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Review

Using Datix Electronic Incident Reporting System to Develop a Palliative and End-of-Life Care Patient-Centered Auditing, Quality Assessment and Reporting System

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ABSTRACT

The need for specialist palliative care services has never been higher as the ongoing coronavirus disease (COVID) pandemic has highlighted. Yet even in the absence of the pandemic, specialist palliative care services in hospitals, hospices and within communities were already stretched beyond their capacity. The current fiscal climate within which most healthcare systems operate are undergoing global economic constraints making it a necessity that healthcare systems explore new ways of working to develop efficient high-quality services, maximising resources whilst maintaining good clinical governance. We describe how a hospital palliative and end-of-life care (PEoLC) specialist team, can harness an existing electronic incident reporting system Datix, adapting it to automatically track the longitudinal performance of the patient-centred, end-of-life care (EoLC) services that they deliver, along national standards in keeping with the Care Quality Commission (CQC) and the National Institute for Health and Excellence (NICE) guidelines for end-of-life care in the UK. Such automated systems can inform the quality of PEoLC services, improve the use of time and resource within specialist palliative care teams, support the delivery of evidence-based clinical governance standards, whilst supporting benchmarking across organisations, strategy development, insight into local/regional variations, and the establishment of standardisations of care.

Keywords
Palliative and end-of-life care (PEoLC); Performance indicator data; End-of-life-care audit; Clinical governance.

INTRODUCTION

Specialist Palliative Care–Demands, Expectations and Timing

Palliative and end-of-life care (PEoLC) is widely recognised for its focus on a systematic, holistic, patient-centred approach to improving the quality-of-life (QoL) for patients living with and dying from life-limiting illnesses.[1,2] Going beyond oncology, the principles of PEoLC have been applied to relieve suffering whether physical, psychological, spiritual or social in conditions as far ranging as cardiovascular disease, major organ failures, frailty through to end-stage chronic illnesses.[1,2] The timing of palliative care engagement with patients is critical as timely engagement with specialist palliative care (SPC) services can result in reduced risk of death in acute care settings, through to improved survival in advance lung cancer albeit the optimal time point is still a subject of debate.[3-5] The benefits of timely palliative care services engagement extend from general benefit through to specific improvements in psychological distress for patients and their families, as well as QoL and symptom management.[6-9] The reduced likelihood of death in acute settings means that healthcare costs are also reduced due to early referral to palliative care therefore reduced focus on intensive care costs.[10]

With people living longer, with ongoing improvements in modern medicine extending life expectancies particularly in the developed world the demand for PEoLC has long exceeded modern medicine's capacity to meet these needs.[11-13] Globally, it has been estimated that only 14% of people who need palliative care received it, however as of 2021, the World Health Organization (WHO) found that only 10% of people who need palliative care are able to access this specialty.[1,2] However, the recent coronavirus disease-2019 (COVID-19) pandemics has laid bare the desperate plight of people needing end-of-life care (EoLC), with doctors identifying COVID-19 on the death certificate of more

than 180,000 deaths in the UK since the pandemic started.[14] With the global death rate from COVID-19 at over 5.5 million people worldwide, the demand for EoLC around the globe is on the rise, and has been predicted to rise by 55% in England alone over the next ten-years.[15-17] This will see the 245,000 people who are expected to receive palliative care in 2021 increase by 2030 to 379,000.[10] Thus, WHO have highlighted how the covid pandemic has further heightened the need for training in palliative care for generalists as the demands for SPC continues to outpace the availability of trained professionals worldwide.[2,12,16,18]

Role of Clinical Governance in PEoLC

High-quality healthcare is underpinned by evidence-based clinical governance,[19-21] with good clinical governance pivotal in modern healthcare as well as PEoLC even within resource-limited, challenging fiscal climates across care settings from acute hospitals, hospices through to community settings.[22,23] Yet the rising demand for PEoLC is putting a significant strain on existing services who are tasked with the development of robust clinical governance systems with the ability to perform regular, standardised, high quality data collection and analysis championing quality care and research.[24-26] The ideal system should systematically enable the collection and analysis of patient-centred data in routine clinical practice in a standard way such that the performances of services can be tracked longitudinally over time, enabling quality metrics alongside the evaluation of change in the quality of care.[22] Thus, supporting bench-marking across organisations, strategy development, as well as insight into local/regional variations and the establishment of standardisations of care.[27]

