

Care at the End of Life: Design Priorities for People with Dementia

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Abstract. This paper discusses pre-design stage research concerned with supporting excellence in end-of-life care (EoLC) for people with dementia (PwD). The discontinuation and replacement of previous with new EoLC guidance provides the opportunity for improving care package materials (CPMs) to support EoLC. Current CPMs tend largely to address governance, recording of treatment and consent for audit purposes. This research identified the need for CPMs to better reflect the complexities, coordination and communication needs between the patient (and those important to them) carers and physicians, and to anticipate discussions, scenarios and consequences of decision-making between all parties involved along a patient's uncertain trajectory at EoL: dementia adds another level of challenge. Findings from evaluating existing CPMs and surveying of new technological developments are discussed in this context.

Keywords. End of life, dementia, technological design, care package materials

1 Introduction

One of the consequences of an ageing population is that more people will require long-term care for illnesses such as dementia. This will lead to an increased need for end-of-life care (EoLC) for those with complex needs living in the community. Providing EoLC relies on the coordination of, and communication between, many kinds of professional and lay expertise to provide both treatment and palliative care in a variety of different settings and situations along uncertain trajectories of frailty and illness [8]. EoLC for people living with dementia (PwD) adds another level of challenge: PwD already receive poorer EoLC compared to those with cancer, with more hospital admissions and worse pain control [1]. EoLC is compounded by the very emotive and challenging scenarios for all involved [2].

This paper outlines the pre-design stage of research, in which the author, a design researcher, was involved, scoping the issues, evaluating new developments, identifying opportunities for the subsequent design phases for new or improved care package materials (CPMs) to support EoLC. This work formed one work stream of a larger programme of research led by a professor of primary care and ageing and involving a

multi-disciplinary team of 15 investigators who were funded to support sharing excellence in EoLC for PwD (SEED) [3]. The project commenced as guidance for EoLC changed.

2 Background

2.1 A Change in Priorities

The Liverpool Care Pathway for the Dying Patient (LCP) had been developed to support palliative care in the 1990's. Although an independent review of the LCP [4] found evidence of both good and poor care, the LCP was found to have become a generic protocol used largely as a 'tick box' exercise tending to standardise care irrespective of individual circumstances and preferences. The review's findings resulted in the LCP being phased out in July 2014, replaced by the new approach detailed in the report of the Leadership Alliance for the Care of Dying People (LADCP) [5]. This states, briefly, that care should be individualised and should reflect the needs and preferences of the dying person and those who are important to them. It proposes five priorities (recognise; communicate; involve; support; and plan and do), recognising variation in need together with a number of commitments to ensure all care given in the last days and hours meets these priorities.

2.2 Opportunities for New Care Package Materials

The discontinuation and replacement of the LCP by the LACDP model allows for the reconsideration of existing and the opportunity to create new CPMs to support EoLC for PwD. CPMs are defined by this author, in this EoLC context, as the broad spectrum of materials and tools which support EoLC which can include, e.g., record of treatment (including, e.g., drugs prescribed) and variance in treatment, team notes, instructions (e.g. not to resuscitate), guidance (e.g., for physicians, paid carers, families, PwD and others), as well as innovative materials and tools to facilitate the sharing of information, initiate and support discussion, and assist decision-making.

2.3 Questions Driving the Pre-design Research

The main questions driving this pre-design research stage are: What are the strengths and weaknesses of existing CPMs? What CPMs are appropriate for use in EoLC for PwD given the new LADCP priorities and the SEED team's own findings? What opportunities are there for improving and innovating CPMs and for (all of) whom should these be designed? What new or emerging developments might be useful in this context?

3 Method

As a precursor to the co-development and trialling of new CPMs which will follow in later stages of this 5-year programme of research, the questions in 2.3 above helped drive the initial requirements capture to inform the design statement and design specification for CPMs with a view to supporting all involved at EoL, i.e. PwD themselves, physicians, paid carers, family (or close friends or other persons important to the PwD), and others (such as, e.g., paramedics, out-of-hours physicians, or clergy) in the many, often uncertain and rapidly changing scenarios during EoLC, and to determine the nature, content and formats of these. Initial scoping and review was facilitated using the methods now described.

