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# Status, demand and practice models of palliative day-care clinics and day hospices: a scoping review

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## ABSTRACT

**Background** Little is known about the structure, accessibility, service provision and needs of palliative and hospice day-care in Germany and abroad. Researchers, healthcare providers and policy makers would benefit from a systematic overview.

**Aim** The aim was to identify, describe and summarise available evidence on status, demand and practice models of palliative day-care clinics and day hospices. A secondary aim was to disclose research gaps and present recommendations for clinical practice and future research.

**Design** The scoping review followed the methodological framework of Arksey and O'Malley. The analysed publications included studies of varying kinds to describe the current state of the art.

**Data sources** Using a highly sensitive search strategy, the authors searched PubMed, Web of Science Core Collection, CINAHL and Google Scholar within the publication window of inception to 12 June 2020. An additional hand search of the reference lists of the identified review articles was conducted.

**Results** The authors screened the titles and abstracts of 2643 studies, retrieved 197 full texts and included 32 articles in the review. The review identified nine major themes: (1) the referral process, (2) models of care, (3) patient characteristics, (4) demand, (5) the discharge process, (6) perceptions of services, (7) funding and costs, (8) outcome measurement and (9) education.

**Conclusions** There is a need for further research to identify groups of patients who would receive the most benefit from palliative and hospice day-care and to determine any necessary revisions in admission criteria.

## INTRODUCTION

The world's first day hospital for patients with preterminal cancer and chronic disease, St Luke's Hospice in Sheffield,

## Key messages

### What was already known?

- Use of palliative day-care clinics and day hospices has been increasing since their inception in 1975.
- The provision of palliative and hospice day-care in Germany and abroad remains largely unsystematic; thus, a scoping review is needed to map the findings reported in the literature.

### What are the new findings?

- Patient satisfaction with these services is undisputed, yet evidence on outcomes and cost-effectiveness to support patients' perceptions is scarce.
- Reports on service provision vary greatly across the palliative and hospice day-care landscape.

### What is their significance?

- Clinical**
  - The preferred model of care seems to comprise a multidisciplinary approach, full-day access and a wide range of activities (including social activities).
  - Health professionals should aim at educating their patients about palliative and hospice day-care to reduce anxiety and minimise barriers.
- Research**
  - There is a need for tools to measure outcomes without an exclusive focus on health-related quality of life.
  - There is a need to identify patient groups with the greatest potential to benefit from palliative and hospice day-care and to revise admission criteria accordingly.

UK, opened 50 years ago.<sup>1</sup> Since that time, palliative and hospice day-care programmes have proliferated across the globe. In Germany, the revision of the Hospice and Palliative Care Act<sup>2 3</sup> (passed in 2015 by the German Bundestag) brought palliative day-care clinics and day hospices into focus. While there

have been several pilot projects to research these facilities,<sup>4</sup> to date no consensus has been reached on who should access palliative and hospice day-care, who should provide these services and how these services should be integrated into existing healthcare structures. Furthermore, research on the provision of palliative day-care clinics and day hospices in Germany is scarce, and international approaches to palliative and hospice day-care seem relatively nascent. To improve the quality of care in these facilities, researchers and healthcare providers would benefit from a systematic overview of what is already known about the provision of palliative day-care clinics and day hospices. Therefore, the present scoping review aimed at reviewing the literature with respect to status, demand and practice models of palliative day-care clinics and day hospices in Germany and abroad.

The results of the review will inform an analysis of the status and demand for palliative day-care clinics and day hospices in Germany within the project 'Improving health care for patients with terminal, progressive illnesses: Status and demand analysis for palliative day-care clinics and day hospices and recommendations for health care planning' (ABPATITE).

#### Study aim

The present scoping review aimed at examining the international literature on adult palliative day-care clinics and day hospices with regard to the following research questions:

- ▶ What is known about the status of and demand for palliative day-care clinics and day hospices?
- ▶ What is known about practice models of care in palliative day-care clinics and day hospices?

## DESIGN AND METHODOLOGY

### Motivations for the scoping review

The scoping review provided insight into the overall state of play with respect to research<sup>5</sup> on palliative day-care clinics and day hospices. By determining the scope of prior research, it was possible to identify gaps in the literature<sup>5 6</sup> and make recommendations for future studies.

In contrast to the systematic review method, scoping reviews are able to consider much wider topics. Furthermore, they allow for the inclusion of any study type, regardless of the quality of evidence; thus, the risk of omitting relevant information due to a narrow search strategy is minimised.<sup>5</sup>

### Scoping review steps

The authors followed the five-stage methodological framework developed by Arksey and O'Malley<sup>5</sup>: (1) identification of the research question(s), (2) identification of the relevant studies, (3) selection of studies, (4) data extraction and charting, and (5) summarisation and reporting of the results. The Preferred Reporting Items for Systematic reviews and Meta-Analyses

extension for Scoping Reviews (PRISMA-ScR) checklist<sup>7</sup> guided the reporting of the results.

### Time span

All databases were searched within the publication window of inception to 12 June 2020. The authors decided against limiting the search to a narrow time span, as palliative care is a young discipline and the number of search results was expected to be manageable. Furthermore, as the research aimed at identifying research gaps, the authors wanted to prevent any omission of relevant information due to a narrow search window.

### Languages

The authors included publications in German and English. International scientific communication, including the publication of research articles, is commonly conducted in English. Thus, the authors assumed that most of the potentially relevant research articles would have been written in English. However, as the authors were concurrently conducting a research project in Germany aimed at improving the quality of palliative care, the inclusion of articles in their mother language (German) was also of interest.

