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Views and experiences of using integrated care pathways (ICPs) for caring for people in the last days to hours of life: results from a cross-sectional survey of UK professionals

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ABSTRACT

Objectives To determine the views and experiences of health and social care professionals on using integrated care pathways (ICPs) for caring for people in the last days to hours of life.

Methods Online cross-sectional questionnaire survey of UK professionals working in UK primary and secondary care settings.

Results 1331 professionals returned completed questionnaires. Ninety-three per cent (1138/1228) of respondents used the Liverpool Care Pathway (LCP) or local variant. Eighty-eight (1089/1234) felt ICPs enabled professionals to provide better care for individuals and their families/carers. ICPs were viewed as promoting patient-centred holistic care, improving pain and symptom control, providing guidance and standards and improving communication with patients/families. Sixty-two per cent (770/1234) had no concerns regarding the use of ICPs. Areas of concern included incorrect use and implementation of the ICP, poor communication with families, junior level staff making decisions and insufficient education and support.

Conclusions There was strong support for using ICPs for caring for people in the last days to hours of life. ICPs were viewed as supporting high-quality patient-centred holistic care. Given the recommendations of the More Care Less Pathway report, those that develop the guidance and support that replace the LCP need to incorporate the aspects of this that have resulted in the benefits seen by professionals within this survey, but also learn from the instances where ICPs have failed to prevent poor care, or worse, have contributed to it.

INTRODUCTION

The Liverpool Care Pathway (LCP) has been suggested as a model of good

practice in the last hours and days of life by successive national policy frameworks.^{1–6} It is a model of care which enables healthcare professionals to focus on care in the last hours or days of life when a death is expected.^{7–9} It is a multi-professional document that covers patient comfort measures and important areas of communication with the relative, carers and the patient, ongoing assessment, which guides the regular assessment of the patient at least every 4 h and care after death, which supports relatives and carers in the immediate hours after the patient's death.⁹

However, because of substantial criticism of the LCP in the media and elsewhere, a group of 20 UK organisations and professional bodies came together during September 2012 to develop a consensus view on ICP for the last days of life.¹⁰ This short report presents the findings from the survey of UK health professionals involved in using ICPs for caring for people in the last days to hours of life end of life.

Aims of the survey

1. To assess views and experience of health and social care professionals of using ICPs for caring for people in the last days to hours of life.
2. To assess the extent, nature and basis of any concerns regarding the use of ICP.

METHODS

Study design

This cross-sectional online secure questionnaire survey (Poll daddy-<http://www.poll daddy.com>) survey software was

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designed, based on expert opinion of an experienced reference group of members of stakeholder organisations and professional bodies who had signed the consensus document. It included 27 Likert-style questions and incorporated both open and closed questions focusing on views and experiences of ICPs specifically in terms of quality of care using an ICP, view regarding extent to which ICPs led to patients dying more rapidly than if an ICP had not been used, knowledge of the decision to initiate ICP and influences to this decision and elements of the ICP that were viewed as helpful, unhelpful or cause for concern. Finally, the respondents were given the opportunity to add any further comments they felt important or relevant. NHS ethical approval was not required for this survey as it was focused on specialist healthcare professionals accessed via stakeholder organisations and professional bodies. Consent to participate in the study was inferred due to the nature of how the participants were recruited that is, voluntarily and anonymously completed the online survey.

Study population and recruitment

The questionnaire was sent to named contacts at the professional bodies (table 1) with guidance on inclusion criteria. These organisations then distributed the online survey to all eligible members.

Inclusion criteria: Registered healthcare or social care professionals directly involved in initiating and using the documentation of ICPs. As the questionnaire was anonymous, no reminders were sent to potential

Table 1 Professional organisations for dissemination of the survey

| Professional groups | Professional organisations represented on the expert reference group and/or dissemination of survey |
|--|---|
| Hospital physicians | Royal College of Physicians APM* British Geriatric Society (BGS)* |
| GPs | Royal College of General Practitioners* |
| Surgeons | Royal College of Surgeons |
| Registered nurses | Royal College of Nursing* Palliative Care Nurse Consultant Nursing and Midwifery Council |
| Healthcare assistants | Royal College of Nursing |
| Care home staff | National Care Forum English Community Care Association |
| Chaplains | Hospital Chaplaincies Council |
| Allied health professionals | College of Occupational Therapists and Physiotherapists |
| Social workers | Association of Directors of Adult Social Services |
| Professional organisations represented on the expert reference group not involved in dissemination | |
| | National Council for Palliative Care |
| | National End of Life Care Programme |
| | Neuberger Review Panel |

*Represented on the expert reference group and used in the dissemination of survey.

