Humber NHS Foundation Trust

RV9

Community end of life careservices

Quality Report

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This report describes our judgement of the quality of care provided within this core service by Humber NHS Foundation Trust. Where relevant we provide detail of each location or area of service visited.

Our judgement is based on a combination of what we found when we inspected, information from our 'Intelligent Monitoring' system, and information given to us from people who use services, the public and other organisations.

Where applicable, we have reported on each core service provided by Humber NHS Foundation Trust and these are brought together to inform our overall judgement of Humber NHS Foundation Trust

Summary of findings

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Summary of findings

Overall summary

We found patient records were complete and accurate. There were enough staff, with the right mix of skills to meet patients' needs. However, while equipment used was safe and well maintained, it was not always available quickly enough for patients to use at home.

The processes for managing risk and measuring quality were not used consistently across the teams involved in end of life care. Not all staff understood the procedures for, or knew how to, report incidents. Information about patient safety was not communicated well and did not encourage learning or improvement by staff.

The trust no longer used the Liverpool Care Pathway for the Dying Patient (LCP). A replacement had been developed, but this had not been used yet. This meant that staff were inconsistent in the way they completed end of life care records as they did not have a universal end of life care pathway. The trust participated in national and local clinical audits.

Staff providing end of life care had the right qualifications and worked as part of a multidisciplinary team. However, they did not always meet their targets. Staff completed mandatory training and appraisals to assess performance were undertaken, however this was inconsistent and did not meet the trust's own acceptable levels.

Information about how the end of life care services were performing was not always available and was not monitored or reviewed effectively to drive improvements.

Staff treated patients with dignity, compassion and respect. Patients and their relatives spoke positively about their care and treatment. Staff also kept patients and their relatives involved in their care and supported their emotional needs. While there was limited information about bereavement and counselling services for patients and their relatives, the trust was in the process of addressing this.

Patients could access care close to home and at any time. However, access to specialist staff was limited out of hours and on weekends. There were no clear guidelines for community nurses to refer patients to the Macmillan nurses. However, processes for admitting, transferring and discharging patients were effective across the services. The inpatient ward also had sufficient capacity to make sure that patients could be admitted quickly and receive the right level of care. There were systems in place to support vulnerable patients.

Complaints about the end of life care services were also managed effectively, but they were not always shared with staff to help learning.

The trust's vision and values were understood and supported by staff. Staff worked well in teams and the leadership was clearly visible.

Summary of findings

Background to the service

Humber NHS Foundation Trust provided hospital and community based end of life care services for people aged 18 years and older who live in East Riding, Yorkshire. A team of 10 Macmillan nurses and a Macmillan Nurse Consultant in Palliative Care provided specialist services, along with eight neighbourhood care (community nursing) teams. The teams were also supported by the district nursing teams and the Marie Curie cancer Care services across East Riding.

The Macmillan Wolds ward in Bridlington Community Hospital was a 12 bedded GP-led ward that provided inpatient end of life care for patients located in or near Bridlington. The trust also provided palliative and end of life care services at Withernsea Hospital and The East Riding Community Hospital.

Our inspection team

Chair: Stuart Bell, Chief Executive, Oxford Health NHS Foundation Trust

Team Leader: Cathy Winn, Inspection Manager and Surrinder Kaur, Inspection Manager, Care Quality Commission (CQC)

The end of life care inspection team included: a CQC inspector and a specialist palliative care nurse.

Why we carried out this inspection

We inspected this core service as part of our comprehensive Wave 2 pilot for mental health and community health services inspection programme.

How we carried out this inspection

To get to the heart of people who use services' experience of care, we always ask the following five questions of every service and provider:

- Is it safe?
- Is it effective?
- Is it caring?
- Is it responsive to people's needs?
- Is it well-led?

We visited the end of life services of Humber NHS Foundation Trust on 12 May 2014. Before visiting, we reviewed a range of information we hold about the core service and asked other organisations to share what they knew. During the visit, we held focus groups with community and district nurses. We visited the Macmillan nurse team based at Driffield. We also visited the community end of life care teams based at Alfred Bean Hospital, Driffield and the Hessle Health Centre, as well as Macmillan Wolds ward in Bridlington Community Hospital.

We spoke with a range of staff including nurses, matrons, service managers, support staff and the senior management team. We also talked to four people who use services and the family members of three others. We observed how people were being cared for and reviewed their care or treatment records.

Summary of findings

What people who use the provider say

The patients and relatives we spoke with were positive about their care and treatment. The comments received from patients demonstrated that staff cared about meeting patients' individual needs.