### Types of studies

All study designs were eligible, as the authors aimed at including all potentially relevant research. Throughout the process, conference contributions and studies that were not published in full text were excluded from the analysis due to their minimal contribution to the knowledge base. Review articles were included in the discussion, yet excluded from the data and results, which instead reported only primary literature. To ensure no relevant research was missed, reference lists of review articles were searched for further articles not identified in the database searches.

### Databases

A presearch was conducted in PubMed, Web of Science Core Collection, CINAHL, PsycINFO, PsycJournals, International Bibliography of Social Sciences (IBSS) and Google Scholar. These represent broad databases, covering various disciplines (eg, medicine, psychology, nursing science, sociology), thereby minimising the risk of omitting relevant publications. As the PsycINFO, PsycJournals and IBSS searches produced no additional results relative to the other database searches, these databases were thereby excluded in the final search. The final search was conducted on 12 June 2020 in PubMed, Web of Science Core Collection, CINAHL and Google Scholar. All identified articles were imported into EndNote V.X8/X9 reference management software (Clarivate, Philadelphia, USA).

### Search string

The authors conducted an iterative literature search, refining the search strategy until a maximum of relevant results was obtained. The final search strategy (see online supplemental file 1) included keywords, along with their synonyms and comparable concepts, grouped by the Boolean operator OR. To link these groups of words, the Boolean operator AND was used. Additionally, PubMed medical subject headings were used to maximise the number of relevant results. Pursuing the same objective, the Boolean operator NOT was used to exclude results that were not relevant to the research questions. Studies focusing on terminally ill children and psychiatric patients, as well as day-care offers for elderly people with the objective of rehabilitation, were excluded. These groups require care that is often addressed in specialised institutions that differ from palliative and hospice day-care providers.

## RESULTS

### Study selection

After duplicates were removed, the total number of results was 2643. In the first step, titles and abstracts were reviewed independently by two authors (TT, FAH). Second, full texts of articles with titles and abstracts that met the inclusion criteria (n=197) were assessed independently by the same authors. This search resulted in 32 articles for the final review, including 5 review articles<sup>8–12</sup> that were not part of the scoping review (see figure 1 for a flow chart of the study selection).

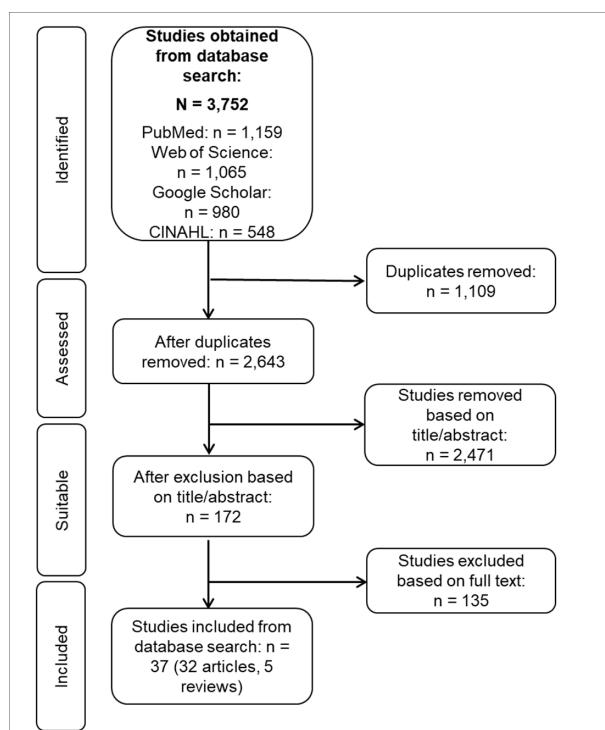


Figure 1 Study selection flow chart.

### Characteristics of the included studies

Geographical location and research aim varied in the included studies (see tables 1–3 for details), with the majority of studies originating in the UK. In 16 studies, the type of care reported was palliative day-care, while 11 studies reported hospice day-care. Participants were mainly palliative or hospice day-care patients (25 studies) or staff members, including volunteers (12 studies). Family members or caregivers participated in four studies; referrers were interviewed in one study.<sup>13</sup>

The sample size varied from 8<sup>14</sup> to 154<sup>15</sup> participants. One study reviewed the medical consultations of 287 patients.<sup>16</sup> The most frequently used methods were qualitative (11 studies) and quantitative (10 studies). Both qualitative and quantitative data were reported in three studies, of which two reported mixed methods. Other methods, including descriptive research, were employed in eight studies.

### Descriptive analysis of topics

The review identified nine major themes with respect to the status, demand and practice models of palliative day-care clinics and day hospices: (1) the referral process; (2) models of care; (3) patients attending palliative day-care clinics and day hospices; (4) the need to counteract the under-representation of patients with non-malignant conditions, ethnic minority patients and younger patients; (5) the discharge process; (6) patient perceptions of palliative day-care clinics and day hospices; (7) funding and cost-effectiveness; (8) evaluation and outcome measurement tools; and (9) education about the goals of palliative day-care clinics and day hospices.

### Referral process

Studies examining the referral process described the establishment of defined referral criteria.<sup>17–23</sup> However, the specific criteria differed across studies. Frequently reported criteria included the diagnosis of a progressive life-limiting disease<sup>20–22</sup> and the need for specific palliative care,<sup>19–22</sup> often in combination.