Challenges of Current Data Systems in PEoLC

Historically, data collection systems for palliative care were paper-based, with significant primary data collection by busy clinicians, most commonly conducting retrospective chart reviews, all of which incurs significant time burden on a stretched-to-capacity, resource-limited, busy PEoLC teams in hospitals, hospices and communities. When evaluating EoLC, electronic patient-data collection systems offer several advantages over the traditional retrospective data collection, with the UK National Audit of Care at the end-of-life (NACEL)[28] utilising a national electronic database to gather data that allows the benchmarking of patients across hospitals within the National Health Service (NHS). Data about the last admission leading to death is collated at set times across hospitals in the NHS in order to compare the quality of care for patients and their love thus benchmarking PEoLC services across different hospital settings.[28] Some independent sector, charitable and hospice sector organisations both in the UK and internationally including Australia, also use electronic patient-data collection systems to benchmark EoLC i.e. the Australian Palliative Care Outcome Collaboration (PCOC).[29]

Electronic Incident Reporting System (Datix)

Datix — an electronic incident reporting system (EIRS) has been in use within healthcare worldwide since 1986; informing the collection and analysis of patient incidents, complaints, risk manage-

ment through to clinical governance in over 900 organisations and 19 countries.[30] Datix is now used within most organisations in the UK NHS, expanding its remit as the EIRS of choice for over 75% of NHS organisations in 2008, to now working with over 3500 organisations across acute, primary, secondary and community settings.[30] With focus primarily on patient safety, risk management and quality improvement through the reporting of incidents, Datix has been gaining steady prominence as highlighted by national scandals pertaining to governance, leadership and opioid mismanagement notably; the Mid-Staffordshire NHS Trust scandal, the Ian Patterson surgical scandal, the general practitioner–Harold Shipman, as well as The Gosport report.[31-34] Such national scandals support Kamal et al[25], Kamal et al[26] and Dy et al's[35] call for a cross-systems EIRS which will collect robust clinical data championing improved QoL, improve patient outcomes and survival.

Using Datix to Report Deaths in Our Hospital

Datix is the EIRS used within our hospital to report all deaths. Our hospital is the largest charitable private hospital in the UK with over 120,000 patient visits per year, supported by a team of over 900 consultants, surgeons and physicians in a hospital complex with 234 beds, 10 theatres and a 13-bed intensive care unit (ICU) covering medical inpatient as well as outpatient treatments focused on three core areas: cancer therapies, general surgery with a focus on digestive diseases, and musculoskeletal conditions.[36] On average we have approximately 60-80 deaths per annum before the coronavirus pandemic. All recorded deaths are for adults aged 18 and over, dying following admission to the hospital under the following heading: surgical, medical, oncological or any other cause for admission, expected and unexpected death. There are no deaths in accident and emergency (A&E)/urgent care/maternal centre because the hospital does not operate an urgent care, A&E or maternal unit and there are no reported suicidal deaths.