Good practice

- The trust's palliative care clinical care network group met on monthly basis and included the Macmillan nurses and matrons, community nurses and physiotherapists from the inpatient and community nursing teams to ensure consistent practices and information sharing across the teams.
- Involvement of the Macmillan nurse team in the Gold Standards Framework groups.
- A multi-agency review of patient deaths was undertaken to support shared learning.

Areas for improvement

Action the provider MUST or SHOULD take to improve

Action the provider SHOULD take to improve

- The trust should improve the processes for reporting and learning from incidents, accidents, near misses, complaints and safeguarding concerns.
- The trust should audit and review the time taken to provide equipment to patients receiving end of life care.
- The trust should improve the records used to document end of life care, so information is recorded in a consistent way by all staff.
- The trust should review processes on an ongoing basis for accessing specialist end of life care during out of hours and on weekends.
- The trust should improve risk management and quality measurement processes within end of life services, to make sure they are consistent across different staff teams.

Humber NHS Foundation Trust

Community end of life careservices

Detailed findings from this inspection

The five questions we ask about core services and what we found

Are services safe?

By safe, we mean that people are protected from abuse

Summary of findings

The trust had systems and processes in place to help staff provide patients with safe care and support. In addition, patient records were complete and accurate. There were enough staff with the right mix of skills to meet patients' needs. However, while equipment used was safe and well maintained, it was not always available quickly enough for patients to use at home.

Not all staff understood, or knew how to, report incidents.

Incidents, reporting and learning

There were no never events (a serious event that is largely preventable) in the end of life care services between March 2013 and March 2014. There were no serious incidents reported by the trust to the National Reporting Learning System (NRLS) and Strategic Executive Information System (STEIS) that were directly related to the end of life care services during the past 12 months.

Staff were familiar with the reporting systems for incidents and all staff had access to the trust-wide electronic reporting system which had been in place since February 2014. Staff understanding and reporting of incidents was inconsistent across the teams providing end of life care services. The inpatient ward staff frequently reported incidents and accidents; the Macmillan clinical nurse specialists told us they had not yet reported any incidents on the electronic reporting system but would report if an incident was identified and the level of reporting varied across the community nursing teams. For example, the community nurses we spoke with at Driffield told us they would only report specific patient safety incidents, such as falls and pressure ulcers.

The inpatient ward staff reported incidents were discussed during routine team meetings. Staff based in the community were unaware of incidents that had been reported within their service or of any lessons learnt following review of such incidents.

Are services safe?

The trust had a 'blue light' alerts process in place where staff were informed by email of serious incidents relating to their team. The majority of staff we spoke with told us they received 'blue light' alerts on a regular basis.

Cleanliness, infection control and hygiene

Staff were aware of current infection prevention and control guidelines. The inpatient ward was clean, tidy and safe. Cleaning schedules were in place, and there were clearly defined roles and responsibilities for cleaning the environment and for cleaning and decontaminating equipment. There were arrangements in place for the handling, storage and disposal of clinical waste, including sharps. There was a sufficient number of hand wash sinks and hand gels.

The matron carried out a quarterly infection control audit to monitor staff adherence to infection control processes. All patients admitted to the ward underwent MRSA screening procedures to ensure any patients at risk were identified and treated. The ward had three single rooms that could be used as isolation rooms.

We observed staff following hand hygiene and 'bare below the elbow' guidance. Staff in the community had access to portable hand gels and personal protective equipment, such as gloves, if needed.

Maintenance of environment and equipment

We found the environment and equipment in the inpatient ward to be clean, safe and well maintained. Equipment such as commodes, trolleys and drip stands were visibly clean. Equipment such hoists and syringe drivers were routinely serviced. Ward staff told us they always had access to the equipment they needed and that all items of equipment were readily available. Emergency resuscitation equipment was available and checked on a daily basis by staff.

The trust had an integrated equipment store. The community nurses told us that they could access the patient equipment they needed. Staff told us that they were well supported and equipment could be delivered the same day if requested. Staff told us that essential equipment, such as syringe drivers, were readily available and could be replaced promptly if they became faulty. However, we saw that other equipment for patients in their own home was not always received promptly. One patient was awaiting an alternative mattress and a wheelchair ramp, which was expected to be delivered within five days of being requested. Another patient was waiting for the delivery of a toilet area grab rail that had been ordered over a week previously.

Medicines

Within the inpatient ward, medicines, including controlled drugs, were securely stored. Staff also carried out routine checks on controlled drugs and medication stocks to ensure that medicines were reconciled correctly. The charge nurse told us only on-call pharmacy support was available on the ward. However, the nurses followed procedures and flow charts for the use of end of life care medicines.

