completed consistently for records to be of value.

> *"I was looking for a carer yesterday, I went into the medical notes. Now there is a section that says carer's details, nobody had completed it, so I looked in two or three patients, thinking, oh… nobody had completed them. So it is not being completed."* (W1b)

Recommendation

5

A process for training practitioners about carer assessment and support

... to ensure staff are aware of protocols for carer assessment and support and confident about using them

Progress on supporting carers requires a skilled-up workforce with a common understanding of what comprehensive, person-centred assessment and support for carers entails, and how this requires a change in practice from current informal approaches to carer support. This requires training.

> *"This is very much about making sure that you're training staff and supporting staff and dealing with these things, and not just making an assumption that they know how to do that."* (FG2)

Stakeholders identified what needed to come across in a training session:

- how a comprehensive framework helps elicit carer needs, prompting and opening up discussions
- the way a person-centred approach can be truly integrated and delivered in practice, including responsibilities of carers and practitioners in the process.

Training is required at several levels:

- at its most basic to raise broader awareness of carers across the multi-disciplinary workforce
- earlier in nurse training to promote understanding of the key role of carers in end of life care
- at an introductory level to skill-up junior frontline staff across all sectors to identify unmet carer needs
- at advanced level to enable more experienced practitioners to *"up their game"*. (W1a)

Preparation at the organisational level, by those leading on carer support, is also needed to accomplish the training and change required to deliver comprehensive, person-centred assessment and support.

Recommendation

6

Available time/workload capacity for carer assessment and support

... to provide the time required to plan, implement and sustain carer assessment and support

Consistent assessment and support for carers has the potential to improve quality of care and outcomes both for carers and the patients they are caring for, by addressing support needs early and averting crises. This requires investment of time in the short term for later gains.

> *"It actually will reduce people's workloads because they'll be doing a lot more signposting, they'll be doing a lot more averting crises earlier on for admission; so I think actually it has the potential if we do it right to actually reduce workload, but then you've got to put the resources in at the beginning with the people to spearhead it."* (FG1b)

Stakeholders told us that to realise such gains it is crucial to address the capacity of the workforce to achieve consistent carer assessment and support in routine practice. Holding positive sentiments about the principle of assessing and supporting carers, is not enough if the practice reality is that frontline staff are *"firefighting"* (FG1a) and barely have adequate time to address patient needs.

Capacity for carer assessment and support is not just about time and resources but also requires *"a considerable mind-shift for practitioners from a focus merely upon the patient"*. (Survey 6)

For carer assessment and support to be implemented and sustained in practice, the leadership in healthcare organisations needs to determine whether it is to be 'core' business for palliative care services, and formalise its processes.

> *"I think there is a perception that carer assessment and support is an add-on to patient care rather than a core part of a healthcare professional's role, therefore time and workload can be used as a reason that this isn't always completed."* (Survey 23)

Recommendation

7

Support from senior managers for carer assessment and support

... to provide leadership and authority to make required changes and ensure protected time and capacity as required

Implementation of carer assessment and support at organisational level requires a wider strategic view and support from senior management, across all settings.

Leadership and authority is required:

- to **initiate a change in practice** within the organisation including ensuring carer assessment and support is core within the organisational strategy
- to **drive the process forward** and put in place conditions to enable comprehensive person-centred carer support:
  - » ensuring the necessary training for practitioners working with carers
  - » enabling practitioners to have the time to undertake carer assessment and support
  - » keeping review of carer assessment and support on the organisational agenda
- to **sustain these changes longer term** and not just start the process:

> *"A dynamic input is always keeping it under renewal, working out how you can improve it and listening to the people who are actually operating the grassroots and getting their feedback as to how to make it work better from their point of view and the patient's and the carer's point of view. […] If you don't refresh the vision the initiative will not keep going."* (W1a)

Stakeholders told us that **support from commissioners** was also needed to help senior managers deliver the carer agenda. As long as only activities related to patients are commissioned and measured, carer support will remain an 'add on' without recognition of the time and resources needed for its delivery.

Recommendation

8

Role models/champions for carer assessment and support

... to provide the facilitation required within teams to embed carer assessment and support

Commitment to champions for carer assessment and support needs to be at the right organisational level to ensure these are formalised roles that receive sufficient support and resources, and which continue even when the original post holders move on.

> *"I think sometimes it's seen as a bit of an easy option, 'oh just find someone in the surgery who can be a carers champion'. They're not paid any extra for it. It's yet another thing for them to do."* (W1a)

It is important to find the right individuals for the role. Stakeholders told us such champions need to be *"committed"*, *"inspired"*, *"passionate"* about person-centred assessment and support to inspire and motivate others. They also need to be credible practitioners who *"own the rationale"* (W1a): who practise person-centred carer assessment and support and have experienced its benefits.