The Process of Data Collection Following a Death

Following the death of a ward or ICU patient at our hospital, the most senior nurse on the unit is tasked with the completion of an end-of-life care Datix incident form (EDIF), recording pre-defined details requested by the organisation (Graph 1). The main feature of the previous EDIF focused on the location of the death (ward, ICU, oncology, transplant unit etc.) and the mode of death or reason for admission i.e. unplanned ICU admission, pressure ul-
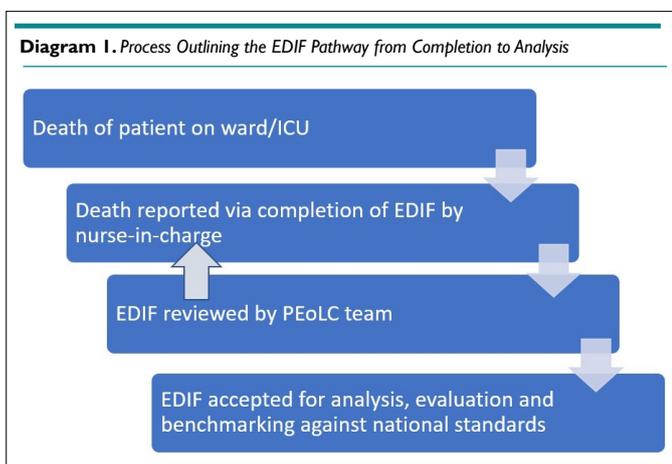
Graph 1. *Data Captured by the Previous Datix Incident Reports on Hospital Deaths*
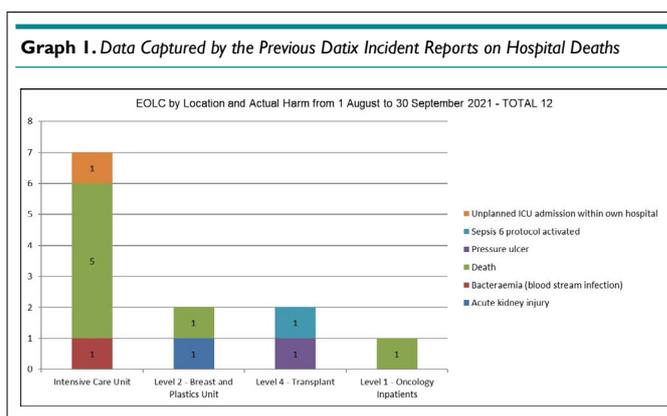
cer or bacteraemia etc., (Graph 1). The previous EDIF was not designed to capture data which Kamal et al[25], Kamal et al[26] and Dy et al[35] argue can be used to improve the QoL for PEoLC patients nor any data on patient outcome and survival.

METHOD

The Re-Design of the Hospital EDIF-Stakeholder Engagement

Working with the Clinical Governance and the ICU teams in our hospital, the PEoLC team (comprising a palliative care consultant and 2 specialist nurses) held several meetings to re-design the EDIF to include questions that captured the quality of the delivery of PEoLC across ward within the hospital. Our re-designed EDIF aligns the data it records with national standards on PEoLC based on recommendations for Care of the Dying Adult from the national regulatory body National Institute for Health and Care Excellence (NICE) guideline (NG)[31,37] the NICE quality standards and the document One Chance to get it right[38] with questions adapted from the NACEL (National Audit of Care at the EoL).[39] Following consensus agreement on adaptation of questions from the NACEL, we settled on a draft of the modified EDIF.

We then held a series of focus group and stakeholder engagement meetings over a 6-month period, alongside our Governance team, ICU team, and Information Technology (IT) team to evaluate the draft, fine-tuning and further develop the modified EDIF draft before agreeing on the current format (Table 1). Utilising plan-do-study-act (PDSA) cycles, these sessions were attended by ward staff across all disciplines in the hospital, with the draft reviewed at the EoL steering group before utilisation. As all deaths within our hospital is recorded as an incident, the IT and Governance teams were able to add the questions in Table 1 to the hospital-wide Datix system. Datix was then modified to ensure that the final sign-off (authorisation) of EDIFs, takes place following a final review by the PEoLC team thus ensuring documentation of appropriate answers to the questions including the uploading of relevant documents unto Datix i.e. patient's EoLC plan. For quality assurance incomplete EDIFs can be returned to the nurse-in-charge for further verification prior to analysis, evaluation and benchmarking against national standards from NICE, CQC and NACEL (Diagram 1).

