Impact of the Liverpool Care Pathway on quality end-of-life care in residential care homes and home care—Nurses’ perceptions

Cecilia Olsson\textsuperscript{1} | Elisabeth Kling\textsuperscript{1} | Karina Grundel Persson\textsuperscript{2} | Maria Larsson\textsuperscript{1}

\textsuperscript{1}Department of Health Sciences, Karlstad University, Karlstad, Sweden
\textsuperscript{2}Municipal Health and Medical Care, Arvika, Sweden

Correspondence
Cecilia Olsson, Department of Health Sciences, Karlstad University, Karlstad, Sweden.
Email: cecilia.olsson@kau.se

Abstract

Aim: Aim was to describe how Registered Nurses (RNs) and assistant nurses (ANs) working in residential care homes and home care perceived quality end-of-life care after implementation of the Liverpool Care Pathway (LCP) in terms of subjective importance of care aspects and actual care given.

Design: Descriptive cross-sectional.

Methods: Registered Nurses (N = 22; 100% response rate) and ANs (N = 120; 59% response rate) working in a Swedish municipality. Data collection with a study-specific questionnaire (50 items) about perceived reality (PR) and subjective importance (SI). Non-parametric statistics.

Results: Implementation of the LCP ensured systematic assessment and alleviation of patients’ symptoms and needs. The ANs, more than the RNs, perceived that the patients received the best possible nursing and medical care (p = .01). Both groups considered that communication with patients and families as well as the information exchange between the team members was facilitated. Areas for improvement were identified about psychological and existential support and patients and families’ participation in care.

Keywords: clinical pathway, community care, end-of-life care, Liverpool Care Pathway, quality of care

1 | INTRODUCTION

The need for palliative care in general and qualified end-of-life (EoL) care in particular is increasing in Western societies because of a growing ageing population often suffering from multiple chronic diseases (Eurostat, 2015; Kinley, Froggatt, & Bennett, 2011; Veerbeck et al., 2008). Out of the approximately 90,000 persons who die annually in Sweden, about 90% are over 65 years and 70% are over 75 years. Most persons are cared for in community care, that is residential care homes (RCHs) or home care (HC) (The National Board of Health & Welfare [NBHW], 2017, 2018), with a higher proportion of people dying in RCHs compared with most other European countries (Håkanson, Öhlén, Morin, & Cohen, 2015). Palliative care has received increased attention in Sweden during the last years, and the government has taken steps to ensure quality of EoL care (Henoch et al., 2015). The need for structured and standardized EoL is also highlighted in the Swedish national guidelines for palliative care, which were launched in 2012 (NBHW, 2013) and revised in 2016 (Confederation of Regional Cancer Centres in Sweden [CRCC], 2016; NBHW, 2016).
End-of-life care is complex and puts high demands on the health-care services about both competence and structure (Finucane, Stevenson, Moyes, Oxenham, & Murray, 2013). A fundamental prerequisite for quality EoL care is honest communication between healthcare personnel and the dying person and their family (Ekeström, Olsson, Runesdotter, & Fürst, 2014; HenoCH, Lövgren, Wilde-Larsson, & Tishelman, 2011; Miettinen, Alaviukola, & Pietilä, 2001). Critical quality indicators are symptom control and management of psychological and existential needs (Chapman & Ellershaw, 2011; Finucane et al., 2013; Jackson et al., 2012). However, research in RCH or HC settings reveals unmet physical, psychosocial and emotional needs, inadequate symptom relief and a lack of social and emotional support (Andersson, Lindqvist, Fürst, & Brännstrom, 2017; World Health Organization [WHO], 2011). Furthermore, in one study, nurses report difficulties in communicating about death and a lack of a shared approach to EoL care (Cronfalk et al., 2015).

In spite of a solid evidence base for effective interventions to meet the needs of the dying person and their family, implementation of best practice is still a challenge (McConnell, O’Halloran, Donnelly, & Porter, 2015). One suggested way to promote high-quality EoL care is to use integrated care pathways, that is, structured assessments and evaluation of a patient’s symptoms and needs, together with a description of process and clear goals for the patient’s care (Ekeström et al., 2014; Ellershaw, 2007; Veerbeck et al., 2008). The Liverpool Care Pathway (LCP) for dying patients is one such tool used bedside to promote optimal care of the dying in the last days and hours of life, aiming to transfer best practice from hospice settings to other care settings (Duffy & Woodland, 2006; Watson, Hockley, & Dewar, 2006). The LCP includes decision-making support to identify imminent death, pharmacological and non-pharmacological strategies for symptom management and communication with the dying person and their family (Ellershaw & Wilkinson, 2011; Ellershaw, Smith, Overill, Walker, & Aldridge, 2001). The LCP was initially developed to ensure high-quality EoL care for patients with cancer but has also been shown to be appropriate irrespective of diagnosis and is now used also in other care settings including RCHs and HC (Brännström, Fürst, Tishelman, Petzold, & Lindqvist, 2016; Chapman & Ellershaw, 2011; Ekeström et al., 2014).

