



NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

Carey, Mariko L.; Zucca, Alison C.; Freund, Megan A. G.; Bryant, Jamie; Herrmann, Anne & Roberts, Bernadette J. "Systematic review of barriers and enablers to the delivery of palliative care by primary care practitioners" Published in *Palliative Medicine*, [In Press], (2019).

Available from: <https://journals.sagepub.com/home/pmj>

© 2019 Reprinted by permission of SAGE Publications. This publication has been accepted for publication in *Palliative Medicine*.

Accessed from: <http://hdl.handle.net/1959.13/1403990>

# **Systematic review of barriers and enablers to the delivery of palliative care by primary care practitioners**

Mariko L Carey<sup>1,2,3</sup>, Alison C Zucca<sup>1,2,3</sup>, Megan AG Freund<sup>1,2,3</sup>, Jamie Bryant<sup>1,2,3</sup>, Anne Herrmann<sup>1,2,3</sup> and Bernadette J Roberts<sup>4</sup>

1. Faculty of Health and Medicine, The University of Newcastle, Australia
2. Priority Research Centre for Health Behaviour, The University of Newcastle, Australia
3. Hunter Medical Research Institute, Australia
4. Cancer Council New South Wales, Australia

## **Corresponding author:**

Mariko Carey, Health Behaviour Research Collaborative, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia

Email: [Mariko.Carey@newcastle.edu.au](mailto:Mariko.Carey@newcastle.edu.au)

## **Abstract**

**Background:** There is increasing demand for primary care practitioners to play a key role in palliative care delivery. Given this, it is important to understand their perceptions of the barriers and enablers to optimal palliative care, and how commonly these are experienced.

**Aim:** To explore the type and prevalence of barriers and enablers to palliative care provision reported by primary care practitioners.

**Design:** A systematic review of quantitative data-based papers was conducted.

**Data sources:** Medline, Embase and PsychINFO databases were searched for papers published between January 2007 and March 2019.

**Data synthesis:** Abstracts were assessed against the eligibility criteria by one reviewer and a random sample of 80 papers were blind coded by a second author. Data were extracted from eligible full-texts by one author and checked by a second. Given the heterogeneity in the included studies' methods and outcomes, a narrative synthesis was undertaken.

**Results:** Twenty-one studies met the inclusion criteria. The most common barriers related to bureaucratic procedures; communication between healthcare professionals; primary care practitioners' personal commitments; and their skills or confidence. The most common enablers related to education; nurses and trained respite staff to assist with care delivery; better communication between professionals; and templates to facilitate referral to out-of-hours services.

**Conclusions:** A holistic approach addressing the range of barriers reported in this review is needed to support primary care providers to deliver palliative care. This includes better training and addressing barriers related to the interface between healthcare services.

## **Keywords**

Palliative care, primary health care, terminal care, review

## **Key statements**

### ***What is already known about the topic?***

- There is increasing policy emphasis on the role of primary care practitioners in palliative care delivery to meet rising demands.
- Given this, it is important to understand the barriers and enablers to provision of palliative care in the primary care setting.
- Past reviews have focussed on very specific topics or populations, and so, findings may not be generalisable to the broader primary care context.

### ***What this paper adds***

- Results of this review show that the most common barriers reported by primary care practitioners are: bureaucratic procedures; communication between healthcare professionals; primary care practitioners' personal commitments; and their skills or confidence.
- The most common enablers are: education; nurses and trained respite staff to assist with care delivery; better communication between professionals; and templates to facilitate referral to out-of-hours services.

### ***Implications for practice***

- The breadth of barriers reported in this review suggests that a multi-faceted approach is needed to support primary care practitioners to provide palliative care.
- In general, commonly reported enablers mirrored the commonly reported barriers, suggesting that these provide useful insights into the strategies needed to better support primary care practitioners in the delivery of palliative care.

## Introduction

Palliative care focuses on prevention and relief of suffering for those with life limiting illnesses and their families.<sup>1</sup> It may be delivered in conjunction with therapies aimed at prolonging life, or on its own.<sup>1</sup> Palliative care is provided by both specialist palliative care teams in the hospital setting, as well as by a mix of specialist and generalist services in the community.<sup>2</sup> Primary care practitioners are recognised as having a key role to play in the delivery of generalist palliative care in the community.<sup>3,4</sup>

In developed countries there is increasing pressure on specialist palliative care services. This is due to aging populations<sup>5,6</sup> and increasing incidence rates and improvements in treatments for a range of diseases, including some types of cancer.<sup>7-9</sup> The latter has meant that there are more people living with chronic conditions which require palliation to improve quality of life. Australian data, for example, suggest that the demand for palliative care services is increasing at a rate of 4% annually;<sup>10</sup> while the use of hospice services in the United States has more than doubled from 540,000 patients served in 1998 to 1,300,000 in 2006.<sup>9</sup> It is projected that by 2040, demand for palliative care will rise by 25% to 47% in England and Wales.<sup>11</sup>

The increasing demand for palliative care services has led to a policy focus on supporting and enhancing the role of primary care practitioners in palliative care delivery.<sup>12-14</sup> Such policies emphasise primary care practitioners as key providers of palliative care, with support and referral from specialist services when needed. In line with this, the majority of people in many developed countries receive end of life care from generalists rather than specialists.<sup>15</sup>

Despite acknowledgement of the important role that primary care should play in the delivery of palliative care, their capacity to provide such care is ill defined.<sup>15</sup> Previous reviews have identified barriers to the delivery of such care, including lack of clarity about professional role boundaries, lack

of palliative care training and lack of access to support from specialist services.<sup>2, 3, 15-20</sup> However, these reviews have focused on a specific aspect of palliative care delivery, such as inter-professional collaboration only,<sup>20</sup> patients with one type of disease<sup>18</sup> or a particular model of palliative care delivery.<sup>2</sup> Further, comparatively few reviews have reported on enablers to service provision.<sup>2, 15, 16</sup> In order to support the development and implementation of models of palliative care services in primary care, it is important to understand the breadth of barriers and enablers experienced by primary care practitioners, and how commonly these are experienced. Therefore, this systematic review aimed to explore the types of barriers and enablers to palliative care provision reported by primary care practitioners, and how commonly these are reported.