Referral processes also differed between facilities. All studies on the referral process were conducted in the UK, with only one exception (originating in Canada).<sup>15</sup> These studies highlighted that referrals were made by community palliative care teams,<sup>19 24 25</sup> palliative care inpatient units,<sup>25 26</sup> various outpatient hospital services,<sup>15</sup> social workers<sup>25</sup> and primary healthcare teams, including general practitioners.<sup>17 25 26</sup> Lohfeld *et al*<sup>23</sup> described that health professionals (including administrators and experienced palliative care providers) demanded that a wide range of professionals be allowed to make referrals to palliative day-care.

The published reasons for referral ranged from caregiver respite<sup>13 18 21 25 27</sup> to psychosocial support for patients and caregivers<sup>13 17–19 21 25 27</sup> and symptom control for patients.<sup>13 17–19 21 27</sup> A review of the studies revealed a discrepancy in priorities between health

**Table 1** Summarised characteristics of the included studies: part 1

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Anonymous (2010) <sup>37</sup>	Newspaper article	USA	Adult day-care and hospice	Describe the advantages and challenges of collaborating services and extract relevant information for implementation.	Qualitative interviews.	Stakeholders and programme leaders of adult day services and hospices (n=N/A).	Status: where collaborations exist, education programmes for hospice staff about adult day-care (and vice versa) are being held. Demand for more staff education regarding referral criteria, symptom and pain management and bereavement.
Svidén <i>et al</i> (2009) <sup>36</sup>	Original research article (quantitative)	Sweden	Palliative day-care	Examine palliative day-care outcomes (health-related quality of life, emotional well-being).	Prospective comparative study and structured questionnaires (Organisation for Research and Treatment of Cancer [EORTC] QLQ-30, MACL) analysed with descriptive statistics.	Patients from day-care group (n=31); patients from comparison group receiving palliative home care (n=17).	Status: existence of hospital-based outpatient service; staff consists mainly of nurses and occupational therapists, as well as a multiprofessional team on demand; no significant differences in outcome of palliative day-care vs comparison group.
Annemans <i>et al</i> (2020) <sup>35</sup>	Original research article (qualitative)	Belgium	Hospice day-care	Explore the impact of the physical environment on palliative day-care.	Observation and semistructured interviews; qualitative analysis according to the Guide of Leuven.	Individual interviews with day-care guests (n=8); three focus groups with staff, volunteers and family members (n=15).	Status: small-scale hospice offering day-care; location in the countryside; physical proximity of residential hospice to day-care hospice creates mainly positive associations among patients and caregivers.
Bradley <i>et al</i> (2011) <sup>13</sup>	Original research article (qualitative)	UK (England)	Palliative day-care	Explore reasons for referrals to day-care.	Semistructured interviews analysed with interpretative phenomenological analysis.	Referrers (n=8), general practitioner (n=1), community-based specialist palliative care nurses (n=4), hospital-based specialist palliative care nurses (n=2), heart failure nurse (n=1).	Status: referrals for physical reasons rather than psychosocial reasons; reasons for referral: physical, social and emotional well-being, continuity of care, caregiver respite, introduction to the hospice environment. Demand for a more standardised referral process to reduce referrer bias.
Cochrane <i>et al</i> (2008) <sup>17</sup>	Original research article (descriptive)	UK (Scotland)	Hospice day-care	Evaluate a pilot project examining day-care for people with non-malignant conditions.	Description of a pilot study and collection of quantitative data on patients to evaluate the project.	Day-care patients (n=28).	Status: multidisciplinary team; attendance on the same day each week to tighten relationships; review after 12 weeks of attendance (discharge or not); training staff about patients with non-malignant conditions. Demand for the evaluation of hospice day-care benefits for patients with non-malignant diseases.

Continued

Table 1 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Corr and Corr (1992) <sup>34</sup>	Original research article (descriptive)	USA	Hospice day-care	Depict the idea and implementation of hospice day-care and its position within the healthcare system.	Descriptive report.	N/A.	Status: hospice day-care is a form of care between home and inpatient care that provides a variety of benefits to participants and encourages their autonomy, while giving carers a break; volunteers benefit from lacking a predefined place in the hospice hierarchy.
Vries <i>et al</i> (2012) <sup>18</sup>	Original research article (qualitative)	UK (England)	Specialist palliative day hospice	Examine the discharge and (re)admission procedure at a specialist palliative day hospice.	Case study including semistructured interviews with patients, carers and staff and examination of documentation, thematically analysed.	Cases recruited (n=5).	Status: reasons for referral perceived as medical by healthcare professionals but social by patients/carers; patient assessment every 6 weeks by a multidisciplinary team to determine whether continued attendance is necessary; periodic discharges once goals are achieved to allow more patients to attend. Patient demand for continuous attendance instead of periodic discharge.
Douglas <i>et al</i> (2003) <sup>31</sup>	Original research article (descriptive)	UK (England)	Palliative day-care	Analyse the cost and effect of palliative day-care attendance on other services.	Cost evaluation through the provision of budgets, qualitative interviews with staff, observations and the review of financial documents; qualitative interviews with patients on their use of health and social care.	Patients in day-care group (n=120) from n=5 palliative day-care centres; comparison group not receiving day-care (n=53).	Status: palliative day-care as a way to access specialist medical care, possibly substituting for community care.
Douglas <i>et al</i> (2000) <sup>19</sup>	Original research article (qualitative)	UK (England)	Palliative day-care	Assess the structure, processes and tools for evaluating outcomes.	Indepth observations analysed with system analysis.	Palliative day-care centres (n=5); at each centre researchers spoke with patients (n=5–10), staff, finance director, senior nursing manager and medical director.	Status: patients receive additional community care and can access medical care through attached inpatient unit; clear referral criteria; counselling for family members; mostly funded by the voluntary sector; range of activities reflects variable patient needs; provision of a specific day for younger attendees. Demand for further research on adequate instruments to measure palliative day-care outcomes.
Douglas <i>et al</i> (2005) <sup>36</sup>	Original research article (quantitative)	UK (England)	Palliative day-care	Identify patient preferences at a palliative day-care centre.	Choice experiment (data collected during interviews) and statistical analysis with probit analysis.	Day-care patients (n=81) from n=4 centres.	Status: full-day vs appointment-based models. Demand for full-day access and access to special therapies.