However, since the Neuberger report from the UK Department of Health (2013), the LCP has been criticized and its benefits questioned. Although the report acknowledged positive effects of the LCP when used as intended, the authors highlighted the risk of poor care related to inappropriate implementation and lack of competence in EoL care. Not least, malpractice was evident in older, non-cancer patients. The need for scientific evidence for the use of integrated care pathways, including the LCP, in EoL care is evident (Brännström et al., 2016; Chan & Webster, 2013; Husebe, Flo, & Engedal, 2017) as is the need for studies focusing quality care in a comprehensive way. This is especially true for the care of the dying in community care settings.

1.1 : Aim

The aim was to describe how Registered Nurses (RNs) and assistant nurses (ANs) working in RCHs and HC perceived quality end-of-life care after implementation of the LCP in terms of subjective importance of care aspects and actual care given.

2 : METHODS

2.1 : Design

A cross-sectional survey study with a descriptive approach was conducted between January–June 2014.

2.2 : Setting and implementation of the Liverpool Care Pathway

This study was conducted in a municipality situated in mid-Sweden. Here, approximately 26,000 inhabitants live in rural and urban areas spread over 2000 km². Patients enrolled in HC or living in an RCH are generally older and suffer from cancer and/or dementia diseases and/or multiple illnesses. During the study period, approximately 35 patients died in HC and 41 patients died in RCHs (N = 6). Healthcare staff primarily consist of ANs responsible for daily care and RNs responsible for nursing and medical care. General practitioners assess patients’ status, make medical diagnoses and prescribe medication on a consultative basis.

During October 2011-December 2013, all RNs (N = 48) and ANs (N = 402) working in RCHs and HC in the municipality were introduced to the LCP version 11. This version was earlier translated by the Swedish coordination group of LCP (Andersson, Lindqvist, Fürst, & Brännström, 2018a). The introduction, carried out in collaboration with the Swedish LCP coordination centre, included a 3-hr session in quality EoL care and use of the LCP in accordance with its guidelines. Thereafter, the chief nurse of the municipality was responsible for quality assurance of the introduction and implementation process and for coordinating the contact RNs appointed at each RCH and HC district in the municipality. The chief nurse and all RNs took part in a web-based LCP training course and thereafter acted as resource persons for the implementation of the LCP. To assure quality and identification of areas in need of improvement, quality indicators in the Swedish Palliative Register were continuously used as guidance and the documentation in every LCP record was reviewed about completeness.

2.3 : Data collection

2.3.1 : Participants

The inclusion criterion was the experience of EoL care during at least one year before implementation of LCP and a minimum of one experience of caring for a patient according to the LCP, resulting in an eligible population of N = 250. Twenty-two RNs and 205 ANs agreed to participate in the study. All 22 RNs (response rate: 100%) and 120 ANs (response rate: 59%) responded to the questionnaire. Reminders were sent twice, 2 weeks apart, to non-responders (Figure 1).
2.3.2 | Questionnaire

A study-specific questionnaire titled ‘LCP—impact on quality care of the dying (LCP-IQCD)’ was developed and structured on the basis of the Swedish LCP version 11 to evaluate how RNs and ANs perceived the impact of the LCP on the care of the dying in HC and RCHs.

Background data include eight items: gender; age; profession; years in the profession; and experience with and introduction of the LCP (four items). The LCP-IQCD includes 50 items about general aspects of quality EoL care; systematic assessment and alleviation of symptoms; communication and information; and care after death. These 50 items were answered in two ways: perceptions of the actual care performed (perceived reality—PR scale) and importance of each aspect of care (subjective importance—SI scale), based on the structure of the Quality from the Patients’ Perspective (QPP) questionnaire by Wilde, Larsson, Larsson, and Starrin (1994) and Wilde Larsson and Larsson (2002). The SI scale measures RNs’ and ANs’ preferences and what is considered important aspects of EoL care. Thus, RNs’ and ANs’ perceptions of the care performed (PR scale) were measured by items introduced with the phrase: ‘This is how I perceive ... to be’ and perceptions of how important each aspect of care was (SI scale) were measured by items introduced with the phrase: ‘This is how important ... is to me in my work’. A 4-point (Likert-type) response scale, ranging from 1 (do not agree at all)–4 (fully agree), was used for the PR scales. The response scale for SI scales ranged from 1 (of little or no importance)–4 (of the very highest importance). The questionnaire ends with three open-ended questions about advantages and disadvantages of the LCP and suggestions for improvement.