## **Methods**

The methods are structured according to recommendations by the Joanna Briggs Institute<sup>21</sup> and the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement.<sup>22</sup> The CoCoPop (Condition, Context and Population) which is recommended for reviews of observational studies was used to define the inclusion criteria for the review.<sup>21</sup>

*Types of participants:* Papers which included both primary care and other practitioners (e.g. specialists) were included if a) the data related to primary care practitioners were reported separately, or b) primary care practitioners made up 50% or more of the sample.

*Condition:* The condition or outcome of interest was participant's views or opinions about barriers and enablers to provision of palliative care to adults. Studies which reported solely on very specific topics which may be applicable outside the palliative care context, such as advance care planning; or which focused on solely on palliative care for children; were excluded.

*Context:* The focus of the review was on barriers and enablers to palliative care in middle to high income countries. Studies reporting views of practitioners in developing countries (classified according to the Organisation for Economic Co-operation and Development; OECD) where there is often less access and availability of health care services,<sup>23</sup> particularly palliative care services;<sup>24</sup> were excluded.

*Types of studies:* Papers which reported on descriptive studies reporting primary quantitative data on primary care practitioners' perceptions of barriers and/or enablers of palliative care delivery were eligible for inclusion. The focus on papers reporting quantitative data was to align with our aim of exploring prevalence of barriers and enablers.

*Search Strategy:* An electronic search of Medline, Embase and PsychINFO databases was conducted to identify eligible papers published between January 2007 and March 2019. The search strategy was developed by a medical librarian and the following three search categories were used in combination: palliative or terminal or hospice or end of life, AND general practitioners/practice or family physicians or primary care, AND attitudes of health personnel or physician practice or physician health knowledge, or clinical competence, delivery of health care, OR barrier\* or obstacle\* or challenge\* or perspective\* or perception\* or facilitat\* or enable\*. As recommended by PRISMA,<sup>22</sup> a complete search strategy for one database is presented in Supplementary file 1. The reference lists of included studies were hand-searched to determine that no eligible studies were missed.

*Study selection:* Titles and abstracts were reviewed by one author (AZ) to determine whether they met the inclusion criteria. If the abstract contained insufficient information to determine whether the paper should be included, a copy of the full text was obtained. A random sample of 80 abstracts were blind-coded by a second author (MC) and agreement calculated using the kappa statistic,

resulting in substantial agreement (Kappa=0.74; 95% CI=0.52-0.95;  $p < 0.01$ ). Disagreements were resolved by discussion.

*Assessment of methodological quality:* To provide an indication of the methodological quality of studies, risk of bias was independently assessed by two authors (AZ, MC) using the Joanna Briggs Institute Appraisal Checklist for studies reporting prevalence data.<sup>25</sup> Sources of bias assessed were those attributable to the appropriateness of the sampling frame, recruitment, sample size, description of study subjects, coverage of the sample, measures development, data collection, statistical analysis and reporting, and response rate.

*Data extraction:* The following data were extracted by one author (AZ) using a template and checked by a second author (MF, AH, or JB) for all included papers: year of publication, setting, participants, design, methods, and relevant results. The latter included the percentage of participants reporting each barrier or enabler of interest. Where results were not reported in sufficient detail, further information was sought from authors.

