This README file was generated on 2023-06-05 by Bardo Driller.
Last updated: 2023-06-07.

GENERAL INFORMATION

// Title of Dataset: Advance care planning and a structured palliative plan in primary health care
// DOI:
// Contact Information
    // Name: Bardo Driller
    // Institution: Møre og Romsdal Hospital trust, Oncology Department
    // Email: bardo.driller@helse-mr.no
    // ORCID: https://orcid.org/0000-0003-3611-5080

// Contributors: Bardo Driller, Anne-Tove Brenne.
// Kind of data: Continuous and categorical.
// Date of data collection/generation: June 2015 to March 2022.
// Geographic location: Møre og Romsdal, Norway
// Funding sources: Møre og Romsdal Hospital Trust

// Description of dataset:
Information on patient demographics, cancer diagnosis and prognosis, place of care, quality of life and performance status was registered at inclusion and collected every four weeks during observation. Use of hospital services, admissions, use of community health care services, and date and place of death were recorded and verified, especially for the last 90 days of life for those patients who died within the observation period. Number of days the patient was not admitted to hospital or nursing home was counted as “days at home”. Whole day stays at outpatient clinics like the oncology unit were not included as hospital stays. Contact with the hospital-based PC team was verified by documentation in hospital EPJ.
The patients responded to questionnaires at inclusion, every four weeks for two years, and thereafter every six months or until death. Data on quality of life (QoL) were collected (EORTC QLQ C15-PAL last question rated 1=very poor to 7=excellent) (29). Furthermore, every 12 weeks the patients stated preferred place of death (PPOD). The question was formulated: “We know from experience that you might change your mind over time. We would like to get your opinion about the next questions again, independently of what you have answered earlier.” 1)”Many people, both healthy and ill, think about where they in time would like to die. When that time comes, and you yourself could choose, where would you prefer to die?” Last responses before death were used to analyse if PPOD was the actual place of death (APOD).
Data on cancer deaths and place of death for the Romsdal region were obtained from the Norwegian Cause of Death Registry (DÅR 18-0503) to get information about pre-study number of cancer deaths at home in our region.

METHODOLOGICAL INFORMATION

Setting
Molde Hospital is a local hospital with an oncology outpatient clinic and a hospital-based PC team. The municipalities in the catchment area of Molde have between 3.000 and 25.000 inhabitants and collaborate with Molde Hospital. Community cancer nurses in the municipalities have expertise in PC and offered

support to patients and family caregivers on top of the support from general practitioners (GPs) and home-care nurses, the patient normally gets, before, during and after the study period. All cancer patients have access to the hospital-based PC team on referral from hospital or primary health care, based on needs and symptom burden. The PC team performs home visits in the municipalities upon request and provides education and support for the patients and their families. The local PC team and cancer outpatient clinic collaborates with nurses from all municipalities within a PC network and undertake education conferences at least once a year. PC physicians from the hospital also collaborate with GPs through visits at the GP offices, common patient visits at home or nursing home and through bi-annual training courses within general PC. Since 2015, home care nurses, nurses at nursing homes and GPs in the municipalities can contact a hospital PC physician by phone 24/7. Before 2015, three municipalities had implemented “Last days of life” (former Liverpool care pathway (26)), a structured guidance in Norway for PC in the last days and hours of life (27). These three municipalities cover 20.000 inhabitants. There was no hospice in the region during the study period.In 2018, Møre and Romsdal county in North-western Norway started providing organized ACP conversations and a structured palliative plan in primary health care to individuals with life-limiting illnesses like non-curable cancer.

Study design

The aim of the current study was to evaluate the effect of organized ACP conversations and a structured palliative plan in primary health care on an individual patient level. The study explores place of care prior to death and place of death for patients with incurable cancer who either did or did not have an organized ACP conversation and a documented structured palliative plan in a primary health care settings. The current retrospective observational cohort study evaluated outcomes from cancer patients enrolled in the ACP conversation program, compared with a control group that did not receive the ACP conversation. The study was conducted in nine municipalities in the Romsdal region with 65,000 inhabitants.