There were effective procedures in place for managing medicines for patients receiving end of life care within the community. The majority of Macmillan nurse specialists were nurse prescribers and there were also a number of nurse prescribers within each community team. Staff with no prescribing responsibilities discussed changes to patients' medicines with the patient's GP. Staff followed clear guidelines for prescribing medicines for patients receiving end of life care and these were reviewed during routine clinical network group meetings and drugs and therapeutic medicines management meetings, to ensure national guidelines were followed.

'Just in Case' boxes were available to support anticipatory prescribing and access to palliative care medications for patients. This meant patients receiving end of life care experiencing new or worsening symptoms outside of normal GP practice hours could access medications in the Out of Hours (OOHs) period.

Safeguarding

Trust data showed that the majority of staff providing end of life care services had received mandatory training in the safeguarding of children and vulnerable adults. For example, over 80% of nurses on the Macmillan ward had received safguarding training for adults and over 70% for safeguarding children.The staff we spoke with demonstrated a good understanding of the different types of abuse and how to detect these. Staff were aware of the process for reporting safeguarding concerns and allegations of abuse within the trust. Staff were issued with a card that included contact details for the local authority and trust-wide safeguarding teams.

Are services safe?

Safeguarding processes and incidents were reviewed by a trust-wide safeguarding committee which held meetings every three months. The staff we spoke with told us they did not routinely receive feedback from the safeguarding team after they had raised a safeguarding alert. This meant that staff were unaware of safeguarding incidents that had been reported within the organisation or of any lessons learnt following the review of such incidents.

Records

The trust used both electronic and paper based patient records. During the inspection we looked at the paper based patient records for nine patients and electronic patient records for four patients. The records were structured, legible, complete and up to date. However, we saw that one patient's district nurse notes were not fully completed during our home visits.

Patient records were stored securely in the inpatient ward. The Macmillan clinical nurse specialists transported paper based patient records in a locked case when carrying out home visits in line with trust policy. The individual staff members were responsible for the security of patient records.

There was a formal system in place to monitor the quality of patient records but this was not consistently applied across the teams providing end of life care services. A trust audit report for the period between January and December 2013 showed that 28 patient records were reviewed for accuracy and completeness within the inpatient ward. However, there was no data relating to audits carried out in the community (district) nursing and Macmillan nurse teams.

Lone and remote working

Staff were aware of the trust's lone worker policy, which outlined the process for managing patient and staff safety where lone and remote working took place. Staff in the community carried out the majority of visits to patient's homes alone. The trust did not use portable electronic call systems for staff. Staff told us they had mobile phones and could contact their office base during emergencies. Where patients received care in their home, staff carried out environmental and health and safety assessments. Where patients (or specific neighbourhoods) were identified as being a risk to staff, visits were carried out by two members of staff.

Adaptation of safety systems for care in different settings

The trust had implemented patient electronic records and used separate electronic reporting systems for safeguarding alerts and for reporting incidents. However, staff were not able to use these systems remotely due to technological restraints, such as availability of remote broadband across all the geographical areas. Staff told us they were required to update both paper and electronic records on a daily basis and that it was difficult to maintain both sets of records.

Assessing and responding to patient risk

On referral to the end of life care services, the community and ward based nurses carried out risk assessments to identify patients at risk of harm. Patient records included risk assessments, such as for venous thromboembolism (VTE), pressure care or nutrition, and these were completed correctly. The Macmillan clinical nurse specialists also carried out a detailed nursing assessment for each patient that was referred to them.

Within the inpatient ward, 'intentional rounding' observations took place on an hourly basis and observations were well recorded. Staff used early warning score systems and care pathways to provide timely treatment to patients at risk. Staff providing community care told us they relied on risk assessments and individual nurses' clinical judgement to determine if a patient was at risk due to deteriorating health. This meant that patient care could vary depending on staff experience. Processes were in place to refer deteriorating patients to the local acute trust.

Staffing levels and caseload

We found that there were sufficient numbers of trained nursing and support staff with an appropriate skills mix to ensure that patients were safe and received the right level of care.

The trust did not employ its own specialist end of life consultant or doctor. Clinical support was mainly provided by patient's GPs. Staff also told us they could obtain telephone support from a consultant based at a local hospice and a GP with special interest in palliative (end of life) care, if needed.

Trust performance reports showed that sickness and absence rates were reviewed monthly. On the inpatient palliative care ward, trust data showed that four staff were

absent with sickness for greater than 17 days during November 2013, which meant that some patients admissions to the ward were reduced. The charge nurse told us overall staff sickness over the past year was manageable and the service was able to cover for staff absence.