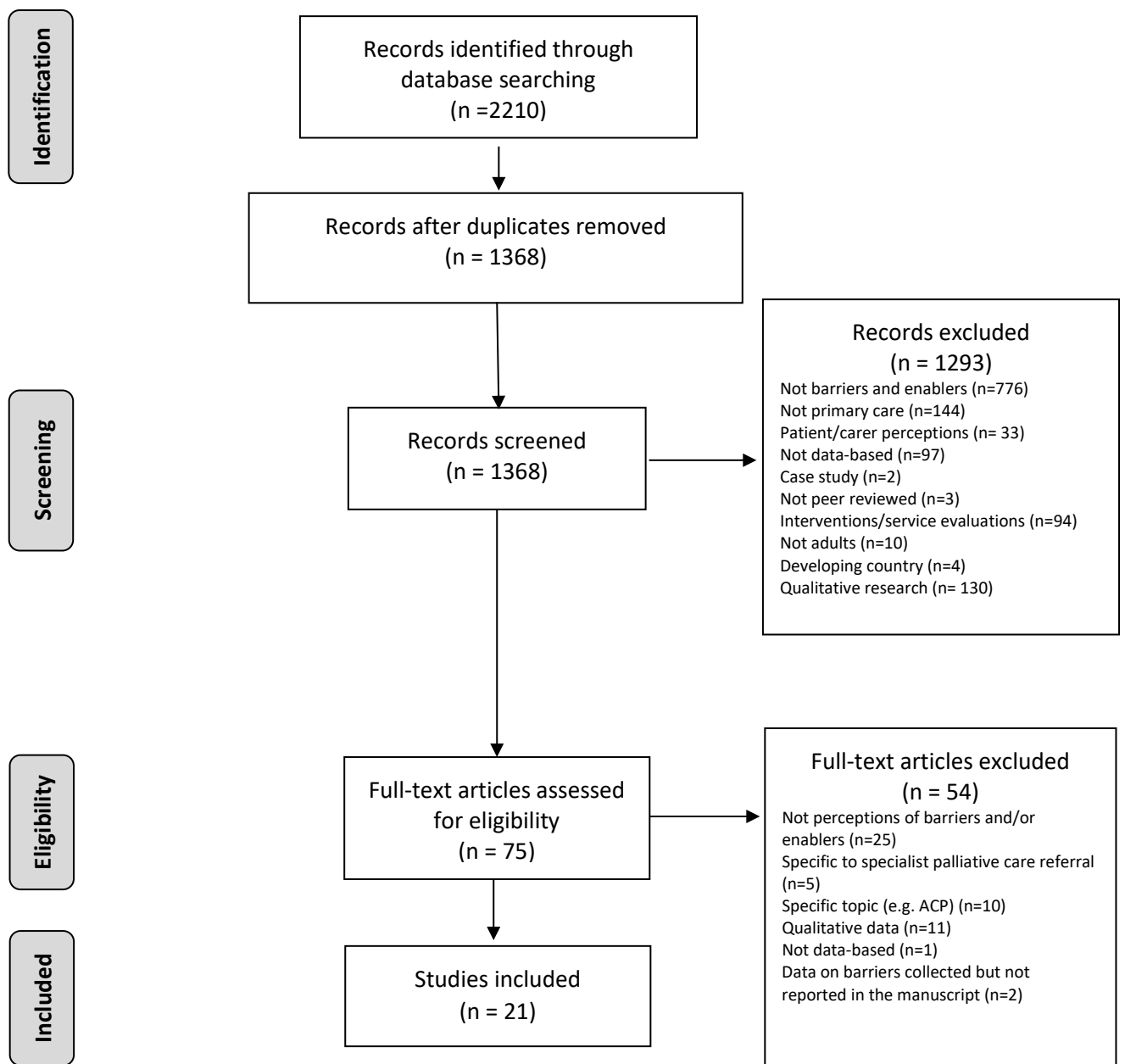
*Synthesis:* Barriers and enablers were coded independently by two authors (AZ and MC) by applying labels to each identified barrier/enablers and then categorising these within domain themes. To ensure we did not miss any relevant domains, we used an inductive approach to coding, rather than using a preconceived theory.<sup>26</sup> Any disparities were resolved through discussion. The number of papers identifying each barrier and enabler was summed. Where barriers or enablers were reported across multiple studies, the lowest; highest; and where applicable, median percentage of participants endorsing the barrier/enabler across studies; were reported. Where the studies included multiple questions on the same topic (e.g. assessing confidence in managing different types of symptoms), prevalence rates for each question were included in the range provided. Narrative synthesis<sup>27</sup> was undertaken to describe the results in text. Given the heterogeneity in the study



methods and outcomes, a narrative approach was considered more appropriate than meta-analysis.<sup>27</sup>

## Results

**Figure 1. PRISMA Flow Diagram.**



The literature search identified 2210 unique records of which 21 met the inclusion criteria (see Figure 1 for the PRIMSA flow chart). Table 1 summarises the 21 articles identified, including data on the sample, setting, recruitment, measures, and barrier and enabler domains described. Six papers reported both barriers and enablers,<sup>28-33</sup> 13 reported barriers only,<sup>17, 34-44</sup> and two reported enablers only.<sup>45, 46</sup>

### ***Setting and participants***

Of the 21 studies, five were conducted in the Netherlands,<sup>17, 35, 38, 42, 45</sup> four in Australia,<sup>33, 40, 41, 43</sup> and three in the United Kingdom.<sup>17, 29-31</sup> One study was conducted in each of the following countries: Canada,<sup>32</sup> United States of America (USA),<sup>36</sup> Austria,<sup>34</sup> Switzerland,<sup>37</sup> Finland,<sup>46</sup> and Denmark;<sup>44</sup> Japan<sup>39</sup> and Hong Kong.<sup>28</sup> One study was conducted across two countries (i.e. Netherlands, Northern Ireland).<sup>17</sup> Fourteen studies included primary care doctor participants only,<sup>17, 28, 29, 31, 32, 37, 38, 40-45</sup> three included primary care doctors and other primary care practitioners,<sup>34-36</sup> and four included both specialist and primary care practitioners.<sup>30, 33, 39, 46</sup>

### ***General or disease specific focus***

Most (n=15) of the studies focused on general palliative care, while six focused on palliative care for people with a specific disease or condition: cancer (n=2),<sup>39, 40</sup> dementia (n=1),<sup>17</sup> heart failure (n=1)<sup>36</sup> and cirrhosis of liver (n=1).<sup>30</sup> One study focused on palliative care for three disease groups (cancer, heart failure and chronic obstructive pulmonary disease).<sup>44</sup>

### ***Risk of Bias***

All studies had at least one high risk of bias or 'unclear' judgement. The most common threats to methodological quality included low response rates (RR)(11 studies with RR <50%),<sup>28, 30-33, 37, 39, 43, 45-47</sup> unclear reporting (n=12)<sup>28-31, 33, 35, 36, 38, 41, 43, 45, 46</sup> or poor reporting of statistical analysis (n=2),<sup>34, 40</sup> and

bias in the coverage of the identified sample (n=10).<sup>17, 30, 31, 33-36, 39, 44, 46</sup> Supplementary file 2 provides a summary of judgements regarding the risk of bias for each individual study.