Evaluation of CPMs. Prior to the LACDP report, CPMs had been modelled on and adapted from the LCP and the Gold Standards Framework (GSF) [7] by different healthcare boards and regions to suit individual practices and preferences. It was essential to review and evaluate current (i.e. pre-LACDP) CPMs and observations arising from these. An analysis was made, by this author, of a sample of three CPMs, recommended by the primary and palliative care members of the SEED team, from: a national ‘last days of life’ pathway; a city-wide palliative care network; and a nursing home basing its CPMs on the GSF [7]. A matrix was populated and circulated by the author to the SEED team members to allow easy sight and comparison of the content of each of these CPMs.

Exploring Insights from the Research Team. The research team had, between them, considerable experience in the study area including primary care, ageing, dementia, geriatric care, EoLC; nursing; and long-term illness management. However, the study was structured into a number of separate work-packages, limiting the potential for cohesive synergy amongst the individual team members on sharing the implications and application of research findings with respect to developing new or improved CPMs. Consequently, team workshops were introduced with a view to discussing on-going findings and implications of the research for new or improved CPMs. The workshops were designed and facilitated by the author, their activities and content being developed and agreed with the team prior to the workshops. The team’s views of and insights into a number of issues were explored using visual-based group workshop methods and activities, such as EoLC scenarios (see Figure 1) which are particularly problematic. Findings from the team’s own reviews of literature and evidence from their research were discussed along with, e.g., the definition of CPMs, the various needs of the different stakeholders in EoLC scenarios, and the content and formats of CPMs. To date, two workshops involving 10 team members have been held. These are now seen as an ongoing feature of the team-building process, and will also include workshops with the patient and public involvement (PPI) group prior to the co-development stages.

Survey of Recent Innovations. A survey was made, by the author, to identify and evaluate recent innovations for opportunities to address some problems associated with existing CPMs and which might assist with the new LACDP and SEED team priorities. The survey scoped dementia care-related innovations, electronic patient record systems concerned with coordinating care, and communication tools associated with EoLC and dementia.

4 Findings

4.1 Issues Associated with Existing CPMs Derived from the LCP Model

Content. The three CPMs reviewed contained (with some variation between the different CPMs): details about the client, their next of kin and contact details; the client's advanced wishes; advanced care plans; DNACPR (do not attempt cardiopulmonary resuscitation) record; the multidisciplinary team's contact details; medical and nursing on-going assessments; care after death; pathway outcome (bereavement and care after death); multidisciplinary team notes; variance from treatment guidance; medication; symptom management; out-of-hours notes; community nursing service notes; doctors' and nurses' notes on drugs prescribed; pain assessment; physical symptom assessment; syringe-driver check chart; and information sheets for clients and families.

Format. Existing CPMs are largely text- and/or tabular-based, paper documents requiring manual (handwritten) input largely by medical and nursing staff. In use their quality can be degraded, e.g., by repeated photocopying. The three CPMs surveyed, typical of CPMs generally, were all paper-based A4 documents, largely concerned with governance and physicians' needs, recording treatment and consent, and had the appearance of an assemblage of a disparate, rather than a coherently designed, set of forms - largely, if not exclusively, oriented to clinical and nursing staff, and to provide an audit trail. Additional guidance materials fell largely into two broad categories: i) guidance for boards or regions to develop, monitor and improve the 'integrated care pathway' for EoLC (the term 'pathway' is now discredited and has since been dropped in usage due to its multiple interpretations including a perception that once on the LCP, this was a one-way 'descent towards death'); and ii) information for clients (patients), their families and carers. The SEED team also felt it useful that other formats for CPMs should be explored, e.g., visual materials to illustrate 'patient journeys' and electronic or on-line formats to assist sharing essential information or promoting discussion.

Access. Different records, information, guidance and instructions are required at different times by different individuals (physician/paid carer/family/PwD/other) for different purposes, in often rapidly changing, unpredictable and highly individualised scenarios sometimes involving many different individuals (frequently with little continuity) delivering medical and palliative care, and often in emotive circumstances.

Locating and accessing the relevant CPMs by all relevant individuals in all situations, if and as required, can be problematic.