Subjects

The current study included cancer patients who could read and write Norwegian and: 1) had advanced loco-regional cancer and/or metastatic disease, 2) were > 18 years of age residing in one of the participating municipalities, and 3) were able to comply with study procedures. Patients treated with curative intent were excluded. The patients were identified through their contact with the local hospital, cancer outpatient clinic or hospital-based PC team.

Intervention group

Patients in the intervention group received an organized ACP conversation with a conclusive and structured palliative plan in primary health care setting.

The participants had information about the intention of the conversation. Confirmed conclusions were documented as a structured palliative plan in community EPJ with consent from the patient. Follow-up of ACP conversation was offered and the palliative plan was reassessed on demand when the patient’s medical condition changed.

Primary health care providers, mostly community cancer nurses but also home care nurses and GPs, decided if and when the patient should be offered an ACP conversation, and they were responsible for organizing and conducting it. They organized the conversation at the patients preferred place, proposing the possibility of having it at home (25).

Control group

The control group consisted of cancer patients who did not have an ACP conversation and a palliative plan in the primary health care setting.

Primary and secondary outcomes

Primary outcome was number of days spent at home during the last 90 days of life.

Secondary outcomes were the proportion of place of death in different settings (home, nursing home or hospital), PPOD and fulfilment of PPOD for those who died during the observation period, number of days at nursing home or in hospital and number of hospital admissions during the last 90 days of life.

Data collection

Longitudinal data were collected through paper-based case report forms (patients’ self-report and health care providers’ report) as part of the data collected in the Orkdal Model Study (ClinicalTrials.gov Identifier: NCT02170168) in collaboration with nine community nurses and The Trial Office, Trondheim University Hospital. Additional data were extracted from hospital and municipality EPJ.

Information on patient demographics, cancer diagnosis and prognosis, place of care, quality of life and performance status was registered at inclusion and collected every four weeks during observation. Use of hospital services, admissions, use of community health care services, and date and place of death were recorded and verified, especially for the last 90 days of life for those patients who died within the observation period. Number of days the patient was not admitted to hospital or nursing home was counted as “days at home”. Whole day stays at outpatient clinics like the oncology unit were not included as hospital stays. Contact with the hospital-based PC team was verified by documentation in hospital EPJ.

The patients responded to questionnaires at inclusion, every four weeks for two years, and thereafter every six months or until death. Data on quality of life (QoL) were collected (EORTC QLQ C15-PAL last question rated 1=very poor to 7=excellent) (29). Furthermore, every 12 weeks the patients stated preferred place of death (PPOD). The question was formulated: “We know from experience that you might change your mind over time. We would like to get your opinion about the next questions again, independently of what you have answered earlier.” 1)”Many people, both healthy and ill, think about where they in time would like to die. When that time comes, and you yourself could choose, where would you prefer to die?” Last responses before death were used to analyse if PPOD was the actual place of death (APOD).

Data on cancer deaths and place of death for the Romsdal region were obtained from the Norwegian Cause of Death Registry (DÅR 18-0503) to get information about pre-study number of cancer deaths at home in our region.

// Facility-, instrument- or software-specific information needed to interpret the data:

We used Microsoft Excel and Access 2016 to gather the data and calculate for example days from Palliative plan to death.

// Describe any quality-assurance procedures performed on the data:

During collection of data we verified exspecially where patients were the last 90 days of life and where they died.

DATA & FILE OVERVIEW

// File List:

DataPublicationACPinPHCBD2023.csv is the only file with data about ACP conversations in primary health care. This is the first public version of this data set.

Additionally the ReadMe file 00_ACPinPHCBDReadme.txt describes the data set.