**Table 1. Summary of quantitative studies: Barriers and enablers to providing palliative care in primary care settings.**

Author, year Aim	Design Recruitment Setting Disease specific	Sample age; sex; work location (rural/urban)	Survey design, including use of a-priori frameworks	Barrier domain assessed	Enabler domain assessed
Plat et al 2018 <sup>47</sup>  To examine the availability of, perceived problems by, and attitude of Dutch GPs regarding providing palliative care for their own patients outside office hours.	Online survey with PCPs  All GPs with a daytime practice in 10 regions across Netherlands (n=1772)  Not disease specific	524 GPs (29% RR)  Age: 50 years average (SD=9)  Sex: 50% female  City (43%); Urbanised rural (41%) Rural (15%)	Study specific survey developed via: - Items based on prior similar surveys administered to GPs. - Two new items pilot tested with two GPs.	Technology/equipment  Access, co-ordination, continuity <sup>^</sup>  Time and prioritisation of PC <sup>^</sup>  Lack of skills and confidence <sup>^</sup>	
Malik et al 2017 <sup>32</sup>  To describe prevalence and characteristics associated with family physician and primary care practitioner (PCP) provision of home palliative care	Postal survey with PCPs  GPs in one urban health region of Ontario, Canada (n=1439)  Not disease specific	302 GPs (21% RR)  Age: average 52 years (range 30-84 years)  Sex: 52% male;  100% urban	Study specific survey developed via: - Literature review - Some items adapted from the National Physicians Survey 2010 and from a previous survey of Australian PCPs (30 questions grouped in 4 categories). - Feedback via 2 focus groups with PCPs	Financial and policy barriers  Access, co-ordination, continuity  Time and prioritisation of PC  Patient and interpersonal barrier  Lack of skills and confidence	PCP knowledge and education
Brazil et al 2017 <sup>17</sup>	Postal cross-sectional survey physicians with responsibility	Netherlands 188 (RR 67%)	Study specific survey developed via:	Access, co-ordination, continuity	

<p>To measure and compare the perceptions of physicians in two European regions regarding the importance and challenges of implementing recommendations for optimal palliative care in dementia patients</p>	<p>for the care of persons with dementia, including at the end of life</p> <p>Netherlands – random sample from elderly care physicians</p> <p>N.Ireland - purposive, cluster sampling of primary care practices with a prevalence of 30 or more patients diagnosed with dementia</p> <p>Netherlands Northern Ireland</p> <p>Dementia</p>	<p>Ireland 129 (41%)</p> <p>Age: Neth (48 years average; SD=9.2); NI (49 years average; SD=8.3)</p> <p>Sex: Neth (67% female); NI (43% female)</p> <p>Rural/urban data not provided</p>	<ul style="list-style-type: none"> <li>- A-priori framework to reflect 11 elements identified by European Association for Palliative Care as the core domains for optimal palliative care for individuals living with dementia</li> <li>- Pilot tested with a convenience sample of elderly care physicians and PCPs</li> </ul>	<p>Patient and interpersonal</p> <p>Lack of skills and confidence</p>	
<p>Le et al 2017<sup>40</sup></p> <p>To determine PCPs' needs when providing home-based palliative care in collaboration with existing palliative care services</p>	<p>Postal survey</p> <p>Convenience and snowball sampling via PCP networks, email, newsletters and PCP events</p> <p>Melbourne region, Australia</p> <p>Cancer</p>	<p>n=56 PCPs (RR not reported)</p> <p>Age: not provided</p> <p>Sex: not provided</p> <p>87% metropolitan PCPs</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- The research team</li> </ul>	<p>Access, co-ordination, continuity</p> <p>Time and prioritisation of PC</p>	
<p>To et al 2017<sup>43</sup></p> <p>To explore the beliefs and practice of South Australian PCPs towards case conferencing for people with palliative care needs.</p>	<p>Online survey</p> <p>All PCPs on a South Australian PCP membership organisation (lists 56% of South Australian PCP)</p> <p>Not disease specific</p>	<p>n=134 (11%)</p> <p>Age: 50 years average (SD=10)</p> <p>Sex: 38% male</p> <p>Rural/urban data not provided</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Written feedback from a reference group of medical, nursing, allied health, management and research.</li> <li>- Pilot tested with the reference group</li> </ul>	<p>Financial, policy, remuneration</p> <p>Access, co-ordination, continuity</p>	

