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REVIEW

Danish Palliative Care Database

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Aims: The aim of the Danish Palliative Care Database (DPD) is to monitor, evaluate, and improve the clinical quality of specialized palliative care (SPC) (ie, the activity of hospital-based palliative care teams/departments and hospices) in Denmark.

Study population: The study population is all patients in Denmark referred to and/or in contact with SPC after January 1, 2010.

Main variables: The main variables in DPD are data about referral for patients admitted and not admitted to SPC, type of the first SPC contact, clinical and sociodemographic factors, multidisciplinary conference, and the patient-reported European Organisation for Research and Treatment of Cancer Quality of Life Questionaire-Core-15-Palliative Care questionnaire, assessing health-related quality of life. The data support the estimation of currently five quality of care indicators, ie, the proportions of 1) referred and eligible patients who were actually admitted to SPC, 2) patients who waited <10 days before admission to SPC, 3) patients who died from cancer and who obtained contact with SPC, 4) patients who were screened with European Organisation for Research and Treatment of Cancer Quality of Life Questionaire-Core-15-Palliative Care at admission to SPC, and 5) patients who were discussed at a multidisciplinary conference.

Descriptive data: In 2014, all 43 SPC units in Denmark reported their data to DPD, and all 9,434 cancer patients (100%) referred to SPC were registered in DPD. In total, 41,104 unique cancer patients were registered in DPD during the 5 years 2010–2014. Of those registered, 96% had cancer.

Conclusion: DPD is a national clinical quality database for SPC having clinically relevant variables and high data and patient completeness.

Keywords: specialized palliative care, cancer, quality indicator, patient-reported outcomes, multidisciplinary conference, EORTC QLQ-C15-PAL

Aim for database

The Danish Board of Health has defined a clinical quality database as:

> […] a register containing quantitative indicators, which are based on the individual patient trajectory and can elucidate the overall quality or parts of the overall quality of the health care system's activity and results for a defined group of patients.[1]

The aim of the Danish Palliative Care Database (DPD) is to monitor, evaluate, and improve the clinical quality of specialized palliative care (SPC) (ie, the activity of hospital-based palliative care teams/departments and hospices) in Denmark.[2]

Study population

The study population for DPD is all patients in Denmark who

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- have been referred to SPC and/or
- have been admitted to SPC.

Patients who have been referred to or have been admitted to SPC prior to the opening of DPD (January 1, 2010) are not part of the study population and are not included in the database.

The reason for including referred patients who have not been admitted to SPC is that access to SPC was judged to be an important aspect of quality: at the time when the DPD was designed, it was often reported in media that particularly the hospices had to decline access due to insufficient capacity.

"Being admitted to SPC" requires the initiation of palliative care, ie, at least one consultation between the patient and the SPC unit in any location (the patient's home, the SPC unit, a non-SPC hospital department, etc). A patient who has only had contact with the SPC unit via telephone or who has only been evaluated with regard to eligibility is not regarded as having been admitted to SPC.

Each patient is registered once in DPD by each SPC unit receiving a referral of or admitting the patient. Thus, a patient having had contact with more than one SPC unit will appear with one registration for each of these SPC units. The same is the case for a patient who has been referred to more than one SPC unit but was not admitted to any of these units.

Between 2010 and 2014, 41,104 cancer patients were registered in DPD (2010: 6,041; 2011: 7,904; 2012: 8,743; 2013: 8,982; and 2014: 9,434). In addition, patients with other diagnoses such as respiratory, cardiovascular, and neurological diseases (in 2014: 4% of all patients) are registered.

According to the rules for clinical quality databases approved by the Danish Board of Health, registration of patients in DPD is mandatory for the SPC units.

Main variables

Table 1 lists all variables and their categories and indicates the variables that are used to estimate the following five quality indicators:

1. Proportion of referred, relevant patients who were actually received in SPC.
2. Proportion of patients who waited <10 days before admission to SPC.
3. Proportion of patients who died from cancer and who obtained contact with a SPC.
4. Proportion of patients screened with European Organisation for Research and Treatment of Cancer Quality of Life Questionaire-Core-15-Palliative Care (EORTC QLQ-C15-PAL)[3] questionnaire at admission to SPC.
5. Proportion of patients discussed at a multidisciplinary conference.

In addition to the variables needed for the quality indicators, the DPD includes clinical and sociodemographic variables and patient-reported outcomes at baseline (EORTC QLQ-C15-PAL scores). The first two quality indicators focus on access and waiting time. Problems related to these issues were often publicly debated before the creation of the DPD, and there was no national data available. The third indicator is a bit untypical by being a measure of access at the regional level. When developing the DPD, there was no knowledge as to whether the proportion of cancer patients who were admitted to SPC was similar in different parts of the country or whether this proportion corresponded to figures in other countries. This indicator will be subdivided into different types of contact (in-patient, out-patient, home visit, and consultation at non-SPC hospital department) when linking with the Danish National Patient Register has been established (work in progress).