![Flow diagram of the study](image)

FIGURE 1 Flow diagram of the study

The LCP-IQCD was reviewed for face and content validity and clarity of meaning by seven RNs working in community care and two university lecturers in nursing with extensive knowledge of and clinical experience in EoL care. In addition, one nurse responsible for introducing the LCP in Sweden, a medical doctor and a professor with long experience in LCP implementation in nursing homes reviewed the questionnaire. The feedback of the review team (N = 12) consisted of minor questions about wording. No questions were added or excluded.

2.4 | Research ethics committee approval

The study was approved by the local ethics committee at Karlstad University (Dnr. C2013/763) and carried out in accordance with the ethical guidelines for nursing research in the Nordic countries (Northern Nurses’ Federation, 2003). Permission to carry out the study was obtained by the Head of Community Care Administration. Verbal and written information about the survey study was given to all RNs and ANs, and informed consent was obtained before start of the study. Information included the aim and study design and information about voluntariness and confidentiality.

2.5 | Data analyses

The Statistical Package for Social Sciences (SPSS), version 20.0, was used for analysis. Descriptive statistics were used to describe participant data, including medians, ranges, per cent, mean values and standard deviation (SD). Mann–Whitney U test was used to compare differences in PR between independent groups: RNs and ANs. Wilcoxon signed-rank test was used to examine differences in PR–SI in depended groups: RNs and ANs, respectively. All statistical tests were two-tailed, and p ≤ .5 was considered statistically significant (Field, 2009). Directed content analysis was used to analyse the open-ended questions (Hsieh & Shannon, 2005). Quotes have been used to illustrate and strengthen the quantitative findings.

3 | RESULTS

This study was based on 142 participants (22 RNs and 120 ANs). Most participants were women (N = 139) with a mean age of 50.45 (Md 50.45, range 23–66) years (Table 1).

3.1 | General aspects of quality end-of-life care

Registered Nurses’ and ANs’ perceptions of general aspects of EoL care after implementation of the LCP are shown in Table 2. Both groups perceived that the implementation of the LCP had meant improvements in EoL care as the LCP meant safe and quality EoL care (RN: PR mean 3.41, SD: 0.67; ANs: PR mean 3.53, SD: 0.59); they also thought that the care had become more structured (RN: PR mean 3.50, SD: 0.67; ANs: PR mean 3.47, SD: 0.57), and interventions had become easier to evaluate (RN: PR mean 3.29, SD: 0.84; ANs:
TABLE 1  Characteristics of participants (N = 142)

| Gender        | N   | %  |
|---------------|-----|----|
| Women         | 139 | 98 |
| Men           | 3   | 2  |
| Age (years)   |     |    |
| Mean          | 50.45 |    |
| Median        | 50  |    |
| Range         | 23–66 |    |
| Profession    |     |    |
| Registered Nurses | 22 |    |
| Assistant Nurses      | 120 |    |
| Years in profession |   |    |
| Median        | 20  |    |
| Range         | 1–43 |   |
| Experience of LCP (no.) |     |    |
| Median        | 4   |    |
| Range         | 1–30 |   |
| Workplace     |     |    |
| Residential care homes (N = 6) | 107 | 75 |
| Home care     | 35  | 25 |

Abbreviation: LCP, Liverpool Care Pathway.

PR mean 3.34, SD: 0.76). Both groups also perceived that initiation of the LCP created awareness that the care provided was EoL care as the patient had been identified as dying (RNs: PR mean 3.14, SD: 0.89; ANs: PR mean 3.48, SD: 0.80).

The care was good before the LCP was implemented, but the structure of the pathway improved security, transparency and participation for all personnel, patients and families and ensured that no mistakes were made. – Everybody feels that they have more control of the patient’s situation.

(AN, female, 48 years, working in HC)

Statistically significant differences were found when comparing the scores for PR and SI about participation of patients and families in EoL care. Both groups considered participation more important than they perceived that it actually was (patient participation: RNs: PR mean 2.10, SD: 1.04; SI mean 2.82, SD: 1.18; p = .01; ANs: PR mean 2.50, SD: 0.99; SI mean 3.35, SD: 0.80; p = .00; family participation: RNs: PR mean 2.67, SD: 1.06; SI 3.14, SD: 0.94; p = .03; ANs: PR mean 2.72, SD: 0.98; SI mean 3.35, SD: 0.80; p = .00) (Table 2).