Staff told us they did not use agency staff and cover for staff absence was managed within individual teams through the use of bank staff made up of existing team members. The Macmillan and district nurses we spoke with told us their caseload increased due to staff sickness and they did not always have sufficient time to take breaks. However, they told us the workload was manageable and did not impact on the delivery of patient care.

Deprivation of Liberty safeguards

Staff received mandatory training in Deprivation of Liberty Safeguards (DoLS). There were no patients with DoLS restrictions within the end of life care services at the time of our inspection. However, the staff we spoke with demonstrated a good understanding of the trust's DoLS policy, which outlined the process for DoLS. Staff we spoke with were aware of this policy and the legal requirements of the Mental Capacity Act 2005.

Managing anticipated risks

All staff we spoke with were aware of the process for escalating risks and concerns to their line managers. Staff on the inpatient ward told us that key risks, such as bed capacity, patient discharge or staffing issues, could be escalated to the matron. Key risks were reviewed on a weekly basis by the operational risk management group, which was chaired by the director of nursing, integrated governance and quality.

Major incident awareness and training

There was a documented business continuity plan for teams providing end of life care services, and this provided instructions for staff on how to manage key risks that could affect the provision of care and treatment. Staff received mandatory training in fire safety and health and safety. There were clear instructions in place for staff to follow in the event of a fire or other major incident.

Are End of life care services effective?

By effective, we mean that people's care, treatment and support achieves good outcomes, promotes a good quality of life and is based on the best available evidence.

Summary

The trust no longer used the Liverpool Care Pathway for the Dying Patient (LCP). A replacement had been developed, but this had not been used yet. This meant although patients received care according to national guidelines, there was no systematic approach to end of life care.

The trust participated in national and local clinical audits.

Information about how end of life services performed was not always available or accessible by staff. Performance was not reviewed effectively to drive improvements.

Staff providing end of life care had the right qualifications and worked as part of a multidisciplinary team.. The number of staff that had completed mandatory training and staff appraisals was above the trusts target for the Macmillan nurse team and inpatient ward staff; community nurses delivering end of life care did not always meet these targets.

Detailed findings

Evidence based care and treatment

Patients received care according to national guidelines. There was an action plan in place for the implementation of Department of Health (DH) and National Institute for Health and Clinical Excellence (NICE) guidelines for end of life and dementia care, and progress was reviewed during routine palliative care clinical network meetings.

The nursing staff followed Royal College of Nursing and Royal Marsden Hospital Manual of Clinical Nursing Procedures. Staff followed procedures based on other national and regional guidelines, including the Preferred Priorities for Care (PPC) and the Gold Standards Framework (GSF). The Macmillan clinical nurse specialists also followed guidelines from other organisations, such as Macmillan Cancer Support and Marie Curie Cancer Care. The Macmillan team were highly trained and had a good understanding of existing end of life care guidelines and implemented these effectively.

The trust had phased out the use of the Liverpool Care Pathway for the Dying Patient (LCP), in line with national guidance and staff confirmed this was no longer used. The trust had developed an end of life care pathway to replace the LCP, but this had not yet been implemented and the staff we spoke with were not clear on when this was due to be implemented.

Staff providing end of life care were required to complete an end of life care record on the electronic patient record system. This included a checklist for staff to confirm patient eligibility for access to Gold Standards Framework funding and whether preferred place of care and 'do not attempt cardio pulmonary resuscitation' (DNA CPR) status had been discussed with the patient.

The Macmillan clinical nurse specialists we spoke with told us that they completed this record for each patient that was referred to them and we saw evidence of this in one electronic patient record. We looked at three electronic records for patients receiving end of life care by district nurses in the Goole and West Wolds team. The end of life care record had not been completed in these records.

The community nursing staff we spoke with also confirmed they did not always complete the electronic record, but documented information, such as preferred place of care, in the visit notes section of the patient records. The paper patient records we looked at showed that the recording of this information was inconsistent, i.e. information was recorded in different sections of a patient record. We saw that there were specific care plans, such as for the use of syringe drivers and the administration of medication. However, staff were confident that the implementation of a trust-wide end of life care pathway would address any inconsistencies.

Pain relief

The patient records we looked at showed that patients received appropriate pain relief and they were treated in a way that met their needs and reduced discomfort. Patient records included specific care plans which provided instructions for staff based on a patient's individual needs. Staff also followed guidelines and procedures and we saw that pain relief medication was administered in a timely manner. The patients and relatives we spoke with told us their pain symptoms were managed effectively by staff.

Are End of life care services effective?