There is evidence that not all the patients' symptoms and problems are detected if a systematic assessment is not conducted.[4–6] This motivates the fourth quality indicator, which requests that the patient has completed the EORTC QLQ-C15-PAL questionnaire at the day of first contact with SPC or up to 3 days before. The EORTC QLQ-C15-PAL[3] is an abbreviated version of the internationally most widely used instrument assessing health-related quality of life in cancer patients, the EORTC QLQ-C30, which was developed by the European Organization for Research and Treatment of Cancer.[7,8] To develop an instrument with minimal patient burden while preserving the advantages of (and comparability with) a well-validated instrument used in thousands of studies, the QLQ-C15-PAL was established by reducing the QLQ-C30 from 30 to 15 items by shortening scales and by deleting the items that were not important for patients in palliative care.[3] The content of the ten scales is shown in Table 1.

Patient-reported outcomes may be very important variables in clinical databases, and data from the EORTC QLQ-C15-PAL can be used to describe the baseline levels of symptoms and problems in the patients admitted to SPC and for other purposes.

SPC is defined as a multiprofessional and interdisciplinary approach.[9] Therefore, the fifth quality indicators measures whether it is documented in the medical record that the patient has been discussed at a multidisciplinary conference with representation from at least four disciplines (medical secretaries not included) present.

Most of the variables in DPD are entered by the SPC units in a web-based data entry system called Clinical Measurement System (in Danish: Klinisk Målesystem [KMS]). The following two paper-based forms are used for this: a data form consisting of 18 items and the patient-completed questionnaire

Table 1 Variables in the Danish Palliative Care Database (DPD): variable name, categories, purpose, data completeness, and data quality

Variable name	Categories	Purpose and relation to indicators	Data completeness (2014), %	Data quality
Variables available for all patients registered in DPD				
Central Person Registration (CPR) number	A unique ten digit number including date of birth and sex	Link to other registers	100	A unique identification number used in all contacts to public authorities, etc
Date of birth	Date	Descriptive	100	Extracted from CPR number
Sex	Male Female	Descriptive	100	Extracted from CPR number
Referral date	Date	Used for indicator 1	100	Referral dates before January 1, 2010 (which leads to exclusion), or after registration date are flagged and checked
Age at referral	Years (estimated from date of birth and referral date)		100	
Referral unit (who referred the patient to SPC)	General practitioner Medical specialist (not working in hospital) Hospital department Another SPC unit The patient or carer Other	Descriptive	100	
Diagnosis	Cancer diagnosis (if applicable) using ICD-10 Noncancer diagnosis Cardiovascular disease (I00-I28, I30-I51, I60-I99) Neurological disease (G00-31, G35-H95) AIDS (B20-24) Other disease	Descriptive	100	Validity has been evaluated; manuscript unpublished
SPC started	Yes No	Used for indicators 1–5	100	Checked by linking with Danish National Patient Register. Any persons registered with SPC contact but not in DPD are flagged and checked
Variables available only for patients not admitted to SPC				
Referral criteria fulfilled?	Yes No Cannot be determined	Used for indicator 1	89	
If referral criteria were fulfilled, why not SPC?	Unsuitable for treatment. Why? Refused SPC Died before SPC Lack of capacity in SPC unit Admitted by another SPC unit Other reason	Used for indicator 1	100	
Reason for not being suitable for treatment	Open ended			
If referral criteria were not fulfilled, which criteria were not fulfilled?	Not cancer Not incurable disease Not symptoms that required specialized or multidisciplinary assistance Diagnostic process not completed The patient was not informed about the disease Other	Descriptive	100	

(*Continued*)

Table 1 (*Continued*)

Variable name	Categories	Purpose and relation to indicators	Data completeness (2014), %	Data quality
Variables available only for patients admitted to SPC				
Date of first SPC contact	Date The date is specified as the first (physical) contact where treatment is considered, thus any prior contact to determine eligibility or telephone contacts are not included	Used for indicators 1, 4, and 5	100	Checked by linking with Danish National Patient Register. Any persons registered with SPC contact but not in DPD are flagged and checked
Type of first contact	Outpatient Inpatient	Descriptive	100	
Place of first contact (to be completed if type of first contact was outpatient)	SPC outpatient clinic Home visit SPC consultation in a non-SPC unit	Descriptive	100	
Status at completion of contact	Dead Alive	Descriptive		
Place of death (to be completed if the patient had been in contact with the SPC unit until death)	At home In this SPC unit In another SPC unit Non-SPC hospital department Respite care Other place/unknown	Descriptive	100	
Children	No children Children, at least one younger than 18 years Children, all at least 18-years-old Unknown	Descriptive	93	
Residence	Private residence (flat, house, etc) Nursing home/senior residence Other Unknown	Descriptive	96	
Cohabitation status	Living alone Living with spouse/partner Living with children Living with spouse/partner and children Living with parent(s) Living with others Unknown	Descriptive	99	
Has the patient been discussed at a multidisciplinary conference in the SPC unit?	Yes, with four or more professions present and specified and a written conclusion in the medical record Yes, with two or three professions present and specified and a written conclusion in the medical record Not documented in the record	Used for indicator 5	100	

(*Continued*)

Table 1 (*Continued*)