When comparing RNs’ and ANs’ PR scores for general aspects of quality of EoL care, we found statistically significant differences in three items. The ANs, much more than the RNs, were of the opinion that the implementation of the LCP meant that patients received the best possible nursing and medical care (RNs: PR mean 3.18, SD: 0.80; ANs: PR mean 3.54, SD: 0.76; p = .01). In addition, the ANs scored higher agreement, compared with the RNs, with the statement that the documentation of nursing interventions had improved since implementation of the LCP (RNs: PR mean 2.68, SD: 1.09; ANs: PR mean 3.37, SD: 0.86; p = .01). Assistant nurses’ responses furthermore indicated higher agreement, compared with RNs, with the statement that pain assessment using the LCP was performed with a VAS or the Abbey Pain Scale (RNs: PR mean 2.55, SD: 0.96; ANs: PR mean 3.05, SD: 0.98; p = .02).

3.2 | Systematic assessment and alleviation of symptoms

The RNs’ and ANs’ perceptions about assessment and alleviation of symptoms after implementation of the LCP are shown in Table 3. Both groups perceived the LCP to be a tool for systematic assessment and alleviation of patients’ physical, psychological and existential symptoms, problems and needs. Both groups also reported that the implementation of the LCP had improved EoL care about psychological support and religious/existential needs. However, both groups considered these issues to be of greater importance (SI) than they had actually been achieved (PR) (psychological support: RNs: PR mean 2.50, SD: 1.10; SI mean 3.10, SD: 1.33; p = .01; ANs: PR mean 2.84, SD: 0.99, SI mean 3.70, SD: 0.62; p = .00; religious/existential needs: RNs: PR mean 2.36, SD: 1.05; SI mean 3.00; SD: 1.21; p = .01; ANs: PR mean 2.67, SD: 0.96; SI mean 3.53, SD: 0.73; p = .00).

Comparing the scores between the groups showed statistically significant differences in three items: the RNs scored lower than the ANs on the item of identification of oral symptoms, urinary problems and pressure ulcers (Table 3).

3.3 | Communication and information

Registered Nurses’ and ANs’ perceptions about communication and information after implementation of the LCP are shown in Table 4. Both groups perceived that dialogues with both the patient and their family about the patient’s imminent death had been facilitated by introduction of the LCP. When comparing the RNs’ and ANs’ PR scores, we found statistically significant differences about whether the patient received the information they needed to understand the plan of the care (RNs: PR mean 2.19, SD: 1.03; ANs: PR mean 2.81, SD: 0.89; p = .01).

When comparing PR and SI scores in groups, the ANs’ scores for SI were statistically significantly higher than their PR scores for most of the items (Table 4). For RNs, the item scores for SI were statistically significantly higher about ‘the doctor explains and discusses the imminent death to/with the patient (p = .01) and family (p = .04),’ ‘my communication with patients (p = .01) and family (p = .02) at EoL has improved’ and ‘the patient gets the information they need to
TABLE 2  Responses to questionnaire items on general aspects of quality EoL care

| Implementation of the LCP means that ... | Registered Nurses (RN) (N = 21–22) | Assistant nurses (ANs) (N = 109–120) | Differences between RNs and ANs |
|----------------------------------------|-----------------------------------|------------------------------------|-------------------------------|
|                                       | Perceived reality (PR) | Subjective importance (SI) | Perceived reality (PR) | Subjective importance (SI) | Perceived reality (PR) | p-value* | p-value** |
| ... the care patients receive at Eol is safe and of good quality. | 3.41 (0.67) | 3.41 (1.18) | 1.00 | 3.53 (0.59) | 3.81 (0.49) | 0.00 | 0.46 |
| ... the care patients receive at Eol is structured. | 3.50 (0.67) | 3.36 (1.00) | 0.80 | 3.47 (0.57) | 3.57 (0.66) | 0.20 | 0.75 |
| ... it is evident that the patient is imminently dying. | 3.14 (0.89) | 2.95 (1.13) | 0.43 | 3.48 (0.75) | 3.52 (0.72) | 0.39 | 0.57 |
| ... the documentation on patients’ medical treatment at Eol has improved. | 2.77 (1.11) | 3.33 (1.06) | 0.01 | 3.24 (0.88) | 3.62 (0.60) | 0.00 | 0.06 |
| ... the documentation on nursing interventions to patients at Eol has improved. | 2.68 (1.09) | 3.24 (1.18) | 0.02 | 3.37 (0.86) | 3.63 (0.64) | 0.01 | 0.01 |
| ... knowledge of the patient’s religious and existential needs has improved. | 2.50 (1.10) | 2.14 (1.11) | 0.72 | 2.40 (0.97) | 1.72 (0.85) | 0.00 | 0.71 |
| ... the family participate in Eol care to a greater extent. | 2.67 (1.06) | 3.14 (0.94) | 0.03 | 2.72 (0.98) | 3.35 (0.80) | 0.00 | 0.84 |
| ... the patient participates in Eol care to a greater extent. | 2.10 (1.04) | 2.82 (1.18) | 0.01 | 2.5 (0.99) | 3.35 (0.80) | 0.00† | 0.11 |
| ... nursing and medical interventions are easier to evaluate. | 3.29 (0.84) | 3.33 (1.11) | 0.85 | 3.34 (0.76) | 3.66 (0.62) | 0.00 | 0.88 |
| ... pain assessment is performed using a VAS or the Abbey Pain Scale. | 2.55 (0.96) | 2.81 (1.29) | 0.31 | 3.05 (0.98) | 3.56 (0.74) | 0.00† | 0.02 |
| ... the patient receives the best possible nursing and medical care. | 3.18 (0.80) | 3.45 (1.10) | 0.18 | 3.54 (0.76) | 3.94 (0.34) | 0.00 | 0.01 |
| ... RNs and ANs treat the patient with respect. | 3.52 (0.81) | 3.45 (1.10) | 0.84 | 3.61 (0.79) | 3.95 (0.33) | 0.00 | 0.47 |
| ... RNs and ANs care treat the patient’s family with respect. | 3.48 (0.81) | 3.45 (1.10) | 1.00 | 3.63 (0.78) | 3.92 (0.36) | 0.00 | 0.21 |