Nutrition and hydration

Patient records showed that staff carried out an assessment of patients' nutritional requirements using the Malnutrition Universal Screening Tool (MUST). Where patients were identified as at risk, there were fluid and food charts in place and these were reviewed and updated by the staff. Patients and relatives we spoke with in the inpatient ward told us they were given a choice of food and drink and we saw that drinks were provided regularly.

Patient outcomes

Our observations and review of patient records showed that patients received safe care. All the patients and relatives we spoke with were positive about the care and treatment they received.

The trust participated in the National Council For Palliative Care minimum data sets home care audit. However, the trust was not able to provide the most recent data.

Commissioning for Quality and Innovation (CQUIN) Payment Framework Data for 2012/13 showed that the trust was meeting the targets for key end of life care measures, such as number of patients with an end of life management plan, number of patients who had stated a preferred place of care and the number of registered nurses trained in end of life care (syringe driver training).

The service manager for Goole and West Wolds told us that CQUIN end of life indicators were based on information from the electronic patient record system. The service manager was aware that not all staff completed the end of life electronic patient records correctly and acknowledged that improvements were needed in the quality of the documentation so that performance against key measures could be accurately measured.

Performance information

Performance reports were in place for the community and hospital-based teams providing end of life care services. However, staff told us that there was no routine performance report for the Macmillan nurse team, which meant that their performance and activities were not effectively monitored. The trust did not have a means for reporting waiting times, specifically for the end of life care services. The trust's electronic patient system was not configured to extract end of life care patient waiting times, but individual patient waits could be reviewed from looking directly in the system on a case-by-case basis. Data from the system had also been used to evidence trust performance that 86% of patients died in their preferred place of care.

We looked at the performance reports for four neighbourhood care (community nursing) teams and the Macmillan Wolds inpatient ward, which included data for the period between April 2013 and March 2014. These performance reports did not include any targets specific to end of life care services. The inpatient ward performance data showed that admissions, bed occupancy rates, staff training and sickness rates were within specified performance targets.

The service managers and matrons received monthly performance reports so that they could be reviewed. However, this information was not readily available or accessible by all staff. There was also a lack of information available to staff relating to patient safety performance, such as the number of infections or pressure ulcers acquired by patients within specific teams.

Competent staff

There was an effective induction process for new staff, which included mandatory training and shadowing an experienced member of staff for a period of time based on their training needs. Staff told us the induction process was effective and they received good support from their peers and line managers.

The trust target was 75% for mandatory training compliance and 85% for personal appraisal and development review (PADR) completion. Trust data up to March 2014 showed that the Macmillan nurse team and inpatient ward staff achieved these targets. However, four neighbourhood care (community nursing) teams did not achieve trust targets for PADR and mandatory training compliance. For example, the North Holderness neighbourhood care team had only completed 47.4% of PADR's and 54.8% of mandatory training.

All the staff we spoke with told us that they had access to routine supervision with their line managers. The Macmillan nurse team and inpatient ward staff also participated in clinical supervision on a routine basis. The community nursing staff told us they did not always get access to clinical supervision.

Patients received care from qualified nursing and support staff. The Macmillan nurse team were experienced and

professionally qualified. They also delivered end of life care training for other staff across the trust. The staff across the community and inpatient ward teams told us they received training through a variety of sources, including professional qualifications and in-house training from the Macmillan nurses. All staff providing end of life care had received training in the use of syringe drivers. However, there was no uniform or consistent approach to end of life care training for community nursing staff, which meant there was a potential risk that the care received by patients could vary depending on the experience of individual nurses.

Use of equipment and facilities

The trust had recently updated syringe drivers and the majority of staff providing end of life care had received training in their use. There was also a syringe driver policy in place which provided staff with guidelines on how to use the equipment correctly. We observed staff using equipment such as syringe drivers correctly, in line with good practice guidelines.

We saw that the environment within the inpatient ward was appropriate to provide end of life care. Staff were able to provide care in a calm, relaxed environment and facilities such as single rooms and communal areas were available to meet the needs of patients and their relatives.

Multidisciplinary working and working with others

There was effective communication and multidisciplinary team working within each local team. Each team routinely conducted staff meetings and multidisciplinary meetings involving nursing and support staff to ensure all staff had up-to-date information about patient risks and concerns.

The trust's palliative care clinical care network group met on monthly basis and included the Macmillan nurses and matrons, community nurses and physiotherapists from the inpatient and community nursing teams to ensure consistent practices and information sharing across the teams.

The end of life care staff engaged with GPs, acute trust staff, local hospices and social workers to ensure that care was coordinated across other organisations within their localities. Staff attended routine Gold Standards Framework (GSF) meetings.