Variable name	Categories	Purpose and relation to indicators	Data completeness (2014), %	Data quality
Date of multidisciplinary conference	Date	Used for indicator 5	100	
Patient completion of EORTC QLQ-C15-PAL questionnaire	Yes No – too ill No – refused No – not explained	Used for indicator 4	100	
EORTC QLQ-C15-PAL	Responses to the 15 items (raw data) and estimated scores for 10 scales: Physical function, emotional function, pain, fatigue, nausea/vomiting, dyspnea, lack of appetite, constipation, sleeping difficulties, overall quality of life			
Date of death	Date	Used for all indicators 1–5	–	Obtained by linking with the Danish Civil Registration System

Abbreviations: SPC, specialized palliative care; ICD-10, International Statistical Classification of Diseases and Related Health Problems Tenth Revision.

EORTC QLQ-C15-PAL.[3] The information for completion of the data form is extracted from the medical record, including documents relating to referral. This typically takes place after the patient's death or after contact has been stopped. The variables in DPD have a high level of data completeness, with completeness ~100% for several variables, reflecting that these fields are mandatory in the reporting (Table 1).

Follow-up

As all data for each patient are entered at a single point of time, there is no subsequent follow-up.

The DPD Board is planning two expansions of the DPD related to follow-up. First, detailed data about all SPC activity subsequent to the first contact will be added to the DPD via linking with the Danish National Patient Register (using the unique personal registration number), which contains all hospital and hospice contacts.

Second, it is planned to add a second assessment with the EORTC QLQ-C15-PAL questionnaire,[3] in addition to the first, which is completed by the patient at the first contact. The second assessment will take place ~1–4 weeks later and will allow evaluation of change in each of the scores after initiation of SPC, ie, "response to treatment."

Examples of research

Two ongoing PhD projects are based on DPD data and take place in the DPD Secretariat at Bispebjerg Hospital (Table 2). In the first, data from DPD are linked with other national registers in Denmark, the Danish Register of Causes of Death,[10] the Danish Civil Registration System,[11] the Danish Cancer Registry,[12] and Statistics Denmark to investigate social inequality in admittance to SPC. In the second project, the data from the EORTC QLQ-C15-PAL are analyzed in order to better understand the epidemiology of symptoms and problems in the patients admitted to SPC.

Table 2 Examples of research with data from the Danish Palliative Care Database (DPD)

Name of the researcher	Title
Projects based on the DPD	
M Adsersen (PhD project)	Inequality in admittance to Specialized palliative care (SPC) in Danish patients with cancer
MB Hansen (PhD project)	Symptoms and problems in patients with cancer in specialized palliative care (SPC)
Projects using data from DPD	
C Bell	Survival time after diagnosis of terminal illness: a Nationwide Danish Cohort Study
KS Benthien (PhD project)	The impact of specialist Palliative Care on Medical Treatment and Place of Care for Patients with Cancer
AT Johnsen	The Danish Palliative Care Trial (DanPaCT)
LR Nylandsted	Use of the VOICES-SF among bereaved carers in Denmark: validation and cultural adaptation
AK Winthereik (PhD project)	General practitioners and end-of-life care

Data from the DPD play an important role in several other projects (Table 2).

Administrative issues and funding

The DPD Secretariat supports the 43 SPC institutions, which report data to DPD, at a daily basis concerning questions and problems in relation to the mandatory entering of data in DPD, and carries out analyses of and validation of data. Data from DPD are continuously validated against the Danish National Patient Register to ensure that all patients are entered in DPD: it is checked whether all patients registered in the Danish National Patient Register as having a contact with an SPC unit are registered in DPD, and whether there is agreement about the date of admission. To clarify any discrepancies, the DPD Secretariat contacts the SPC units if there is disagreement between the two data sources. Any errors detected are corrected. This ensures a high completeness of patients in the database: in 2014, the patient completeness was 100%, ie, all patients registered with an SPC contact in the Danish National Patient Register were also registered in the DPD. The DPD Secretariat, in collaboration with the DPD Board, produces an Annual Report in Danish showing the results of the indicators overall and at the SPC unit level and at the regional level.[2]

The SPC institutions have access to their own data, and the DPD Secretariat offers courses in handling and analyzing their own data.

DPD is funded by the Danish Regions (who are the owners and administrators of the public hospitals) via The Danish Clinical Registries (RKKP).

Conclusion

Prior to the establishment of DPD, there was no knowledge about the quantity or quality of SPC at the national level. The past years of work with the DPD have shown that it is possible to establish a national clinical quality database with a high level of completeness even in a newly established, very busy, and very heterogeneous part of the health care system. This positive development probably reflects the perceived importance of the data produced by the DPD (both about quantity and quality), the high level of professional motivation in the SPC units and the DPD Board, the relatively modest registration burden, the availability of support from a dedicated Secretariat, and the fact that registration in the clinical databases, which are officially approved by the Danish Board of Health, is mandatory.

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Disclosure

Mogens Groenvold is chairman of the DPD Board and Mathilde Adsersen and Maiken Bang Hansen, PhD students, work part time in the DPD Secretariat. The authors report no other conflicts of interest in this work.

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