Continued

Table 1 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Fisher <i>et al</i> (2008) <sup>14</sup>	Original research article (qualitative)	Australia	Palliative day-care	Explore palliative day-care experiences in Western Australia.	Semistructured interviews analysed with constant comparative analysis.	Day-care patients (n=8).	Status: palliative day-care reduces patients' feelings of being bound socially, physically, temporally and medically. Demand for a flexible service to meet patients' changing needs.

MACL, Mood Adjective List; N/A, not available; QLQ-30, Quality of Life Questionnaire 30.

professionals and patients: health professionals put more weight on medical reasons, including symptom control,<sup>13 18 19</sup> while patients valued social contact above all else and placed a greater emphasis on psychosocial factors.<sup>18 28</sup> Only one study described referrals by a home care nurse for psychosocial reasons.<sup>24</sup>

### Models of care

The analysed studies reported very different models of care. Frequently, they distinguished between palliative day-care clinics and day hospices that focused on social aspects of care<sup>28–30</sup> and those that emphasised medical aspects.<sup>19 31 32</sup> However, most centres described in the literature operated on a mixed model.<sup>13 24 27 33</sup> Health professionals working in palliative day-care clinics and day hospices seemed to favour the medical model. Many patients appreciated the opportunity to access medical care, but preferred a mixed model, emphasising the value of psychosocial support and social contact in both palliative and hospice day-care. Several authors<sup>19 22 33 34</sup> suggested that palliative and hospice day-care should be understood as a form of care falling between home and inpatient care, possibly even substituting for community care.<sup>19</sup> Corr and Corr<sup>34</sup> portrayed day-care as a suitable introduction to the hospice environment for terminally ill patients, enabling them to stay at home for as long as possible. Finally, the literature described some free-standing palliative day-care clinics and day hospices,<sup>35</sup> as well as palliative day-care clinics and day hospices integrated with residential hospices or hospitals,<sup>15 32 35 36</sup> or community centres.<sup>28</sup>

The analysed studies showed that most palliative day-care clinics and day hospices were staffed with a multidisciplinary team providing a diversity of services and activities. Nurses and nursing care played a key role.<sup>14–27 30–34 36–44</sup> Medical care was mostly provided by physicians on the core staff<sup>15–17 22 27 31 36 37 41 44</sup> or physicians from an associated inpatient unit<sup>19</sup> or hospital.<sup>15</sup> Furthermore, patients were offered physiotherapy,<sup>15–20 22 24–27 30–32 34 36 39 41 42</sup> occupational therapy,<sup>16 17 19–22 25 27 30 32 34 36 41</sup> art and music therapy/crafting,<sup>19 21 22 24 26 27 30–33 36 42 44</sup> body care (eg, hairdressing and bathing),<sup>16 25 27 30 32–34 38 43</sup> complementary therapies (eg,

aromatherapy and massage)<sup>16 19–22 24–27 30 32 34 39 44</sup> and shared meals.<sup>25 26 30 32–34 36 42–44</sup> Three studies reported family/carer support groups.<sup>15 21 37</sup> Higginson *et al*<sup>21</sup> found that patients codetermined the activities on offer. Most authors reported that the palliative day-care centres and day hospices relied on volunteers<sup>15–17 19–21 23–26 28 30 32–35 37 40 44</sup>; however, the importance of the volunteers' tasks differed greatly, ranging from transport<sup>17</sup> to being the only staff employed at a day hospice.<sup>28</sup> The role of the doctor was addressed by White and Johnson<sup>16</sup> and Hearn and Myers,<sup>27</sup> who described that the physician's main task was to manage patients' complex needs<sup>27</sup> and identify any deterioration in their condition.<sup>16</sup> Other caregiving professions in palliative day-care clinics and day hospices, extending across the core and extended teams, included social workers,<sup>15 20–22 25 30 36 41 44</sup> chaplains,<sup>15–17 21 25 26 36 37 41 44</sup> psychologists,<sup>15 19 20 26 41</sup> dietitians,<sup>15 17 21 22</sup> chiropractors,<sup>16 21 25</sup> hairdressers<sup>16 21 25</sup> and pharmacists.<sup>15 30</sup>

The literature showed that palliative day-care clinics and day hospices were open 1–7 days per week,<sup>18 21 28 33 41</sup> and offered weekly access to patients between the hours of about 10:00–15:00.<sup>17–21 24 25 30 32 34 36</sup> One study reported an appointment-based model,<sup>25</sup> while Hirose *et al*<sup>29</sup> provided an example of service-themed meetings. Attendance options described in the studies vary considerably from an unlimited number of days a week the patients can attend<sup>33</sup> to monthly appointments.<sup>25</sup> Patients seemed to prefer spending an entire day in day-care over appointment-based attendance.<sup>38</sup> Furthermore, two authors showed that giving patients the opportunity to attend the day hospice on the same day each week enabled them to build stronger relationships with other patients and staff.<sup>17 30</sup>