Co-ordinated integrated care pathways

As part of the East Riding End of Life Care Securing Sustainable Service Pathway, Macmillan nurses participated in six-weekly meetings involving the local acute and community trusts and a local hospice. The meetings involved a retrospective death audit and review of one patient from each organisation. We looked at the records for a meeting held in February 2014, which showed that patient experience had been reviewed to assist learning and improve care.

Are End of life care services caring?

By caring, we mean that staff involve and treat people with compassion, kindness, dignity and respect.

Summary

Staff treated patients with dignity, compassion and respect. Patients and their relatives spoke positively about their care and treatment. Staff also kept patients and their relatives involved in their care. While there was limited information about bereavement or counselling services for patients or their relatives, the trust was in the process of addressing this.

Detailed findings

Compassionate care

We observed that all staff treated patients with dignity, compassion and respect in the hospital ward and within the patient's own home. We observed staff speaking with patients and providing care and support in a kind, calm, friendly and patient manner. The patients and relatives we spoke with were complimentary about staff attitude and engagement. Comments received included, "the staff are very caring, smile and ask what you need" and "staff are consistent across morning to evening". The comments received from patients demonstrated that staff cared about meeting patients' individual needs.

Dignity and respect

Patients and relatives told us that they felt safe and that their privacy was always respected. Within the hospital ward, we saw that same sex accommodation guidelines were followed. Relatives were asked to leave the patient rooms or bay areas when staff provided personal care to patients to respect their privacy. We saw that staff treated patients with dignity in their own home. The comments received from patients' relatives included "the personal care is always kept up to date and [patient] looks very well cared for" and "the care and staff are second to none".

Patient understanding and involvement

Staff had the appropriate skills and knowledge to seek consent from patients or their representatives. The staff we spoke with were clear on how they sought verbal informed consent and written consent before providing care or treatment. The patient records we looked at showed that verbal or written consent had been obtained from patients and that planned care was delivered with their agreement.

Staff respected patients' right to make choices about their care. We observed staff speaking with patients clearly in a way they could understand. We saw staff discussing options relating to areas such as equipment or medication to allow patients to make an informed decision. The patients and relatives we spoke with told us the staff kept them up to date and involved in their care.

Emotional support

We observed staff providing reassurance and comfort to patients. The relatives we spoke with told us the staff were reassuring and supportive. We saw that staff were able to provide overnight accommodation for relatives of patients within the inpatient ward, and relatives told us they were offered drinks and snacks when they were visiting patients on the ward.

Patients could access the multi-faith chaplaincy services for spiritual support. Staff told us they provided emotional and bereavement support for patients and their relatives, including home visits to relatives following bereavement. Patients could also be referred to CRUSE bereavement sessions across East Riding that provided drop in, group and one to one sessions. However, there was no specialist bereavement or emotional support service within the trust. Staff told us patients or relatives that needed specialist psychological or emotional support were referred to services provided by local hospices or the acute trust. The trusts' palliative care clinical network was in the process of developing bereavement booklets.

Promotion of self-care

Due to the complex needs of patients receiving end of life care services, it was not always possible to promote self-care. However, the patient records we looked at included person-centred care plans based on the individual needs and preferences of patients. A patient in the inpatient ward told us they had been seen by a physiotherapist and the staff had encouraged them to be more self-caring and independent.

Are End of life care services responsive to people's needs?

By responsive, we mean that services are organised so that they meet people's needs.

Summary

Patients could access care close to home and at any time and the processes for admitting, transferring and discharging patients were effective across the services The inpatient ward had sufficient capacity to make sure that patients could be admitted quickly and receive the right level of care. Access to specialist staff was limited out of hours and on weekends. There were systems in place to support vulnerable patients.

Complaints about the end of life care services were also managed effectively, but they were not always shared with staff to help learning.

Detailed findings

Service planning and delivery to meet the needs of different people

The trust provided a range of end of life care services across the communities it served. This included hospital-based inpatient care, as well care in people's homes. The trust only provided services for adult patients aged over 18 years of age. End of life care services for children were provided by external organisations such as local hospices (these were not in the scope of our inspection).

The staff we spoke with had a good understanding of the needs of the local population. Staff worked in multidisciplinary teams and routinely engaged with other healthcare providers, local hospices, GPs (through local Gold Standards Framework meetings), adult social care providers and other professionals involved in the care of patients. This meant staff were kept informed and could make arrangements for patients who were waiting for referral for end of life care services..

Access to care as close to home as possible

The Macmillan nurse team were allocated to cover different localities across the community. The team visited people in their homes and also visited patients based in local community hospitals, residential homes and prisons. The neighbourhood care (community nursing) teams were also located across the East Riding area, to allow access to care people as close to their home as possible.