Giezendanner 2017 <sup>37</sup>	Postal survey with PCPs  Random sample stratified by language region, sex, and age from official medical association register  Switzerland  Not disease specific	n=579 (31% RR)  Age: 37% were 50-59 years  Sex: 77% male  Rural/urban data not provided	Study specific survey developed via - Qualitative focus groups (n=3) and 23 interviews with PCPs and other health professionals study - Piloted-tested by 10 PCPs	Lack of skills and confidence	
Low 2016 <sup>30</sup>	Online survey of health professionals  Purposive sample of professionals from liver teams, specialist palliative care teams, and PCPs interested in Gastroenterology  UK  Cirrhosis of liver	n=514 (8% RR). 95 liver professionals, 273 specialist palliative care professionals, and 46 PCPs  Age, sex, rural/urban data not provided  (Only PCP data reported)	Study specific survey developed via - The research team	Lack of skills and confidence	PCP knowledge and education  Enhancing communication with palliative care services and professionals
Winthereik et al 2016 <sup>44</sup>	Population- based cross-sectional survey of PCPs.  Central Denmark Region.  Cancer, heart failure and chronic obstructive pulmonary disease (COPD)	573 (68% RR)  Age: 54 years old; median (inter quartile range 14.5 years)  Sex: 51% female  Urban (72%); rural (28%)	Study specific survey developed via - Eight per-defined themes, four of which were the focus in the paper. - Previously used items by the research team - Literature review - Pilot tested with 20 PCPs.	Lack of skills and confidence	
Magee 2016 <sup>31</sup>	Postal survey	n=203 (20% RR)	Study specific survey developed via:	Lack of skills and confidence	PCP knowledge and education

<p>To examine the confidence of out-of-hours PCPs in symptom control and end of life prescribing, and identifies their educational needs and preferences.</p>	<p>1005 PCPs employed by an independent provider of out-of-hours services</p> <p>England</p> <p>Not disease specific</p>	<p>Age: 30-39 yrs 37% 40-49 yrs 29% 50-59 yrs 26%</p> <p>Sex: 54% male</p> <p>Rural/urban data not provided</p>	<ul style="list-style-type: none"> <li>- Literature review, including commentary from key experts.</li> <li>- Review of previous surveys on this topic.</li> </ul>		
<p>Dunlay 2015<sup>36</sup></p> <p>To examine clinicians' practices, expectations, and personal level of confidence in discussing goals of care and providing end of life care to their patients with heart failure.</p>	<p>Online survey of physicians, nurse practitioners, and physician assistants</p> <p>Recruited from one tertiary centre and sites in surrounding community (Tertiary Care Cardiology, Community Cardiology, and Primary Care)</p> <p>USA</p> <p>Heart failure</p>	<p>95 clinicians (52% RR)</p> <p>50 physicians 45 nurses and assistants</p> <p>n=41 tertiary; 25 community; 29 primary care</p> <p>Sex, age and rural/urban data not provided</p> <p>(PCPs; community card; and specialists data reported)</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Literature review</li> <li>- Feedback from palliative care and heart failure experts</li> </ul>	<p>Time and prioritisation of PC</p> <p>Patient and interpersonal barrier</p> <p>Lack of skills and confidence</p>	
<p>De Korte Verhoef 2014<sup>45</sup></p> <p>To explore PCPs perspectives of: 1) whether and how hospitalisations could have been avoided in the last 3 months of life;</p>	<p>Survey of PCPs, also a qualitative component</p> <p>Nationwide random sample selected from Dutch Medical Address Book</p> <p>Netherlands</p>	<p>n=322 (34% RR)</p> <p>Age: 49 years average (range from 32 to 64 years)</p> <p>Sex: 55% male</p> <p>46% highly urbanised</p>	<p>Study specific survey developed via</p> <ul style="list-style-type: none"> <li>- Literature review</li> <li>- Qualitative interviews with 5 doctors</li> <li>- Written feedback from 14 PCPs</li> </ul>		<p>Proactive communication with the patient</p> <p>Access to services and resources</p>

and 2) barriers to avoiding hospitalisations.	Not disease specific				Enhancing communication with palliative care services and professionals
Hirooka 2014 <sup>39</sup>  To explore confidence in the ability to provide palliative care and associated difficulties and to explore correlations between these variables.	Postal survey  Sample included hospital and PCPs and registered nurses.  4 regions in Japan  Cancer	235 (21%) PCPs 409 (31%) hospital doctors  2160 (41%) hospital nurses  115 (42%) home visit nurses  PCPs Age: 57 years average (SD=11) Sex:-92% male  Rural/urban data not provided (but regions listed)  (Only PCP data reported)	Study specific survey developed via: - Literature review - The research team	Lack of skills and confidence	
Hong 2013 <sup>28</sup>  To examine the willingness and barriers faced by family physicians to provide palliative care in Hong Kong	Postal survey  All local members of the Hong Kong College of Family Physicians  Not disease specific	n=750 (48% RR)  Age: not specified  Sex: 70% male  100% Urban	Study specific survey developed via: - Results from qualitative analysis of three focus groups and five interviews - Pilot tested with 20 doctors.	Access, co-ordination, continuity  Time and prioritisation of PC	PCP knowledge and education  Access to services and resources