GPs, general practitioners.

respondents nor were the study team able to compare the characteristics of responders and non-responders. Data were analysed using the Statistical Package for Social Scientists (V.20) and used descriptive frequencies and distributions. Qualitative free text open responses were analysed independently by two experienced qualitative researchers (PH/KC) and due to the large volume of data was subject to a summative content analysis. This involves counting and comparisons, usually of keywords or content, followed by the interpretation of the underlying context.¹¹

RESULTS

A total of 1331 complete questionnaire survey responses were received. Over half of respondents (58%, 773/1329) had a medical background, 30% (397/1329) a nursing background and 12% (159/1329) other (including social work and education).

Almost a fifth (18%) of respondents classified themselves as Hospital Medicine/Surgery—Consultant, while 13% are Palliative Medicine—Consultant. The next largest groups represented are Primary Care general practitioners (9%) and Generalist Nurses (9%). Specialist Palliative Care Nurses accounted for 8% of respondents (table 2).

Table 2 Professional background

| What is your professional background? (n 1331) | Per cent |
|--|----------|
| Hospital Medicine/Surgery—Consultant | 18 |
| Primary Care—GP | 9.4 |
| Palliative Medicine—Consultant | 13.3 |
| Specialist Palliative Care Nurse | 8.3 |
| Generalist Nurse Banding (all settings) | 9.0 |
| Other | 2.9 |
| Hospital Medicine/Surgery—Specialty Trainee | 5.5 |
| Palliative Medicine—Specialty Doctors/Staff Grade/Associate Specialist | 4.1 |
| Primary Care—GP Trainee | 1.5 |
| Community Nurse | 6.1 |
| Hospital Medicine/Surgery—Specialty Doctors/Staff Grade/Associate Specialist | 1.7 |
| Specialist Nurse (Other) | 4.4 |
| Hospital Medicine/Surgery—Core Medical/Surgical Trainee | 1.1 |
| Primary Care—GP with Special Interest | 0.9 |
| Community Matron | 0.6 |
| Hospital Medicine/Surgery—Foundation Year Trainee | 0.2 |
| Consultant Nurse in Specialist Palliative Care | 0.8 |
| Consultant Nurse (Other) | 0.2 |
| Allied Health Professional | 3.0 |
| Chaplaincy | 5.8 |
| Health Care Assistant/Assistant Practitioner | 0.7 |
| Palliative Medicine—Specialty Trainee | 2.6 |
| Social Work | 0.2 |
| | 100.0 |

GP, general practitioner.

Almost half of the respondents (46% 609/1323) stated hospital as their main place of practice. When adding in the people with multiple places of work, this increased to 58% (767/1323) conducting some level of hospital work. Almost two-fifths (39% 516/1323) worked in the community (to some extent) with over a quarter (29% 384/1323) exclusively working in the community. Almost a fifth (19% 251/1323) stated a hospice/Palliative Care Unit as main place of practice with 9% (119/1323) working solely in this area.

The majority of respondents (93% (1138/1228) used the LCP or a locally developed variation of the LCP (61%, 749/1228) and 32% (389/1228) respectively.

Three substantive areas were included within the survey and these are presented alongside each other to provide some detail to the survey findings.

Use of ICP enabling better care

Eighty-eight per cent (1089/1234) of respondents said that they agreed/strongly agreed that the use of an ICP enables professionals to provide better care for the individual and their families and carers. The content analysis undertaken on the qualitative responses supported these findings. Important themes concerning the helpfulness of the pathway were: its role in the redirecting of care; acting as a prompt or checklist; providing guidance and standards; and in documenting care. Concerning patient care were the promotion of patient-centred and holistic care; improved symptom control; and improved communication with patients and families. Concerning the team were: the coordination of care; providing a structure for care; its role in helping advance preparation; and support for staff. Improvements in care since the introduction of a pathway were also noted. Themes from those who disagreed were the discouragement of individualised care; the rigid introduction or application of the pathway and the unsuitability of the pathway for some patient groups.

Use of ICP leading to patients dying more rapidly

Seventy-six per cent of respondents (942/1234) disagreed with the statement that the use of an ICP has led to patients dying more rapidly than if an ICP had not been used. Eighteen per cent of respondents were neutral (218/1234) with only 6% (77/1234) agreeing with this statement. The qualitative data supported these results with a reiteration that death was not hastened by its use. In addition, the contrary was said by some respondents: that use of the pathway and the withdrawal of burdensome treatment could extend life. Additionally the value of helping people to have a pain free, peaceful and dignified death was a further theme. There were views from the minority accepting that death might be more rapid, (although this was generally considered marginal) and ascribing it to the use of drugs or withdrawal of treatments.