DATA-SPECIFIC INFORMATION FOR: DataPublicationACPinPHCBD2023.csv

<Repeat this section for each dataset, folder or file, as appropriate. Recurring items may also be explained in a common initial section.>

<For TABULAR data, provide a data dictionary/code book containing the following information:>
// Variable/Column List:
ID patient identification number; DATO_INCL date of inclusion; PLACE_INCL place of inclusion 1=home 2=outpatient clinic 3=hospital 4=nursing home; PAT_SEX 1=male 2=female; ETHNIC 1=norwegian 2=other; CIVIL_STATUS 1=single 2=married 3=separated 4=widowed; LIVING_STATUS 1=alone 2=with partner 3=with partner and children 4=with children 5=with other adults; LIVING_STATUS2 Living together with partner 0=no 1=yes; LIVING_PLACE 1=one-family house 2=row house 3=appartment 4=generation house 5=care appartment 6=rest home 7=nursing home; EDUCATION 1=elementary school 2=high school 3=college; PEORTC15_1 EORTC QLQ C15-PAL last question rated at inclusion 1=very poor to 7=excellent; PEORTC15_x EORTC QLQ C15-PAL last question rated at follow-up 1=very poor to 7=excellent; PPD1_INKL preferred place of death at inclusion 1=home 2=nursing home 3=hospital 4=other; PPD3M_FOLL preferred place of death follow up 1=home 2=nursing home 3=hospital 4=other; PPD_CHANGE preferred place of death changed 0=no 1=yes; PPD_LAST last preferred place of death 1=home 2=nursing home 3=hospital 4=other; PPD_LAST_APD last preferred place of death is actual place of death 0=no 1=yes; PPCARE1 preferred place of care at inclusion 1=home 2=nursing home 3=hospital 4=other; PPCARE3M Importance at inclusion of beeing cared for at home next three months 1=not important at all 2=some important 3=more important 4=very important; PPCARE1_x preferred place of care at last follow up 1=home 2=nursing home 3=hospital 4=other; PPCARE3M_x Importance at last follow up of beeing cared for at home next three months 1=not important at all 2=some important 3=more important 4=very important; TREAT_NOIND at inclusion treatment not indicated 0=no 1=yes; TREAT_BREAK at inclusion treatment break 0=no 1=yes; ESTSUR_TIME at inclusion estimated survival time 1=less than one month 2=between one and 6 months 3=between 6 and 12 months 4=more than one year 5=between one and 5 years 6=more than 5 years; GPHOME_VISIT general practitioner home visit 0=no 1=yes; HCNURSE_CARE home care nurse home care 0=no 1=yes; HCNURSE_MED home care nurse responsible for medication 0=no 1=yes; NURS_HOME being in nursing home 0=no 1=yes; APD actual place of death 1=home 2=nursing home 3=hospital; DYING_PHC dying in primary health care 0=no 1=yes; DYING_HOME dying at home 0=no 1=yes; DYING_HOSPITAL dying in hospita l0=no 1=yes; CONTACT_PCTEAM contact with hospital-based palliative care team 0=no 1=yes; PALLPLAN palliative plan in primary health care 0=no 1=yes; LIV_STAT_ALONE living alone 0=no 1=yes;
<List variable/column name(s), description(s), unit(s) of measurement, decimal separator (comma or point), value labels, and source(s) as appropriate for each.>
// Missing data codes:
#NULL!

SHARING/ACCESS INFORMATION

<Whenever applicable, the following information should be registered in the metadata schema.>

// Links to publications that cite or use the data: Related Publication: Advance care planning and a structured palliative plan in primary health care decrease cancer deaths in hospital: A prospective controlled non-randomized intervention trial
Driller, Bardo; Talseth-Palmer, Bente; Hole, Torstein; Strømskag, Kjell Erik; and Brenne, Anne-Tove, submitted to BMC Palliative care,
https://www.researchsquare.com/article/rs-3025464/private/timeline