<p>Kiely 2013<sup>29</sup></p> <p>To describe PCPs perceived current barriers to care provision for palliative care patients OOH (out-of-office hours).</p>	<p>Survey of PCPs</p> <p>All PCPs registered in the Irish Medical Directory in the southwest of Ireland invited</p> <p>Ireland</p> <p>Not disease specific</p>	<p>214 (52%RR) PCPs completed questionnaire</p> <p>Age: mean 47 years (SD=11)</p> <p>Sex: 63% male</p> <p>Rural/urban data not provided (but regions listed)</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Literature review</li> <li>- Feedback from a panel of 15 PCPs</li> <li>- Pilot testing with 50 randomly selected PCPs.</li> </ul>	<p>Access, coordination, continuity</p> <p>Time and prioritisation of PC</p> <p>Patient and interpersonal barrier</p>	<p>Formalised procedures, policy</p>
<p>Silvoniemi 2012<sup>46</sup></p> <p>Finnish physicians' perceptions about skills and training needs for palliative pain management.</p>	<p>Cross-sectional survey of PCPs</p> <p>PCP names obtained from the register of the Finnish Medical Association.</p> <p>Finland</p> <p>Not disease specific</p>	<p>n=720 medical oncologists (59), PCPs (302), specialists in internal medicine and geriatrics (33) (32% RR)</p> <p>Other specialists only: 35% male</p> <p>Age: 36-50 years old=38%; &gt;50 years=40%</p> <p>Rural/urban not provided</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Qualitative focus groups with palliative care experts.</li> <li>- Pilot tested with 26 fourth year medical students</li> </ul>		<p>PCP knowledge and education</p>
<p>Schweitzer 2009<sup>42</sup></p> <p>To investigate the views of PCP on the transfer of information about terminally ill patients to the out-of-hours PCP co-operatives.</p>	<p>Emailed web-based survey (posted if no email address)</p> <p>All PCPs listed in an Amsterdam PCP directory (n=424)</p> <p>Netherlands</p> <p>Not disease specific</p>	<p>n=177 (42% RR)</p> <p>Age: 50 years average (range 33-66 years)</p> <p>Sex: 61% male</p> <p>Urban</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Literature review</li> <li>- Feedback from PCPs and specialists</li> <li>- Pilot tested with 239 PCPs</li> </ul>	<p>Access, co-ordination, continuity</p>	

<p>de Graaff 2009<sup>35</sup></p> <p>To explore the perceptions of PCPs and home care about home care for terminally ill Turkish and Moroccan migrants and their families in the Netherlands.</p>	<p>Survey of PCPs and home care nurses</p> <p>Purposively sent to home care organisations and PCPs working in areas with high proportion of target migrants</p> <p>Netherlands</p> <p>Not disease specific</p>	<p>n=352 PCPs (60% RR)</p> <p>Age: Mean 49 years Sex: 57% male</p> <p>n=124 nurses (38% RR)</p> <p>Age Mean 43 years Sex: 92.5% female</p> <p>Rural/urban data not provided (but regions listed)</p> <p>(PCP and nurse data reported)</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Feedback from eight academics and clinicians</li> <li>- Pilot tested with 3 nurses and 2 PCPs</li> </ul>	<p>Lack of skills and confidence</p>	
<p>Tan 2009<sup>33</sup></p> <p>Investigates the gaps in care, in after-hours service, from the perspective of PCPs and PC nurses.</p>	<p>Survey of PCPs and palliative care nurses</p> <p>PCPs (n=524) affiliated with the participating 3 Divisions of primary care in Victoria</p> <p>Nurses (n=112) members of the Palliative Care Special Interest Group of the Australian Nursing Federation</p> <p>Australia</p> <p>Not disease specific</p>	<p>114 PCPs (22% RR) 52 PC nurses (43% RR)</p> <p>Age: not reported Sex: 76% male</p> <p>1 rural division of PCP; 1 urban 1 mixed invited</p> <p>(only PCP data reported)</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Results from a qualitative interview study with PCPs, nurses, managers, patients and carers.</li> </ul>	<p>Financial and policy</p> <p>Technology/equipment</p> <p>Access, coordination, continuity</p> <p>Time and prioritisation of PC</p> <p>Patient and interpersonal barrier</p>	<p>PCP knowledge and education</p> <p>Communication with the patient and family</p> <p>Access to services and resources</p> <p>Procedure, policy and laws</p>
<p>Rhee 2008<sup>41</sup></p> <p>To determine the level of participation of Australian urban PCPs in palliative</p>	<p>Postal survey of PCPs</p> <p>Random sample of PCPs from AMPCO database</p>	<p>269 (61% RR)</p> <p>Age: 48 years average; range 28-80 yrs (provides no pall care)</p>	<p>Study specific survey developed via:</p> <ul style="list-style-type: none"> <li>- Consulting palliative care specialists and PCPs</li> </ul>	<p>Financial and policy</p> <p>Access, coordination, continuity</p>	

care, and to determine the main barriers facing them in providing this care.	Sydney Australia Not disease specific	to 52 years average; range 34-84yrs (provides pall care) average  Sex: 57% male  Urban	- Pilot tested in one group practice.	Time and prioritisation of PC  Patient and interpersonal barriers  Lack of skills and confidence	
Becker 2007 <sup>34</sup>  To explore PCPs and nurses' self-assessment of professional education, competency and educational needs in palliative care.	Survey of PCPs and home care nurses  All PCPs and nurses from the province of Styria  Austria  Not disease specific	547 (30% RR)  228 PCPs 318 nurses  Age: 41 years average (range 19-77 years)  Sex: 66% female  Urban/rural: not specified  (PCP and nurse data reported)	Study specific survey developed via:  - Literature review  - Pilot tested with PCPs and nurses	Lack of skills and confidence	
Groot 2007 <sup>38</sup>  To identify the prevalence and obstacles for the delivery of primary palliative care and their determinants.	Postal surveys  All the PCPs practicing in three regions  Netherlands  Not disease specific	n=320 (62% RR)  Age: 46 years average (range 31-62 years)  Sex: 72% male  52% country/rural; 46% urban	Study specific survey developed via:  - Results from qualitative focus group study  - Pilot tested and feedback from 10 PCPs  - A-prior factor structure generated	Financial, policy, remuneration  Technology/equipment  Access, coordination, continuity  Time and prioritisation of PC	