Concerns regarding the use of ICPs

Sixty-two per cent (770/1234) of respondents had no concerns about inappropriate use of ICPs in their local area or organisation. Twenty-nine (356/1234) had minor concerns and 9% (108/1234) had moderate/major concerns. The qualitative data supported these results. Themes identified were enhanced care, improved comfort and symptom control. Concerns included incorrect use of the pathway, particularly, rigid use as a protocol; implementation of the pathway in inappropriate circumstances, particularly where other care might have been better; poor communication with families on the nature of the pathway and what it means in use; staff making decisions being at too junior a level; and insufficient initial and ongoing education and support.

DISCUSSION

These findings broadly support previous reports^{12 13} conclusions that when the LCP is operated by well trained, well-resourced and sensitive clinical teams, it works well. The LCP and similar ICPs for the last days of life were, thought by the majority to enable professionals to provide better care for the individual and their families and carers and promoted patient-centred and holistic care. However, there were examples of poor implementation, lack of individualisation, misunderstanding, misinterpretation and misuse to be of concern. While, when implemented well, benefits were reported, communication, training and support were key concerns and where these did not accompany implementation the LCP did not only fail to prevent poor care but occasionally may have inadvertently contributed to it. Levels of self-reported competence were generally high but these may not reflect performance.¹⁴

While the majority found all aspects of the elements covered by ICPs and guidance helpful the least helpful were relating to clinical decision-making around continuing or withdrawing clinically assisted nutrition and hydration, decisions when individuals have reduced mental capacity and decisions about removing a patient from an ICP. These were the areas where most concerns have been raised about poor practice and therefore guidance on these clearly needs to improve.

This survey has all the limitations of an on-line survey canvassing responses via a range of strategies through professional body contacts. In 2012 the NHS employed 146 075 doctors, 369 868 qualified nursing staff. The majority of these will be in England. While not all will be involved in caring for dying patients a significant proportion will as part of their working lives. Therefore, the potential response is far higher than the actual response rate. We do not know who completed the online survey or reasons for declining and therefore we are unable to compare the characteristics of responders and non-responders in terms of

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their views and experiences of ICP. There will have been a degree of self-selection towards those who were interested in the topic and perhaps a bias towards those who had strong views one way or the other.

However, a key strength of the survey was that it was UK based with a sample of more than 1300 respondents from a whole range of settings and professional groups with experience of the ICP working in the field of specialist palliative care and non-specialist palliative care settings. Additionally, the use of qualitative open-ended survey responses also allowed for nuanced interpretation of the quantitative elements and provided a more detailed understanding of the views of HCPs towards the use and implementation of ICPs. The survey's findings are similar to the *BMJ* survey findings of broad support for the pathway by doctors.¹⁵

CONCLUSIONS

There was strong support for using ICPs for caring for people in the last days to hours of life.

ICPs were viewed as supporting high-quality patient-centred holistic care. Health Services needs to give more priority to the care of patients who are dying and the families and carers that support them. Professionals caring for dying patients need to be better trained, be given more time for sensitive communication with patients and carers and have better access to support from Specialist Palliative Care when their skills or resources are stretched. Given the recommendations of the recent More Care Less Pathway report,¹² those that develop the guidance and support that replace the LCP need to both incorporate the aspects of this that have resulted in the benefits seen by professionals within this survey but also learn from the instances where ICPs have failed to prevent poor care, or worse, have contributed to it.

Contributors The Association of Palliative Medicine (DB) initiated the study. GF and DB with input from an expert reference group and support from professional bodies listed in [table 1](#) designed and distributed the survey. DB and KAC had overall responsibility for the study. KAC, PMH, RI undertook the analysis and interpretation of data. KAC wrote the first draft of the paper. All authors helped to prepare the final report and have seen and approved the final version. KAC and DB are the guarantors for the study.

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Competing interests None.

Ethics approval This study was a National online survey of specialist healthcare professionals accessed via stakeholder

organisations and professional bodies therefore NHS ethical approval was not required for this study. Consent to participate in the study was inferred due to the nature of how the participants were recruited that is, voluntarily and anonymously completed the online survey.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Consent was not obtained from participants for data sharing as it was an online survey that was voluntary and participants were not required to provide personal identification details. The presented data are anonymised and risk of identification is low.

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