Champions can have a central role in the process of implementation by:

- creating a positive culture around carer assessment and support
- cascading training on carer assessment and support within organisations
- providing exemplars for practice
- providing problem solving and peer support.

> *"Role models and champions, we felt that really aided communication, both going top up and bottom down [sic], we felt there was a real need to inspire others and to help them with their confidence, and that could be done through role modelling and with the champions, it keeps a project driven."* (FG1b)

Recommendation

9

Pathways for communication about carer assessment and support

... to ensure common purpose and procedures, feedback of practitioners' concerns to managers, shared problem solving and sharing of good practice

Clear pathways of communication are required within organisations to embed and sustain comprehensive, person-centred carer assessment and support in the longer term.

Two way communication between organisational levels:

- Top down from service leads and champions to frontline practitioners supporting carers:
  - » setting expectations and common goals
  - » providing advice and problem solving.
- Bottom up from practitioners to champions and service leads:
  - » providing feedback about carer assessment and support at operational level
  - » identifying problems about delivery to be resolved.

Communication between peer practitioners:

- Planned time to talk through experiences of using person-centred assessment and support for carers.
- *"To pick the brains of colleagues around 'how I do deal with it', 'this is what I did', 'what do you think?'."* (W2b)
- Providing learning and support opportunities.

Communication specific to carers in their own right:

> *"Yeah, with the communication process, because I think that's where it hasn't happened necessarily with our hospice because carers aren't recognised, e.g. at MDTs in their own right, they're tagged on with patients, and the same from the CNS meetings I've sat in; sometimes they're mentioned, sometimes they're not, there's not a slot 'and what about the carers?' with each patient."* (FG1b)

Recommendation

10

Procedures for monitoring/auditing processes and outcomes of carer assessment and support

... to assess progress towards targets, enable review and communicate impact

Monitoring/auditing and reporting of carer assessment and support is a key organisational activity.

For internal purposes:

- to assess whether goals about carer assessment and support are being met
- to identify where any problems may lie
- to enable organisations to demonstrate, review and assess the benefits of the work done over time.

> *"But our Service Development Manager is also developing some audit tool because she's quite interested to review to see how much time [two carer champions] have spent on the pilot, and looking at the outcomes so that we can sell that and say this is what we've done with our pilot of 20. And she'd like when we roll it out to have an audit tool that everybody can use, so [our hospice] can use that to show the benefits."* (FG1b)

For external communication:

- to demonstrate achievements and outcomes for carers to external agencies such as commissioners and other funders.

It is important not just to focus on numbers, the quality of support for carers also needs to be considered.

> *"We talked very much about actually we don't get a lot of money for carers so we need to be able to prove that we actually do the work and that enables us to get resources in as well as core funding; making sure we're looking at the quality, not just the quantity."* (FG1b)

Conclusion

To achieve comprehensive, person-centred assessment and support for family carers towards the end of life, two overarching challenges have to be addressed:

1. the general challenge of embedding person-centred carer assessment and support, which is a different way of working from current practice, within busy healthcare organisations
2. the carer-specific challenge of resolving where carers 'fit' within end of life care service provision.

Enabling comprehensive, person-centred assessment and support for carers

Within healthcare organisations the introduction of a different way of working is always challenging. There are common themes identified in this project which are shared with other national programmes of change, including introduction of holistic needs assessment for patients[8], personalised care planning for people with diabetes[9] and for those with long-term conditions generally[10], and implementing shared NHS decision making[11]. These common themes about managing practice change need to be more visible so that solutions for overcoming difficulties also can be shared to facilitate implementation across sectors.

This project has identified a set of 10 recommendations to achieve comprehensive, person-centred carer assessment and support. This represents a whole systems approach to change and a cultural shift both at practitioner and organisational level.

Recommendations 1 – 4 indicate what needs to be in place within an organisation to provide comprehensive, person-centred assessment and support for carers, and recommendations 5 – 10 outline what is required to implement and sustain this approach in practice.

Addressing the question of where carers 'fit' within end of life care service provision

Perhaps the more difficult challenge is resolving where carers 'fit' within end of life care: whose responsibility are they? The ethos of palliative and end of life care services is one of being there for the family, not just the patient. While this is a strong philosophy, several factors hinder its translation into practice. **Carers are not routinely identified and their details recorded, nor are their support needs consistently assessed or addressed**.

Hurdles include record systems that are set up for patients only, and carer assessment and support which is informal and ad hoc depending on workforce capacity, and professionally-led rather than person-centred. Leadership and champions for carers are not commonplace.

To overcome these barriers we must resolve the question of whether or not carers are to be viewed as true clients of services and therefore their assessment and support can become legitimised. Ultimately this would need to be reflected in commissioning (and specific funding) for carer assessment and support in end of life care.

We know that carers play a crucial role in end of life care, but unless we support them to support the patient and look after their own wellbeing, patient care and carer health are likely to suffer.

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