Staff at the Macmillan Wolds ward in Bridlington Community Hospital told us there were originally two dedicated beds for end of life care patients in this ward, but they increased the number of end of life care beds to meet the needs of patients admitted to the ward. A specialist consultant from a local hospice and a GP with specialist interest in end of life care also conducted weekly outpatient clinics from this hospital.

Staff told us that they discussed the preferred place of care with patients if it was appropriate to do so, and made arrangements to ensure patients could receive the right level of care based on their preferences. Trust data showed that between April 2012 and March 2013, the trust was able to meet the preferred place of care preferences for 86% of patients where this had been discussed with the patient.

Access to the right care at the right time

Staff told us patients were referred to the end of life care services through a number of routes including via GP or consultant referral, or they could visit local hospices or access the services via outpatient appointments.

Staff across the three teams told us there were minimal or no waiting times for patients awaiting end of life care services and patients would be seen promptly upon referral. Trust data between April 2013 and March 2014 showed that bed occupancy within the inpatient ward ranged from 49% to 67%, which meant that there were no bed constraints and patients could be admitted promptly to the ward.

The majority of patients received end of life care from district and community nurses and only patients with complex needs were referred to the Macmillan clinical nurse specialists. There were no clearly defined criteria for community nurses to refer patients to the Macmillan nurses. On referral to the service, staff carried out risk assessments and used clinical judgement to determine if a patient needed to be referred to the Macmillan team. The Macmillan team had a target to visit patients referred to them within five days, however performance against this target was not routinely measured.

Flexible community services

The Macmillan nurse team was available during weekdays, which meant there was no specialist nursing cover available out of hours and on weekends. Out of hours and weekend community nursing and medical cover was provided by an out of hours GP service run by the trust.

Are End of life care services responsive to people's needs?

Systems were in place to ensure patients receiving end of life care were flagged on the electronic record system, so the out of hours service were aware. However this dependent on staff completing the record appropriately.

Community and ward-based nurses told us that it was sometimes difficult to access the Macmillan clinical nurse specialists for advice and support. Since January 2014, the trust had employed three additional Macmillan nurses to improve accessibility to the specialist service.

Meeting the needs of individuals

Staff carried out mental capacity assessments to identify patients that could not make decisions for themselves. We saw evidence that capacity assessments had been carried out in the patient records we looked at. Where patients lacked the capacity to make their own decisions staff told us they would take part in best interest meetings with the involvement of the patient's representatives and other healthcare professionals, such as the patient's GP.

We saw that staff identified patients for whom a decision had been made not to attempt cardio pulmonary resuscitation (DNA CPR). We looked at the records for two patients where DNA CPR decisions had been clearly documented in the patient's notes.

There were a range of booklets and information leaflets about end of life care services. We did not see written information readily available in different languages or other formats, such as braille. However, staff told us these could be made available on request. Where patients were unable to speak English, staff could access a language interpreter if needed. Where a patient was identified with learning disabilities or mental health needs, staff could contact the mental health teams for advice and support.

Moving between services

The process for the admission, discharge and transfer of patients was well managed within the end of life care services. Trust data showed that performance relating to admission, referral and discharge of patients was collated on a monthly basis and sent to the relevant matrons and managers for review and analysis.

Staff carried out risk assessments and had processes in place to refer deteriorating patients to the local acute trust. Patients that no longer required specialist end of life care support were transferred to the care of community and district nurses. There was a discharge form in the patient records that included a checklist to ensure patients were discharged in a planned and organised manner.

Complaints handling (for this service) and learning from feedback

Information on how raise complaints was made available through information leaflets. The patients and relatives we spoke with during the inspection spoke positively about the care they received.

Complaints were managed through a centralised complaints and patient advice and liaison services (PALS) team. The trust target was to respond to formal complaints within 25 days. The matrons or team leaders investigated formal complaints relating to their specific team and told us they aimed to respond to requests from the complaints team within 10 days. Trust data showed the inpatient ward received two complaints and the Macmillan nurse team received one formal complaint during the past year.

We saw that learning from complaints was inconsistent across the teams. Within the inpatient ward, we looked at meeting minutes that showed a complaint received during July 2013 was discussed by the ward staff to improve staff learning and aid improvements in the service. The community nursing staff we spoke with were not able to describe how information about complaints relating to end of life care was shared and lessons learned.

Are End of life care services well-led?

By well-led, we mean that the leadership, management and governance of the organisation assure the delivery of high-quality person-centred care, supports learning and innovation, and promotes an open and fair culture.