### Patients attending palliative day-care clinics and day hospices

The analysed publications described the 'typical' palliative day-care patient as white, over 65 years old<sup>24 26 30 32 39</sup> and with a cancer diagnosis.<sup>15 19 21 24–26 28 29 32 36 39–43</sup> A few palliative day-care clinics and day hospices were reported to also focus on patients with non-malignant conditions, such as motor neuron disease, chronic

**Table 2** Summarised characteristics of included studies: part 2

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Gagnon <i>et al</i> (2015) <sup>15</sup>	Textbook chapter	Canada	Palliative day-care hospital	Examine the role of palliative day-care (hospitals) within the healthcare system.	Review and assessment (ESAS); review (Delphi method) involving experts with 6 years of experience.	Consecutively referred patients (n=154).	Status: palliative day-care hospitals care for patients at all stages of the disease trajectory and represent a link between community care and other healthcare services. Demand for the evaluation of cost-effectiveness and the identification of patients who would benefit most from palliative day-care.
Goodwin <i>et al</i> (2003) <sup>39</sup>	Original research article (quantitative)	UK	Palliative day-care	Evaluate day-care effectiveness (pain improvement, symptom control and quality of life).	Prospective comparative study with structured questionnaires (McGill Quality of Life Questionnaire [MQOL] and POS), analysed with statistical analysis.	Day-care patients (n=120) from n=5 palliative day-care centres.	Status: The MQOL did not find significant differences between groups; POS 'pain control' and 'symptom control' were better in the day-care group; quality of life could not be measured by health status alone. Demand for the integration of social contact and support into future studies aimed at measuring palliative day-care outcomes.
Goodwin <i>et al</i> (2002) <sup>24</sup>	Original research article (qualitative with a quantitative component)	UK	Palliative day-care	Explore patient perspectives on palliative day-care.	Semistructured interviews analysed with thematic content analysis; quantitative assessment of epidemiological data.	Day-care patients (n=120) from n=5 palliative day-care centres.	Status: most important aspect of palliative day-care is social contact. Demand for more dialogue between centres; reconsideration of staffing levels; further consideration of location and type of patient.
Greaves (2012) <sup>26</sup>	Thesis (mixed methods)	UK (England)	Palliative day-care	Explore factors determining access to palliative day-care.	Quantitative assessment of epidemiological data; document analysis and semistructured interviews analysed thematically (constant comparison and content analysis).	Staff and volunteers (n=32), patients (n=11) and carers (n=7).	Status: 18 factors determining access to palliative day-care. Demand for access to palliative day-care for younger patients, patients with non-malignant diseases and ethnic minority patients; further clarification of funding.
Guest <i>et al</i> (2015) <sup>20</sup>	Original research article (mixed methods)	UK (England)	Palliative day-care	Implement and evaluate a therapeutic day-care programme.	Emotional touchpoints (tool for evaluating patient experiences) and distress thermometer analysed with quantitative analysis; semistructured questionnaire analysed quantitatively and with thematic analysis.	Attending patients (n=23) and staff (n=10).	Status: 6-week multidisciplinary programme to educate patients with cancer on how to cope with problems and manage life with the disease, possibly reducing hospital admission rates and enabling patients to die at home; admission and discharge criteria.

Continued

Table 2 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Hearn and Myers (2001) <sup>27</sup>	Anthology	UK	Palliative day-care	Provide information on the diversity of palliative day-care, including needs and struggles.	N/A.	N/A.	Status: therapy-based medical models vs psychosocial models emphasising emotional and social care; multidisciplinary team approach (including a doctor) to address patients' complex needs; clinical audit to assess quality of care. Demand for the identification of patients who would benefit most from palliative day-care; continuous needs assessment in day units; further research on ethnic minorities in palliative day-care; care for patients with non-malignant diseases; evaluation tools.
Higginson <i>et al</i> (2010) <sup>32</sup>	Original research article (quantitative)	UK (England)	Hospice day-care	Evaluate patients' use of other health services while attending hospice day-care.	Prospective comparative trial and structured interviews analysed with a multivariate analysis of covariance.	Day-care group participants (n=37), standard palliative care group participants (n=50) and standard palliative care group participants waiting for new hospice to be built (n=76).	Status: day unit attached to inpatient hospice; use of hospice day-care in addition to existing services; use of other services seems insignificantly affected by the use of hospice day-care; significant reduction in use of therapy services within the day-care group. Demand for the identification of patients who would benefit most from palliative/hospice day-care; a therapy-based model of care.
Higginson <i>et al</i> (2000) <sup>21</sup>	Original research article (quantitative)	UK (England)	Palliative day-care	Examine models of care in different palliative day-care centres.	Questionnaire survey analysed with univariate analysis.	Palliative day-care centres (n=40).	Status: 1.77 places per 10 000 people in the region; median occupancy at 71%; various activities offered; carers support group; bereavement follow-up; admission criteria; discharge policy; volunteers as essential staff.

Continued



Table 2 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Hirose <i>et al</i> (1997) <sup>29</sup>	Original research article (descriptive)	Japan	Outpatient salon	Establish palliative day-care through an outpatient salon.	Descriptive report and discussion of the value and implications of the project for palliative day-care.	Patients (n=39), with a variable number of staff members.	Status: themed meetings for outpatients in the Department of Radiology ward twice monthly, managed by two counsellors; focus on psychological needs and support; promote self-help by involving patients in the planning process; include patients at all stages of the disease trajectory.
Hopkinson and Hallett (2001) <sup>40</sup>	Original research article (qualitative)	UK (England)	Hospice day-care	Explore patient perceptions of hospice day-care.	Open interview analysed with phenomenological analysis.	Hospice day-care patients (n=12).	Status: high satisfaction among patients, who value the ability to make independent decisions and escape the patient role; hospice day-care reduces patients' sense of isolation; offer a range of activities for patients.