Diagram 1. *Process Outlining the EDIF Pathway from Completion to Analysis*

Death of patient on ward/ICU

Death reported via completion of EDIF by nurse-in-charge

EDIF reviewed by PEoLC team

EDIF accepted for analysis, evaluation and benchmarking against national standards

Dissemination of EDIF at Ward Level

Although Datix is well established within most teams in our hospital, we recognise that the addition of extra questions regarding each death necessitates additional education, training and support in order to facilitate compliance, adherence and quality data collection. Hence the PEoLC team alongside the governance team, attend ward manager meetings, established educational sessions, staff communication sessions, in order to educate, train, support and raise awareness of the redesigned EDIF within the wards, ICU, across the hospital. We also targeted ward managers, advance and disease-specialist nurses to support the new EDIF data collection.

The next phase of the project will focus on the analysis, evaluation and benchmarking of the outcome of the newly designed EDIF following its current roll out in the private hospital. This will allow us to evaluate the care delivered the EoL in the private hospital against national and NHS standards, thus allowing us to benchmark the PEoLC delivery to our patients against national standards.

RESULT

Outcome of Stakeholder Engagement – the New EDIF

The outcome of the stakeholder engagements is the new EDIF form which was reached by stakeholder consensus at the focus group meetings (Table 1). As all deaths within our hospital is recorded as an incident, we were able to add the questions in Table 1 to the hospital-wide Datix system, to facilitate the collection of data in keeping with the stipulated PEoLC outcomes in Table 1.

Table 1: *EDIF Assessment Tool*	
1. Demographics	DOB, clinical condition
2. Was an EOLC Plan started for the dying patient?	Consultant signature?
3. Evidence of discussion about dying with patient, and or a reason why this was not recorded?	
4. Evidence of discussion about dying with family/carers?	
5. Evidence of ACP (recognition of the possibility of imminent death)	
6. Evidence of DNACPR	
7. If indicated, has a lasting power of Attorney for health been nominated?	
8. Spirituality and spiritual care needs documented?	
9. Evidence that families/carers were asked about their needs? (i.e. practicalities, psychological support offered)	
10. Evidence of rationalisation of drug chart at the EOL	
11. Evidence of setting of ceiling of care -? venepuncture, fluids, antibiotics	
12. Evidence of EOLC anticipatory medications (opiate, anti-emetic, anti-secretory and anxiolytic)	
13. Evidence of plan for nutrition and hydration	
14. Documentation of plan for care after death i.e. detail of funeral director, cremation or burial	
15. Has the patient recorded a decision NOT to donate or belong to an excluded group on the organ donation register?	
ACP- Advance Care Plan; DNACPR-Do Not Attempt Resuscitation; EOLC-End-of-life Care Plan	

DISCUSSION

Death as an Incident

In 2019/2020, according to the UK Office of National Statistics (ONS),[40] the leading cause of death in the UK was COVID-19 (73,766 deaths, 12.1%), followed closely by dementia and Alzheimer's disease (70,047 deaths; 11.5% of all deaths), then ischaemic heart diseases (55,807 deaths; 9.2%), followed by cerebrovascular diseases (29,737 deaths 4.9%) and lastly malignant neoplasm of trachea, bronchus and lung (28,745 deaths; 4.7%). Hence our intervention captured essential PEoLC quality indicator data as recommended by national guidelines in the UK. Firstly, we will explore the advantages and limitations to this theoretical concept of death as an 'incident'.

The National Patient Safety Association (NPSA) defines an incident as an event that could have had or did lead to an unintended or unexpected harm, loss or damage occurring during the care of the patient.[41] Whilst prognostication is notoriously challenging, it may be argued that deaths secondary to dementia, Alzheimers disease, cerebrovascular disease and cancer (all of which account for 42% of total deaths in the UK in 2019/2020), are not entirely 'unexpected', thus 'the harm, loss or damage caused' has elements of predictability inherent in the disease trajectories of these conditions.[42-45] For example, whilst complexities exist in the classification of dementia as a disease group, common components of dementia include elements of progressive degeneration, alongside both acute as well as chronic progression over time. These characteristics are not unique to dementia thus it may be argued that death in these disease trajectories are not 'incidents' as they did not lead to 'an unintended or unexpected harm' as per the NPSA definition of incidents.