Conclusion. From the above it was felt important to understand and distinguish, through audit and from the evidence-base, which (all) kinds of materials work well, for whom, in which formats, in which scenarios, from those that don't work well, need significant adjustment, or are completely absent. Additionally, it was felt that new developments and media could be explored for their relevance to new or improved CPMs.

4.2 Recent findings from the Team's EoLC Research

It is intended that findings from research conducted by other work streams in the research team would feed into the design of these CPMs. For example, Barclay et al [8] provide case studies presented in visual diagrammatic form of the different trajectories of dying individuals' last months and days through care, illustrating, e.g., their symptoms and treatment, physicians' visits, their admittance to and discharge from care home to hospital into care home or hospice, logging with each incident or change in condition the important decisions required for, e.g., treatment, site of treatment or care, pain reduction, and quality of life.

4.3 Survey of Recent Innovations

There is insufficient space to be exhaustive here but, for illustrative purposes, a few examples are outlined and thematically grouped below for both their strengths and their limitations.

Facilitating Discussions with PwD. As the new LACDP model prioritises the needs and preferences of the dying person and those who are important to them, this presents a significant challenge if that dying person has moderate to severe dementia. However, 'talking mats' [9], now available as an app, has been reported beneficial for helping to elicit and convey the views of people with moderate to late stage dementia. Although the findings in the report by Murphy, Gray and Cox [10] are positive in this regard, the question remaining for those researchers was of how helpful the tool is in helping PwD make *key* decisions (e.g., such as might be required at EoL).

Knowing the Individual. Given the number, and sometimes high, turn-over of, different individuals who may be involved, across a number of services, in delivering EoLC for a PwD, knowledge of the person is important for individualised care. The Alzheimer's Society has developed 'This is Me' [11] a low-tech paper-based tool that PwD can use 'to tell staff about their needs, preferences, likes, dislikes and interests'. In the same vein, software has been developed to act as a communication bridge between carers and PwD. 'Portraits' [12] contains important but limited personal and

social information about PwD for their care staff to access where PwD's biographies are presented on a combination touch screen computer system. It has been designed specifically targeting the 'real life' work schedules and usability needs of care staff and provides what is required in a few minutes.

Guidance. Physicians will require LACDP guidance to hand and app-based tools may be a way of making available LACDP priorities in easy-to-access formats. To this end HELIX [15] has provided 'a strong, clean and simple visual identity, using appropriate formats to present the LACDP guidance to clinicians on the front line, to include posters, leaflets and apps. However, findings from other analysis by this author underline the need for tools to be developed not only for clinicians but also those which can be accessed - and are usable - by all involved, including PwD.

EoL Care Journeys. There is often the desire to map or provide an overview of the patient trajectory or 'pathway' of care. As previously mentioned, Barclay et al [8] found four types of trajectory. The designers of Hospitaltohome [16], a digitally interactive visualised pathway, have been working with health and social care practitioners, older people, their families and informal carers 'to identify and improve care pathways from hospital to home with the aim of enabling a more positive experience for all'. However, Samsi and Manthorpe [17] discuss the seductiveness of the concept of a neat 'care pathway', advising caution in taking shared understandings of this for granted in scenarios characterised by their complexity and uncertainty, an issue underlined in Barclay et al [8].

Coordinating Care. One of the challenges in the EoL scenario, as highlighted in Barclay et al [8], is the dynamic and uncertain trajectory of the health, care and treatment of PwD at EoL. The issue of information sharing, management and coordination of care between all individuals and services involved can be problematic. A pilot clinical service, 'Coordinate My Care' [13, 14], sharing information between healthcare providers coordinating care, and recording wishes of how patients would like to be treated and cared for, has been developed and trialled. This ensures their wishes and personalised care plan is available to view by all those who care for them, i.e. those who have a legitimate relationship with the patient, e.g., the out-of-hours GP, NHS 111, the ambulance service, or community, primary or acute care.

5 Discussion

The above outlines some aspects of the pre-design scoping phase of this work. The early identification and discussion of issues and potential directions for appropriate innovations will inform future team workshop activities and the means and modes of stakeholder engagement, e.g., 'talking mat' style apps [9] could potentially assist in the engagement of PwD in participant workshops, and visualised EoLC trajectories based on Barclay et al's work [8] and the use of scenario methods could assist discus-

sion of which tools could improve communication, understanding and joint decision-making processes, and between whom.