ESAS, Edmonton Symptom Assessment System; N/A, not available; POS, Palliative Care Outcome Scale.

airway disease and HIV.<sup>15 17–19 21 22 25 39 42</sup> Several articles described facilities accepting patients across a wide range of disease trajectory, moving away from a focus on the terminal stage of illness.<sup>15 28–30 33</sup>

#### **Demand to counteract the under-representation of patients with non-malignant conditions, ethnic minority patients and younger patients**

A few authors highlighted the general importance of the under-representation of patients with non-malignant conditions, ethnic minority patients and younger patients.<sup>15 17 26 27</sup> The benefits to patients with non-malignant conditions were expected to equal those of patients with cancer, because patients with a chronic disease often have needs that can be easily addressed in hospice and palliative day-care facilities, thus enabling them to stay at home for a longer period of time.<sup>34</sup> Some palliative day-care clinics and day hospices were reported to have established a specific day for younger patients.<sup>19 21</sup> Finally, the literature reported the following barriers to access for patients from different ethnic backgrounds: social inequalities,<sup>27</sup> different family structures<sup>26</sup> and language barriers.<sup>26</sup>

#### **Discharge process**

The available publications reported a wide range of policies for the discharge of patients from palliative day-care clinics and day hospices, as well as attitudes towards these policies. The authors described palliative day-care clinics and day hospices with a fixed time, after which patients were assessed to determine whether they had achieved the treatment goal (and

hence should be discharged) or whether they should continue with the programme. One article described that, once discharged, patients either found support through a community palliative care team or, where necessary, continued to receive psychological support at the hospice day-care centre.<sup>20</sup> Patients were reported to often feel anxious about their impending discharge<sup>25</sup> and to prefer continuous care.<sup>18</sup>

#### **Patient perception of palliative day-care clinics and day hospices**

Douglas *et al*<sup>38</sup> found that, above all else, some patients valued the opportunity to access medical therapies in palliative day-care. However, several studies showed that patients mostly valued the sense of community<sup>14 24 25 41 42</sup> and the opportunity to build strong relationships and friendships.<sup>25</sup> Patients enjoyed receiving palliative day-care because, at the day hospice or palliative day-care clinic, they felt removed from their role as a patient and regained a sense of autonomy.<sup>14 24 30 40</sup> In addition, they felt comfortable and relaxed in the safe, yet informal atmosphere.<sup>19 25 35 40</sup> Several authors highlighted the importance of patients' reduced sense of isolation while attending day-care<sup>13 15 21 25 26 28 33 34 40 42 44</sup> and ability to 'get out'.<sup>24 34</sup>

#### **Funding and cost-effectiveness**

Little research had been conducted on funding for these facilities. Most centres were reported to have relied, at least in part, on fundraising and the voluntary

**Table 3** Summarised characteristics of included studies: part 3

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Husić (2009) <sup>41</sup>	Original research article (quantitative)	Bosnia and Herzegovina (Tuzla)	Hospice day-care	Explore whether a 3-month day hospice programme might improve patients' physical and mental health following a mastectomy.	Short Form Health 36 (SF-36) scale, statistically analysed.	Surveyed patients (n=35).	Status: multidisciplinary approach improves patients' physical and mental health.
Hyde <i>et al</i> (2011) <sup>42</sup>	Original research article (qualitative)	UK (England)	Palliative day-care	Explore patient experiences.	Descriptive cross-sectional study with focus groups and semistructured interviews, analysed with framework analysis.	Patients (n=29) and carers (n=8).	Status: sense of community and social interaction most valued. Demand for integration of patients' preferences into palliative day-care.
Kabel (2013) <sup>30</sup>	Original research article (qualitative)	UK	Hospice day-care	Explore how hospice philosophy is interpreted and implemented in a day hospice.	Observation and indepth interviews analysed with constant comparative analysis.	Interviews with patients (n=3) and staff (n=35), as well as observations (n≈50).	Status: provide an environment in which patients feel safe to explore their sense of personhood through various activities; start the day with a welcome drink and sitting together (sense of normality); patients at different stages of the disease trajectory. Demand for coping techniques for patients at various points in the disease trajectory.
Kernohan <i>et al</i> (2006) <sup>25</sup>	Original research article (qualitative/quantitative)	UK (Northern Ireland)	Hospice day-care	Explore patient experiences with hospice day-care.	Exploratory patient satisfaction survey and review of medical records, analysed with descriptive/content analysis.	Hospice day-care patients (n=50), of whom n=26 completed the questionnaire.	Status: attendance for emotional support, respite care and social interaction (most valued). Demand for education about the various offerings of hospice day-care.
Kilonzo <i>et al</i> (2015) <sup>22</sup>	Original research article (quantitative)	Ireland	Specialist palliative day-care	Implement outcome measures in a palliative day-care unit operating an enhanced therapeutic model.	Edmonton Symptom Assessment System, Edmonton Functional Assessment Tool, McGill Quality of Life Index, Palliative Care Problem Severity Scale and quantitative analysis.	Attending patients (n=102 at baseline; n=34 after 8-week cycle).	Status: 2-month programme, after which patients may continue or be discharged; collaboration with an inpatient unit and a hospice home care team. Demand for regular outcome measurement.