Abbreviations: LCP, Liverpool Care Pathway; SD, standard deviation; VAS, visual analogue scale.
*Wilcoxon signed-rank test (two-tailed).
**Mann–Whitney U test (two-tailed).
†N = 101.
‡N = 102.

understand the plan of the care’ (p = .01). Registered Nurses’ item scores for SI compared with the PR scores were also significantly higher about improvement of cooperation between different professions (p = .02) and transfer of information between the working shifts (p = .03). RNs perceived that implementation of the LCP had improved the transfer of information between doctors and nurses, and they considered it to be more important than it actually was (PR mean 2.90, SD: 1.09; SI mean 3.38, SD: 1.20; p = .04) (not shown in the Table).

The team works ... and continuity makes a holistic assessment of the patient’s situation and needs. The families feel more involved in the care process.

(RN, female, 46 years, working in a RCH)

It feels safe and secure to work with the LCP and it enables good communication between different professions on the team.

(AN, female, 41 years, working in a RCH)

4 | DISCUSSION

Both RNs and ANs in this study perceived that implementation of the LCP in RCHs and HC meant improved EoL care for the dying persons and their families. In line with the original goals of the LCP, namely, to transfer best practice from hospice settings to other care settings (Ellershaw & Wilkinson, 2011), the LCP functioned as a tool for ensuring high-quality EoL care. Initiating LCP meant that focus
### TABLE 3  Responses to questionnaire items on systematic assessment and alleviation of symptoms