5.1 PPI and Co-Design

Patient Professional Involvement (PPI) is a term commonly used within healthcare for what the design community broadly refers to as participatory design, co-creation and co-development. Savory [18] provides a useful model for design-healthcare collaborations as it distinguishes levels of PPI 'engagement'. Within the context of the research described in this paper, dementia adds another level of challenge in a number of senses. One is with regard to the sensitivity of conducting research at the EoL. A second is around the challenges of involving PwD and their families, as two of the many stakeholder groups, in the 'co-design' of CPMs. However, thinking and practice has moved on substantially in both the design and healthcare fields since the LCP was designed in the 1990s. In design, the greater democratization of designing through the participatory, co-design and service design movements has brought stakeholders into the centre of the process. In this regard, findings from approaches embracing co-design principles, such as Experience Based Co-Design (EBCD) [19, 20], have proved positive and significant, albeit limited in the types of intervention they can generate, and would suggest that modified aspects of these approaches could be used in the co-development stage. The SEED team membership includes a patient and public involvement group who are being integrated into the project team workshop schedule in the initial stages, in advance of the later co-development phase for new CPMs which will itself involve all the main stakeholder groups, namely: people with mild/moderate dementia, family carers; primary care professionals; community nurses; secondary care professionals involved in old age psychiatry, geriatrics, palliative and social care; care home staff; and commissioners. A further stage beyond this co-development process will see these new CPMs being trialed in two different settings.

5.2 Care 2.0?

One of the findings in Barclay et al (2014) [8] was that EoLC tools 'were used infrequently'. An understanding of why will be essential, particularly anticipating the move of CPMs into the technological realm. One of the points made about the apparent success of the 'Coordinate My Care' [CMC] system is that the CMC "... *was never conceived as an IT project; the IT was always led by the clinical need... We tried to develop our solution with Connecting for Health using the summary care record, but that was a technology-led project which restricted it severely. With CMC it is the other way round and as a result the solution is very intuitive and easy to use and fits in nicely with the way clinicians work everyday*" [22]. The examples provided in 4.3 above are predominantly electronic/digital tools. Whilst introducing IT systems in healthcare has been fraught with set-backs [21] and there is the problematic issue of 'platform fatigue' [6], i.e. the learning of new interfaces and new procedures for accessing and logging into multiple systems, one has to ask whether, given the com-

plexities and uncertainties of EoLC scenarios, the need for continuity between the many individuals and services involved, and the need for ready access to essential information including the PwD's wishes, if we can afford not to move these CPMs (or at least some aspects of them) into the digital-electronic realm? However, we need be cautious about how these are developed and by whom, so that these can be used intuitively, and so that they will be used by all who need – and should be able - to access them, as a matter of course within everyday EoLC practice, and particularly, with the concerns of this current SEED project, involving people with dementia.

6 Conclusion

With the new LACDP model's repositioning of the priorities of the patient and all 'individuals important to them' to the centre of EoLC, how should these and the findings from the SEED team's own research be manifest in the design of new CPMs? What are the challenges, opportunities and priorities for design here? This author's survey of existing CPMs found, as stated previously, that the design of CPMs primarily addressed physicians' and nurses' recording and auditing needs. However, in this highly complex and unpredictable stage of life, CPMs need to support all those concerned: PwD, their families, paid carers, clinicians, and others (e.g., ambulance, clerical, and out-of-hours GPs). It is therefore felt vital that the nature and type of CPMs be expanded, and their formats better considered to, e.g., better assist coordination of care, help acknowledge the uncertainties, help anticipate and deal quickly with changing and unpredictable scenarios, be available to provide information, initiate or assist important discussions, and communicate and develop better understanding of consequences of decisions made for all parties involved. To achieve this will require the iterative design, co-development, prototyping and evaluation of improved or new CPMs based on emerging evidence from the types of scoping activities described in 3 above whilst recognising new, perhaps under-exploited opportunities (e.g., digital documents, apps, etc.) and from the findings from others in this SEED team.

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