Continued

Table 3 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Lohfeld <i>et al</i> (2000) <sup>43</sup>	Original research article (qualitative)	Canada	Hospice day-care	Explore perceptions of hospice day-care among healthcare administrators, healthcare providers and lay people.	Multiple case studies, semistructured interviews, researcher field journal entries and qualitative content analysis (first or most frequent responses equalised with the most important ones).	Hospital administrators (n=9), palliative care providers (n=11) and lay people (n=8).	Participants share a strong demand for a day hospice, but different opinions on location, admission criteria, volunteers, services offered and transportation.
Miyashita <i>et al</i> (2008) <sup>43</sup>	Original research article (quantitative)	Japan	Hospice day-care	Assess patients' quality of life and explore the need for day hospices and the satisfaction of patients and caregivers.	Cross-sectional questionnaire measuring health-related quality of life (Short Form Health 8 [SF-8]), with the calculation of summary scores.	Patients and caregivers (n=23) from three day hospices and patients and caregivers from eight home palliative care services (n=34).	Demand for hospice day-care in Japan, especially for caregivers (time and education).
Payne <i>et al</i> (2008) <sup>44</sup>	Original research article (quantitative)	UK (England)	Palliative day-care	Explore social objectives at a palliative day-care unit and improve practice development.	Questionnaires and structured interviews analysed with qualitative content analysis.	Questionnaires completed by staff and volunteers (n=48) and interviews with patients (n=40).	Status: positive perceptions among staff and patients; shared social objectives, yet differences in the perceived importance of these objectives; importance of both group activities and unstructured time.
Vandaele <i>et al</i> (2017) <sup>33</sup>	Original research article (qualitative)	Belgium	Palliative day-care	Explore the benefits and challenges of palliative day-care centres.	Semistructured interviews and focus group analysed with qualitative content analysis.	Focus groups (n=6 from four day-care centres) and interviews with staff from five day-care centres (n=7).	Status: customised care approach; collaboration with palliative home care teams; no discharge policy—visits are reduced over time; variable number of days patients can attend day-care; include patients at a non-terminal stage of disease. Demand for improved funding and occupancy rates through advertising; clear admission criteria; change in the perception that palliative day-care is only for terminally ill patients.

Continued

Table 3 Continued

Author (year)	Publication type	Geographical location of study	Type of care provided	Research aim	Study design	Study population and sample size	Results regarding status and demand of palliative and hospice day-care
Watts (2009) <sup>28</sup>	Original research article (qualitative)	UK (England)	'Drop-in' sessions	Explore why patients attend day hospices and how they make sense of the support they receive.	Participant observation and informal and guided conversations analysed with narrative thematic analysis.	Participants (n=8–10 per session).	Status: afternoon 'drop-in' sessions for patients with cancer twice weekly; mainly social activities; patients at various points in the disease trajectory; some former users become volunteers; value of volunteers. Demand for further research into the benefits of hospice day-care.
White and Johnson (2004) <sup>16</sup>	Original research article (quantitative)	UK (England)	Hospice day-care	Examine the role and importance of a doctor in a day hospice setting.	Retrospective case study of medical consultations and structured questionnaire.	Medical consultations at the day hospice (n=287) and attending patients (n=15).	Status: a doctor seems to be an essential member of the hospice day-care team; daily medical consultations.

sector.<sup>19 21 31</sup> In the USA, some projects were supported by Medicare.<sup>34 37</sup> In the UK, the National Health Service was identified as the funding body behind a few palliative day-care centres,<sup>19 21</sup> some of which were facing increased pressure to demonstrate effectiveness in order to ensure continued funding.<sup>19</sup> One British day hospice operating on a social model had to change to a therapeutic model in order to receive funding.<sup>20</sup> Higginson *et al*<sup>21</sup> reported that several palliative day-care centres were demanding that patients pay for some services, such as the provision of meals or hair-dressing. One author<sup>15</sup> described funding as a major issue faced by palliative day hospitals, yet argued that, without defined, desired outcomes, it would be difficult to prove cost-effectiveness and hence determine optimal funding levels.

#### Evaluation and outcome measurement tools

Several studies aimed at measuring the outcomes of palliative day-care using tools such as the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire 30, the Mood Adjective List,<sup>36</sup> the Palliative Care Outcome Scale (POS),<sup>31 39</sup> the McGill Quality of Life Questionnaire,<sup>31 39</sup> the choice experiment method<sup>38</sup> and quality-adjusted life years.<sup>27</sup> However, none of these tools was able to clearly determine the benefits or outcomes of palliative day-care.<sup>15 27 31 36 38</sup> Only one study reported patients' significant improvement, using the Edmonton Symptom Assessment System/Symptom Distress Scores and the Edmonton Functional Assessment Tool. However, the results could not be accredited to the implemented programme due to a lack of a control group.<sup>22</sup> The authors acknowledged

that an optimal outcome measurement had yet to be determined and that the value of palliative day-care could not be assessed by health status alone.<sup>38 39</sup>

Several authors demanded that more effort be put into the identification of patients likely to benefit the most from palliative day-care,<sup>15 19 24 27 28 32</sup> and hence the development of ideal admission criteria.<sup>15</sup>

#### Education about the goals of palliative day-care clinics and day hospices

Douglas *et al*<sup>19</sup> found that referrals to palliative and hospice day-care centres were strongly reliant on the knowledge of community and hospital health professionals. In this respect, Vandaele *et al*<sup>33</sup> highlighted the need for further education to clear up misconceptions about palliative day-care within the general public and referrers. Greaves<sup>26</sup> reported that hospices and palliative day-care centres had to push back against patients' fear of the term 'hospice', which they perceived as describing a one-way road to death. This aligns with Cochrane *et al*'s<sup>17</sup> reporting of the main reasons offered by patients who declined attendance: fear of the hospice and anxiety or uncertainty about what this service would offer. Only 2 of the 16 interviewed patients who declined referral indicated that they were satisfied with their existing services and hence not interested in palliative day-care.<sup>17</sup> Corr and Corr<sup>34</sup> advocated for encouraging the active role of patients in improving their quality of life, instead of distracting patients from their disease. Finally, the literature reported that palliative day-care clinics and day hospices could provide a link between the home and hospital care,<sup>15 34</sup> and hence improve the home

care situation,<sup>33</sup> enabling patients to stay at home for a longer period of time.