| Implementation of the LCP means that... | Registered Nurses (RN) (N = 21–22) | Assistant nurses (AN) (N = 109–120) | Differences between RNs and ANs |
|-----------------------------------------|-----------------------------------|------------------------------------|--------------------------------|
|                                         | Mean (SD) | Subjective importance (SI) | Mean (SD) | Subjective importance (SI) | Mean (SD) | Subjective importance (SI) | p-value* | p-value** |
| Perceived reality (PR)                  |          |                         |          |                         |          |                         |          |          |
| ... I have been given a tool for identifying the patient’s symptoms and problems. | 3.41 (0.73) | 3.18 (1.18) | 0.30 | 3.44 (0.78) | 3.62 (0.65) | 0.01 | 0.74 |
| ... physical symptoms and problems are identified. | 3.41 (0.73) | 3.27 (1.16) | 0.62 | 3.37 (0.78) | 3.68 (0.58) | 0.00 | 0.92 |
| ... psychological symptoms and problems are identified. | 3.41 (0.80) | 3.32 (1.17) | 0.81 | 3.24 (0.81) | 3.65 (0.59) | 0.00 | 0.32 |
| ... existential symptoms and needs are identified. | 2.95 (0.84) | 3.14 (1.17) | 0.59 | 3.08 (0.84) | 3.57 (0.64) | 0.00 | 0.50 |
| ... physical symptoms and problems are relieved. | 3.55 (0.67) | 3.36 (1.18) | 0.57 | 3.38 (0.74) | 3.69 (0.57) | 0.00 | 0.36 |
| ... psychological symptoms and problems are relieved. | 3.10 (0.89) | 3.25 (1.21) | 0.34 | 3.16 (0.73) | 3.69 (0.58) | 0.00 | 0.90 |
| ... existential symptoms and needs are relieved. | 2.81 (0.93) | 3.19 (1.17) | 0.18 | 3.06 (0.75) | 3.58 (0.62) | 0.00 | 0.25 |
| ... overall symptom relief is achieved. | 3.45 (0.67) | 3.43 (1.12) | 1.00 | 3.41 (0.72) | 3.80 (0.50) | 0.00 | 0.89 |
| **Implementation of the LCP means systematic assessment and alleviation of symptoms such as** | | | | | | | |
| Pain | 3.68 (0.65) | 3.52 (1.03) | 0.67 | 3.53 (0.74) | 3.86 (0.42) | 0.00 | 0.29 |
| Anxiety/agitation | 3.64 (0.66) | 3.52 (1.03) | 0.80 | 3.50 (0.77) | 3.86 (0.42) | 0.00 | 0.43 |
| Respiratory tract secretions | 3.73 (0.63) | 3.52 (1.03) | 0.53 | 3.50 (0.77) | 3.84 (0.45) | 0.00 | 0.14 |
| Nausea/vomiting | 3.68 (0.65) | 3.52 (1.03) | 0.53 | 3.50 (0.76) | 3.83 (0.48) | 0.00 | 0.23 |
| Dyspnoea | 3.64 (0.66) | 3.52 (1.03) | 0.80 | 3.52 (0.77) | 3.86 (0.40) | 0.00 | 0.50 |
| Oedema | 3.32 (0.89) | 3.19 (1.25) | 0.67 | 3.48 (0.77) | 3.83 (0.44) | 0.00 | 0.45 |
| Itching | 3.27 (1.03) | 3.19 (1.25) | 0.80 | 3.35 (0.82) | 3.75 (0.52) | 0.00 | 0.96 |
| Hiccups | 3.14 (1.12) | 3.05 (1.24) | 0.94 | 3.28 (0.89) | 3.62 (0.70) | 0.00 | 0.82 |
| **Since implementation of the LCP the care has improved regarding** | | | | | | | |
| Oral care | 2.77 (1.11) | 3.20 (1.24) | 0.04 | 3.37 (0.86) | 3.80 (0.44) | 0.00 | 0.01 |
| Urinary problems | 2.68 (1.04) | 3.10 (1.25) | 0.08 | 3.32 (0.90) | 3.77 (0.52) | 0.00 | 0.01 |
| Pressure ulcers | 2.77 (1.19) | 3.15 (1.27) | 0.08 | 3.40 (0.90) | 3.83 (0.46) | 0.00 | 0.01 |
| Psychological support | 2.50 (1.10) | 3.10 (1.33) | 0.01 | 2.84 (0.99) | 3.70 (0.62) | 0.00 | 0.17 |
| Religious and existential needs | 2.36 (1.05) | 3.00 (1.21) | 0.01 | 2.67 (0.96) | 3.53 (0.73) | 0.00 | 0.15 |

**Note:** LCP, Liverpool Care Pathway; SD, standard deviation.  
*Wilcoxon signed-rank test (two-tailed).  
**Mann-Whitney U test (two-tailed).
of care turned to EoL care. The LCP supported decision-making and pharmacological and non-pharmacological strategies for symptom management and facilitated the communication in the team and with the dying person and family. A consistent result was that both RNs and ANs scored SI higher than PR highlighting a need for improvement about critical areas of high-quality EoL care in terms of general aspects, systematic assessment and alleviation of symptoms and communications. However, the results have to be interpreted with caution due to type I error.

Both RNs and ANs perceived EoL care post-LCP implementation to be safe and structured to a high extent. They also perceived interventions to be easier to initiate and evaluate. One could argue that a structured pathway such as the LCP might jeopardize individualized person-centred care, one core pillar in quality EoL care (WHO, 2002; WPCA, 2002) and risk of a prescriptive and less individualized care has been reported (Sleeman et al., 2015). However, other studies report that the LCP implemented in RCHs supported and encouraged the personnel to tailor individual care.