				Patient and interpersonal Lack of skills and confidence	
--	--	--	--	------------------------------------------------------------	--

GP: general practitioner; PC: palliative care; PCP: primary care practitioner; RR: response rate

^Perceived as a barrier regularly, often or always

**Table 2. Prevalence of barriers to delivery of palliative care.<sup>a</sup>**

<b>Barrier domains</b> (number of papers reported in)	<b>Participants reporting barrier (%)</b>	<b>Median %</b>	<b>References</b>
<b>Skills and confidence (n=14 papers)</b>			
Lack confidence in managing specific symptoms (n=6) e.g. pain, constipation, nausea and vomiting, agitation, breathlessness	9-90%	34%	31, 34, 37, 39, 41, 44
Lack confidence with dealing with psychological/social aspects for patient and/or family (n=6) e.g. recognising and treating anxiety and depression, coping with distress, handling loss and grief	19-88%	48%	34, 37-39, 41, 44
Lack skills/confidence with treatments, medications or home care technology (n=6) e.g. use of syringe drivers, subcutaneous medication, opiates and non-opiate analgesia, anticipatory medicine	6-78%	37%	31, 34, 37, 38, 41, 44
Lack confidence with communication (n=3) e.g. initiating prognosis and end of life care discussions, advanced directives, the wish to die, assisted suicide	10-76%	15%	31, 36, 37
General confidence in delivery of palliative care (n=7)	3-55% Mean = 5.0-5.7*	20%	17, 30, 32, 36, 41, 44, 47
Lack confidence dealing with PC emergencies (n=1)	43%	-	31
Lack of confidence with coordination of health care networks/services (n=2) e.g. enrolling patients in hospice	17-35%	26%	36, 37
<b>Access, co-ordination and continuity (n=9 papers)</b>			
Communication with PC services/professionals (n=7) e.g. poor communication/information flow between GP and hospitals, specialists, nurses, and GP co-operatives	14-83%	39%	29, 32, 33, 38, 40-42
Access to allied health and support services after hours (n= 1) e.g. limited availability of PC nurses, interpreters, emergency medications	49-79%	72%	33
Barriers related to case conferencing (n=1) e.g. too time consuming, limited availability of attendees, too much follow-up	11-70%	13%	43

Lack of care pathways to support PCPs in delivery of after-hours care (n=2) e.g. lack of anticipatory plan from primary GP or hospice, unclear where to direct a patient in an emergency	4-69%	33%	29, 47
Access to palliative care services/professionals (n=7) e.g. lack of access to hospice or hospital, specialist telephone advice, PC nurses; specialist support	18-65% Mean= 6.2* (Northern Ireland)	38%	17, 28, 32, 38, 40, 41
Continuity/coordination of care within and between services (n=2) e.g. home care staff turnover, lack of clarity about principal doctor in attendance during the palliative phase	11-45% Mean= 5.7* (Northern Ireland)	33%	17, 38
Knowledge of PC services (n=2)	22-39%	29%	38, 40
Organising admissions and services out-of-hours (n=1) e.g. hospital and nursing home admissions, organising home care	14-24%	19%	47
<b>Time and prioritisation of palliative care (n=8 papers)</b>			
Home visits (n=4)	31-81%	56%	32, 33, 40, 41
Time (general) (n=6) e.g. lack of time to provide palliative care; time pressure reduces ability to initiate end of life discussions, to care for relatives, deliver care out-of-hours	8-77%	47%	28, 29, 36, 38, 41, 47
Personal/family commitments (n=2) e.g. family caregiving	42-72%	68%	32, 41
Personal interest (n=2) e.g. lack of interest in PC	9-32%	30%	32, 41
<b>Patient and interpersonal barrier (n=7 papers)</b>			
Dealing with dynamics of family relationships (n=2) e.g. disagreements between relatives, relatives' hidden agendas, unexpressed grief between the patient and family	36-59% Mean= 5.5* (Northern Ireland)	57%	17, 38
Unwillingness of patients to use after hours services (n=1) e.g. patient unwilling to call after hours services	59%	-	33
Patient expectations about service delivery (n=2) e.g. patient assumes that GP automatically knows their problems, high expectations in out-of-hours GP services	40-49%	45%	29, 38
Patient/family unwilling to discuss palliative care (n=2) e.g. patient or family not ready to discuss end of life, patient does not initiate end of life discussion	12-21%	13%	36, 38

Discomfort in discussing palliative care (n=3) e.g. emotional response to death and dying	9-16%	11%	32, 36, 41
<b>Financial and policy barriers (n=5 papers)</b>			
Bureaucratic procedures within organisations (n= 2) e.g. too time consuming to claim reimbursement for case conferencing	25-84%	55%	38, 43
Cost of providing locum services for after hours (n=1)	54%	-	33
Insufficient remuneration (n=3)	17-35%	30%	32, 41, 43
<b>Provision of care to culturally and linguistically diverse patients (n=2 papers)</b>			
General lack of confidence (n=1)	84%	-	37
Communication difficulties (n=1) e.g. hamper the organisation of entry into home care, and care delivery	57-79%	65%	35
Cultural taboos on discussing end of life issues (n=1)	46-67%	57%	35
<b>Technology/equipment (n=3 papers)</b>			
Lack of mobile phone coverage for nurses providing PC after hours (n=1)	40%	-	33
Difficulties in arranging home care technology (eg. medication pump) (n=2)	11-38%	25	38 47
<b>Dementia-related barriers (n=1 paper)</b>			
Lack of acceptance among the public that palliative care applies to dementia (n=1)	Mean= 5.1-5.6*		17
Failure to minimise aggressive, burdensome, or futile dementia treatment that will not extend life or provide comfort (n=1)	Mean= 5.6* (Northern Ireland)		17
Lack of accurate prognosis to allow for timely recognition of dying in dementia patients (n=1)	Mean= 5.1* (Northern Ireland)		17