However, in contrast to the NPSA definition, in their International Delphi analysis 'Towards Learning from patient safety reporting systems', Lord Ara Darzi in collaboration with Howell et al[46] identified an incident simply as 'an event that either could or did lead to patient harm', of which death is undoubtedly a 'harm'.

Linking 'incident' to Patient Safety

The principle of incident reporting serves as a mechanism for detecting and analysing adverse events, as well as capturing key learning surrounding these deaths.[47] This is one of the reasons why death is reported as an incident in our hospital, as an approach to harness learning around each death, cascading any notable insights through the Governance team to the rest of the hospital on a regular basis as is the mechanism for the utilisation of Datix incidents to improve patient safety. Thus, healthcare organisation should consider the improved utilisation of EIRS systems embedded in their organisations as a means of capturing learning from each death with a view to improving the organisational patient safety.[48]

The recent introduction in April 2019 of the medical examiner role by the UK Department of Health, a role which aims to proportionately review all deaths within the organisation, drawing together the attending doctor's views alongside any issues raised by the bereaved family in order to identify the appropriate 'cause of death' would be supported by the use of a modified Datix incident system i.e. our EDIF.[49] Whilst the medical examiner role incorporates key organisational learning, the use of the proposed EDIF may also facilitate 'clinical governance systems, to highlight deceased patients who require a mortality case record review so that any learning can be gained by the provider organisation'.[50] Thus, in light of opioid scandals such as The Shipman and even Gosport enquiries, there is a notable argument that the reporting of all deaths as an incident is of overall benefit for the organization, serving as a means of providing an opportunity for all deaths to have some level of scrutiny whilst utilising the organisation's existing EIRS.[32-35] Incorporating EDIF alongside the identification of patient safety incidents and cascading of knowledge through the appropriate organizational channel would aim to improve the overall quality of care within the healthcare organisation.

LIMITATIONS

The quality of the EDIF is dependent on the information entered hence the need for verification prior to finalization of the form. The need to train staff is a critical step which may address issues around compliance and adherence to its utilisation. There are also challenges governing the use of Datix which must be balanced with the benefits of organisational learning, and improved safety, notably concerns over its weaponisation, potential mis-use as a means of apportioning blame, as well as the possibility of increasing anxiety for junior staff given the involvement of middle management in the oversight of Datix forms within hospitals.[51-56]

However, a systematic review by Stravlopolous et al[48] on incident reporting systems showed that whilst these systems can improve clinical settings and processes, the evidence that they ultimately improve patient outcomes or enable cultural change is limited. One significant limitation resulting in the paucity of evidence from their systematic review is the inherent challenge in the definition of an 'incident' which is buttressed by the challenges identified above in defining death as an incident.

CONCLUSION AND RECOMMENDATION

Thus, the use of Datix to report deaths may further enhance the learning, culture and utilisation of quality metrics around deaths.[49] Ultimately whilst Datix as a tool is limited by its negative association with a blame culture, the power of Datix lies in the information captured and what we do with that information which is why we have re-designed our EDIF, with the aim of improving PEoLC data– its interpretation, analysis, evaluation, synthesis as well as its use to improve practice. It is likely that EIRS such as Datix will remain an option for PEoLC teams to choose as a means of improving the collection of patient data and its subsequent utilisation to improve patient safety. However, as Kamal et al,[25] Kamal et al[26] and Dy et al[35] have demonstrated, healthcare organisations must continue to explore the benefits of a robust electronic data collecting system, particularly systems that improve QoL, survival and patient outcomes.

As a tool, Datix needs to be supported by the appropriate

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educational, training and system wide engagement within health-care organisations alongside a cultural shift in order to facilitate their utilisation as a meaningful tool for the improvement of patient safety. However, further research is needed with regards to the role of automated EIRS in PEoLC particularly around the effective use of digitalised, automated support tools in the management of EoLC patients across care settings.

INSTITUTIONAL REVIEW BOARD

This study is exempt from Institutional Review Board (IRB) and does not meet the criteria for ethical approval. Accessed February 24, 2021.

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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