## DISCUSSION

### Summary of the evidence

The present scoping review provided a narrative account of the wide range of hospice and palliative day-care service models. The types of staff employed differed greatly between individual palliative day-care clinics and day hospices. Outcome measurement and the definition of tools for this purpose remain key challenges for stakeholders and researchers. While patients are highly satisfied and put great value in the social component of palliative and hospice day-care, current tools to evaluate the outcome of these services mainly focus on physical health. These tools often produce contradictory results, and where the results are significant they frequently cannot be reproduced.<sup>12</sup> Some tools, such as the POS, do not focus exclusively on physical health. However, the produced results can only be interpreted in the context of the formulated goal of the palliative day-care clinic or day hospice. Following our literature search, They *et al*<sup>45</sup> published a study protocol for a multicentre randomised controlled trial aimed at assessing a palliative care day-hospital project for patients with advanced cancer. This trial, comparing the palliative care day-hospital with standard outpatient palliative care,<sup>45</sup> could represent a significant step towards achieving a standardised approach to palliative day-care. However, until goals and suitable outcome measurements are clearly defined and applied for palliative day-care clinics and day hospices, cost-effectiveness will be difficult to measure. This challenge is reflected in the small number of studies that have been conducted on cost-effectiveness, despite the importance of demonstrating the economic efficiency of these services. While funding from governmental institutions and health insurance providers does exist, it does not usually cover all expenses. Guest *et al*<sup>20</sup> reported that the British Palliative Care Funding Review of 2011<sup>46</sup> ceased funding for social models of palliative day-care, with the result that one programme had to change to a therapeutic model. Payne *et al*<sup>44</sup> stated that the specification of clinical objectives could help to determine whether a service is cost-effective. Additionally, they suggested that palliative day-care provision should be considered in the local context of other palliative care services.<sup>44</sup>

It appears that ethnic minority patients, younger patients and patients with non-malignant conditions are under-represented in palliative day-care. In the early days of palliative care, patients without cancer were accepted much more frequently.<sup>47</sup> Currently, the referral criteria for palliative day-care clinics and day hospices usually comprise a combination of a progressive life-limiting disease<sup>20–22</sup> and specific palliative or hospice care needs<sup>19–22</sup>; these criteria should

be equally applicable to patients with non-malignant diseases, such as chronic heart failure, chronic obstructive pulmonary disease and motor neuron disease. Of note, three of the analysed articles also reported on patients with AIDS in a palliative situation, dating from the years 2000,<sup>21</sup> 2003<sup>39</sup> and 2008.<sup>17</sup>

Only one study collected data on patients who declined to attend a palliative day-care clinic or day hospice.<sup>17</sup> Most of these patients required additional care, but declined because they felt anxious about the concept of palliative and hospice (day) care. Relevant lessons could be learnt from further research on similarly minded patients, as already suggested by Davies and Higginson<sup>9</sup> in 2005.

Little attention has been given to the experience of patients once discharged from palliative day-care clinics and day hospices. Some authors described programmes with fixed time spans,<sup>17 18 22</sup> while others allowed for multiple treatment cycles. The proportion of patients who show sufficient improvement to be discharged to their home, the proportion of patients who are discharged to a hospital or inpatient unit and the proportion of patients who die during attendance remain largely unknown.

Naturally, patients who felt too unwell to give an interview or complete a questionnaire were excluded from the reported studies.<sup>14 20 24–26 32 38 40</sup> Douglas *et al*<sup>38</sup> addressed this as a limitation, as these excluded patients may represent very different preferences and feelings about palliative day-care clinics and day hospices. This limitation should be recognised before any generalisations of the results are drawn.

### Limitations

Relevant publications may have been overlooked due to the language-based search criterion (ie, only articles published in German or English). A similar limitation pertains to the small number of databases searched. Finally, the quality of the reported evidence was not assessed, as broad literature results are desired for scoping reviews.<sup>5</sup>

### CONCLUSIONS

The present scoping review aimed at providing an overview of the literature on palliative day-care clinics and day hospices. Past research suggests that patients highly value palliative and hospice day-care for a variety of reasons. While few (or no) guidelines or recommendations have been reported in the literature, palliative day-care clinics and day hospices have nonetheless found ways to provide care to patients to the best of their abilities. Future studies should aim at identifying and applying tools to more fully analyse the extent of care and outcomes within palliative and hospice day-care services for patients with severe illnesses. Furthermore, research should seek to identify patients with the most to gain from palliative and hospice day-care, including those who have been

under-represented within both research and practice. It will be necessary to uncover why these groups have been under-represented, to consider their experiences<sup>27</sup> and to explore how palliative and hospice day-care could benefit a wider range of patient groups.<sup>26</sup> Finally, adaptation of admission criteria would help to ensure that care is provided to the patients who are likely to benefit the most.

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