Summary

The trust's vision and values were understood and supported by staff. Staff worked well in teams and local leadership was clearly visible. The clinical lead for the Macmillan nurses had been absent for 2 months; a matron had been put in charge of the team but was not in day-to day management. This had resulted in initiatives, such as the implementation of the end of life pathway, being put on hold.

Processes for managing risk and managing quality were not used consistently across the teams.

Information about patient safety was not communicated well and did not encourage learning or improvement by staff.

Detailed findings

Vision and strategy for this service

The trust vision and values had been cascaded across the end of life care services and staff understood and supported what these involved. Staff providing end of life care services had a clear understanding of their roles and responsibilities and where they fitted in as part of the multidisciplinary care process.

The trust's clinical quality strategy for 2013 to 2016 included clear objectives relating to patient safety and providing effective care. However, it was not clear how well this strategy had been embedded across the teams we inspected, as the majority of staff we spoke with were unable to describe specific objectives within their teams.

Guidance, risk management and quality measurement

Trust policies were accessible by all staff in paper format or via the trust intranet. The policies we looked at were up to date and referred to national guidelines. The trust used a number of IT systems, for example for incident reporting and for patient records. The majority of staff we spoke with told us they received basic training in the use of these systems and felt further training was needed so they could use these more effectively.

The governance arrangements allowed for risks and concerns to be escalated to the trust's Board through a number of committees and subcommittees. Risks relating to end of life care services were incorporated into departmental and trust-wide risk registers. The inpatient ward staff used local risk registers effectively and were able to describe how local risks could be escalated to the trust-wide risk register. However, staff in the Macmillan and community nursing teams we spoke with were aware of risks within their teams or the use of risk registers.

Staff performance was reviewed and monitored. Each team received monthly performance reports, which included information data for patient flow, financial performance and staff training and sickness. However, staff were not clear if monthly performance data for the Macmillan nursing team was collated and reviewed. The inpatient ward performance data showed that staff training and sickness rates were within specified performance targets. We saw that routine audit and monitoring of key processes took place across the teams we inspected. However, information relating to core patient safety objectives, such as patient falls or pressure ulcer rates, was not readily available in the areas we visited.

Leadership of this service

The inpatient ward was well led with clearly defined and visible leadership. The team was managed on a day-to-day basis by a charge nurse (ward manager), and the matron for the service was based on the ward for 1.5 days each week. Ward staff told us they understood their roles and responsibilities and felt they received good support from the charge nurse and matron.

The community and district nurses we spoke with also told us they felt well supported by their immediate line managers and community matrons. The Macmillan clinical nurse specialists were led by a clinical lead that was highly respected within the team and across the organisation. However, the clinical lead had been absent for approximately two months and, although a matron had been put in charge of the team, they were not involved in the day-to-day management of the team. The Macmillan clinical nurse specialists were highly organised and were able to manage their own visit schedules.

Are End of life care services well-led?

Staff in the inpatient ward and community services were less clear about the visibility and involvement of service managers and general managers. Some community based staff we spoke with were not aware of who their respective service manager was. Staff responses also varied in relation to the visibility of the chief executive and other members of the trust's executive team.

Culture within this service

All the staff that we spoke with during the inspection were positive about working for the trust. They told us that they worked well within their teams and received good support from their line managers. We spoke with a district nurse and a Macmillan clinical nurse specialist that had recently been appointed and both told us there was an open and supportive culture, and that they had been well supported through their induction and encouraged to access training.

Public and staff engagement

Staff in the end of life care services obtained informal feedback from patients or relatives through ad hoc questionnaires, discussions, compliments and complaints. The staff we spoke with told us there was no formal process for seeking patient feedback through engagement or patient survey questionnaires.

Innovation, improvement and sustainability

The trust monitored the performance of end of life care services through monthly performance reporting.

There was a positive and patient focused culture within the trust. The processes for reporting and learning from incidents, complaints and safeguarding concerns were not consistent across the teams providing end of life care services. This was particularly evident in the community nursing teams.

The Macmillan nurse team were involved in a number of research projects, including a research study on rapid pharmacovigilence in palliative care. The Macmillan nurse team also carried out collaborative work with other local and regional end of life service providers as part of the North East Yorkshire and Humber Clinical Alliance and the East Riding End of Life Care Securing Sustainable Services group.

The clinical and management staff we spoke with were confident about the ability of the service to meet patient needs in the future. The community based teams identified staff sickness and the implementation of the IT based systems as key risks to the service. The charge nurse in the inpatient ward staff told us bed capacity was consistently below than the expected target of 85%. This meant the ward was not cost effective as all patient beds were not routinely used. The trust had plans to increase the number of patients with general nursing and rehabilitation needs in addition to end of life care patients to ensure the ward was used effectively.