### TABLE 4 Responses to questionnaire items on communication and information

| Implementation of the LCP means that | Registered Nurses (RNs) | Assistant nurses (ANs) | Differences between RNs and ANs |
|-------------------------------------|-------------------------|------------------------|---------------------------------|
|                                    | Perceived reality (PR)  | Subjective importance (SI) | Perceived reality (PR)  | Subjective importance (SI) | Perceived reality (PR)  |
|                                    | Mean (SD)               | Mean (SD)              | p-value*                      | Mean (SD)               | Mean (SD)              | p-value*                      | p-value**                      |
| ... dialogues with the family about the patient’s imminent death have been facilitated. | 3.23 (0.92) | 3.45 (1.06) | 0.47 | 3.06 (0.83) | 3.61 (0.66) | 0.00 | 0.26 |
| ... dialogues with the patient about his/her imminent death have been facilitated. | 2.95 (1.13) | 2.95 (1.13) | 1.00 | 3.33 (0.78) | 3.33 (0.78) | 1.00† | 0.22 |
| ... the doctor explains and discusses the imminent death to/the patient. | 2.76 (1.04) | 3.50 (0.74) | 0.01 | 2.66 (1.02) | 3.39 (0.76) | 0.00‡ | 0.71 |
| ... the doctor explains and discusses the patient’s imminent death to/the family. | 3.18 (0.85) | 3.62 (0.74) | 0.04 | 3.04 (0.86) | 3.62 (0.63) | 0.00§ | 0.52 |
| ... my communication with patients at EoL has improved. | 2.45 (1.22) | 3.24 (1.30) | 0.01 | 2.68 (1.06) | 3.65 (0.58) | 0.00¶ | 0.44 |
| ... my communication with the patient’s family at EoL has improved. | 2.82 (1.22) | 3.35 (1.23) | 0.02 | 2.95 (0.97) | 3.68 (0.54) | 0.00 | 0.82 |
| ... RNs and ANs give honest answers to patient questions regarding EoL. | 3.00 (1.05) | 3.41 (1.10) | 0.25 | 3.32 (0.91) | 3.84 (0.46) | 0.00 | 0.15 |
| ... the family gets the information they need to understand the plan of the care. | 3.36 (0.58) | 3.52 (0.98) | 0.43 | 3.22 (0.74) | 3.64 (0.64) | 0.00 | 0.52 |
| ... the patient gets the information they need to understand the plan of the care. | 2.19 (1.03) | 2.91 (1.19) | 0.01 | 2.81 (0.89) | 3.45 (0.74) | 0.00 | 0.01 |
| ... the cooperation between different professions has improved. | 2.86 (0.99) | 3.38 (1.12) | 0.02 | 3.16 (0.95) | 3.74 (0.50) | 0.00 | 0.17 |
| ... the transfer of information between ANs and RNs has improved. | 2.95 (1.05) | 3.29 (1.15) | 0.25 | 3.19 (0.94) | 3.75 (0.49) | 0.00 | 0.32 |
| ... the transfer of information between the working shifts (day, evening, night) has improved. | 2.76 (1.14) | 3.35 (1.23) | 0.03 | 3.18 (0.92) | 3.74 (0.50) | 0.00 | 0.11 |

Abbreviations: EoL, end of life; LCP, Liverpool Care Pathway; SD, standard deviation.
*Wilcoxon signed-rank test (two-tailed).
**Mann-Whitney U test (two-tailed).
†N = 98.
‡N = 90.
§N = 99.
¶N = 102.
and interventions (Andersson et al., 2018a; Seymour, Kumar, & Foggatt, 2011) and families have reported perceptions of person-centred care (Andersson, Lindqvist, Fürst, & Brännström, 2018b). One probable explanation is that persons usually live in an RCH or are cared for in HC for a period of time, in Sweden often several years, increasing the likelihood that the personnel get to know the patients and their families as individuals. Our study, on the other hand, showed a need for improvement about both patient and family participation as both RNs and ANs scored significantly higher on the SI scale compared with the PR scale, showing that insufficient attention was given to an important aspect of EoL care. This result emphasizes the importance of realizing that implementation of the LCP does not mean implementation of person-centred care per se (Ekman et al., 2011). Our study underlines that special attention and routines must be established to ensure that person-centred care is consistently practised during EoL care. As the LCP involves documentation bedside (Ellershaw & Wilkinson, 2011), one way to increase participation may be to actively involve patients and families in the documentation.

Symptom control is paramount in high-quality EoL care (WHO, 2002; WPCA, 2014). Both the RNs and the ANs in our study meant that the LCP improved quality of care by serving as a reminder of symptoms and needs to look out for, as also reported by other recent studies in RCHs across Europe (Andersson et al., 2018a; Lemos Dekker, Gysels, & Van der Steen, 2017). As the LCP also includes recommendations for evidence-based interventions to treat common symptoms such as pain, agitation, respiratory tract secretions, nausea/vomiting and dyspnoea, it was also seen as a tool for systematic alleviation of symptoms. Although surprisingly few studies examine the efficacy of the LCP about symptom relief (Chan & Webster, 2013; Husebø et al., 2017), our result is supported by a controlled before–after study by Brännström et al. (2016) who found symptom burden related to nausea and dyspnoea to be lower in RCHs using the LCP compared with those using standard care. In our study, ANs compared with RNs scored statistically significant higher about structured pain assessment and improvement of documentation of nursing interventions. One explanation could be that ANs as opposed to before, through LCP got a structured tool for assessment of symptoms and needs, interventions and documentation. Future studies on integrated pathways should incorporate outcome measures related to important aspects of EoL, that is robust studies evaluating patient and family experiences of care in addition to process.

In addition to control of physical symptoms, psychological support and existential support are important aspects of EoL care (WHO, 2002, 2011; WPCA, 2014), which in this study were statistically significant identified by both RNs and ANs as areas in need of improvement. At the same time, both RNs and ANs reported that dialogues about patients’ imminent death had been facilitated. This finding sheds light on the complex and advanced task of caring for the dying and suggests that no pathway can replace competence in EoL care for achieving positive outcomes (Husebø et al., 2017). Patients and their families should be confident that, when facing a life-threatening illness and in need of EoL care, they will receive high-quality care according to their needs and preferences (Sandsdalen, Hov, Høye, Rystedt, & Wilde-Larsson, 2015). Consequently, for successful implementation of the LCP, it is necessary to ensure adequate competence and skills in communication about psychological and existential needs. Openness, communication and collaboration have been identified as key factors for successful implementation of integrated pathways including the LCP (McConnell et al., 2015). Hence, the improved communication and cooperation in the care team that were seen in our study can be assumed to contribute to quality EoL care as this has been shown to contribute to a shared approach to care and, importantly, to consistent care regardless of who was working on the shift (Andersson et al., 2018a; Clark, Marshall, Sheward, & Allan, 2012; Lemos Dekker et al., 2017).

The LCP has been phased out in the UK since publication of the Neuberger report (Department of Health, 2013), but the pathway continues to be used in Scandinavian countries (Husebø et al., 2017). In Sweden, a new care pathway has been developed for implementation in palliative care (CRCC], 2016). The misuse of the LCP, for example using it as a ‘tick-box exercise’, due to uneducated personnel and lack of competence in EoL care (Department of Health, 2013; Neuberger, 2016; Regnard, 2014), highlights the need for education in what characterizes high-quality EoL care, solid implementation of every integrated pathway and strong leadership. Moreover, the Neuberger report revealed that diagnosing dying was the key issue for initiating the LCP. In our study, initiation of the LCP was a signal communicating the fact of the transition to EoL care, which is also reported in other studies (Andersson et al., 2018a; Brännström et al., 2016; Lemos Dekker et al., 2017; Sleeman et al., 2015). Several studies highlight that determining the onset of dying is complex (Chapman & Ellershaw, 2011; Kennedy et al., 2014; Watts, 2013; Wrigley, 2014). Kennedy et al. (2014) stress the importance of recognizing the uncertainty in diagnosing dying and of viewing it as a process rather than a specific event. Therefore, we want to highlight the importance of flexibility in using the LCP or any care pathway in EoL care. It is important to continually assess the patient’s status to be able to take the patient off the LCP when indicated and not continue a care plan with fatal consequences. In achieving high-quality EoL care, nothing can replace adequate competence and training in EoL care.

4.1 Methodological considerations and limitations

The questionnaire was controlled about face and content validity by experts (Field, 2009). The validity test showed that the questionnaire included items related to the impact of the LCP on EoL care. Only a few items were rewritten for linguistic clarity. The questionnaire was also judged to present the items in a logical order. This is important to avoid perceptions that the questionnaire is disorganized, which could jeopardize the validity of the findings (Field, 2009; Streiner, Norman, & Cairney, 2015). Furthermore, to avoid misconceptions the questionnaire was developed in sections based on the structure of the LCP. As the questionnaire was study-specific, no further psychometric testing was carried out to test potential dimensions for
internal consistency. However, the two-dimensional scale reflecting PR and SI contributes to the accuracy of the questionnaire (Polit & Beck, 2012).

The high-response rate contributed to high validity and can be explained by the items being perceived to be relevant and understandable even if there is always a risk that items can be misinterpreted or that a respondent answers ‘what they think the questioner wants to hear’. However, there is a risk that the results do not reflect the true situation as ANs had a lower response rate than RNs. A limitation of the study is that information about non-participants is missing. There were also few male participants, meaning that the gender perspective of health carers is limited, although it should be acknowledged that the number reflects the true situation.

5 CONCLUSION

Both RNs and ANs perceived that the introduction of the LCP improved community EoL care. The LCP contributed to safe care through structured and systematic assessment, alleviation and evaluation of the patient’s symptoms and needs. The construction of the questionnaire in this study with items answered from two perspectives, perceived reality and subjective importance, made it possible to identify areas in need of improvement. In particular, the need for improved competence among healthcare personnel about managing patients’ psychological and existential needs was highlighted. The pathway served as a basis for dialogues about areas of relevance for quality EoL care. However, deficiencies about patients and families’ participation in the care were identified. This highlights the complexity of caring for the dying and underlining that no pathway can replace competence and skills in EoL care. Future studies should give attention to outcomes of care in addition to patients’ and families’ experiences of care to provide a strong evidence base to be used when implementing integrated pathways for EoL care.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHORS’ CONTRIBUTIONS

EK, KGP and ML were responsible for drafting the final version. All authors have approved the final version of the manuscript.

ORCID

Cecilia Olsson https://orcid.org/0000-0002-0944-5650
Maria Larsson https://orcid.org/0000-0003-0417-6161

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