GP: general practitioner; PC: palliative care; PCP: primary care practitioner

<sup>a</sup> Where the studies included multiple questions on the same topic (e.g. assessing confidence in managing different types of symptoms), prevalence rates for each question are included in the range provided.

\* calculated<sup>17</sup> score using a 10point Likert scale (0= not a significant barrier and 10= very significant barrier). Mean scores of 5 and above have been recorded.

### ***Domain, type and prevalence of barriers***

Barriers were categorised into seven domains: skills and confidence; access, co-ordination and continuity; time and prioritisation of palliative care; patient and interpersonal; financial and policy; providing care to people of culturally and linguistically diverse (CALD) backgrounds; and technology and equipment. Of the 19 papers that reported on barriers, most of these (n=11, 58%) sought participants' views on two or more different barrier domains regarding palliative care delivery. The remaining eight papers focused on one barrier domain only, for example, skills and confidence in delivery of palliative care (see Table 2). Skills and confidence was the most commonly examined domain (14 studies; 74%), while issues related to providing care to CALD patients, and technology/equipment barriers were examined by the fewest studies (2 studies, 11%; and 3 studies, 16% respectively).

The barriers with highest reported rates of endorsement included: lack of skills or confidence in managing symptoms (range= 9-90%), psychosocial aspects of care (range= 19-88%), bureaucratic procedures (median= 55%; range = 25-84%); communication with palliative care services and professionals (median= 39%; range = 14-83%); treatments (range= 6-78%), communicating with the patient about palliative care issues (range= 10-76%) and personal and family commitments of the primary care practitioner (range= 42-72%). Most of the barriers examined in more than one study showed a considerable range of prevalence values (see Table 2). Notably, four barriers had a range of greater than 65% for rates of endorsement across studies, reflecting a large variation in reported prevalence in the literature.

### ***Types and prevalence of enablers***

Enablers were categorised into five domains: Primary care practitioner knowledge and education; access to services and resources; enhancing communication with patients; enhancing communication with palliative care services and professionals; and formal procedures, policies and



laws. Of the papers that reported on enablers, four (50%) sought participants views on a number of different enabler domains regarding palliative care delivery. The remaining four papers focused on one enabler domain only, for example, primary care practitioners' knowledge and education regarding palliative care (see Table 2). Enablers related to primary care practitioner knowledge, education and experience were the most commonly assessed (seven studies); with issues related to the remaining domains assessed in two to three studies each.

Enablers with the highest reported rates of endorsement included: templates to assist with referral to out-of-hours services (96%); education on symptom management (range= 24-91%); more nurses to provide home visits and to staff after-hours telephone service (range= 78-86%); better communication and liaison between professionals (range= 36-85%); more palliative care trained respite staff (83%); and education on communication and psychosocial issues (range= 21-80%). Most of the enablers that were examined in more than one study showed a considerable range of prevalence values.

**Table 3. Prevalence of enablers to palliative care delivery.**

<b>Enabler domains</b> (number of papers reported in)	<b>Participants reporting enabler (%)</b>	<b>References</b>
<b>PCP knowledge, education and experience (n=7 papers)</b>		
Pain and symptom management (n=5) e.g. need for further education and training, via a series of information sessions; symptom control for non-cancer patients; breathlessness and agitation/confusion	24-91% symptoms in general; 16-42% for specific symptoms	30-32, 34, 46
Communication and psychosocial issues (n=4) e.g. training in interpersonal skills, psychosocial and counselling, communicating difficult news, bereavement counselling	21-80%	28, 30, 31, 34
Mentorship from specialists/support & debriefing for PCPs and nurses (n=2) e.g. mentorship from a PC consultant physician; networking with the palliative care specialists; support and debriefing for GPs and nurses in after-hours services	64-76%	32, 33
Experience caring for terminal patients (n=1) e.g. frequent exposure to PC patients	74%	28
Palliative care emergencies (n=1) e.g. education assessing and managing PC emergency situations, such as haemorrhage, convulsions, severe exacerbation of symptoms	62%	31
Medication prescribing and administration (n=2) e.g. education about using a syringe driver; opioid prescribing and other analgesics, palliative sedation	18-53%	31, 46
General palliative care education (n=1) e.g. basics of palliative care	38-50%	46
End of life care pathways (n=2) e.g. care delivery during last days of life	24-44%	31, 46
Ethical and legal issues (n=2) e.g. educational opportunities to explore ethical questions and ethical decision making in palliative care	15-27%	30, 46
<b>Support of and communication with the patient and family (n=2 papers)</b>		
More support/instructions for carers and patients <sup>a</sup> (n=2) e.g. provide instructions about "if needed" medication	10- 58%	33, 45
Proactive communication/early discussion about withholding treatment in hospital (n=1)	30%	45
Proactive communication/early discussion about limited prognosis (n=1)	22%	45
<b>Access to services and resources (n=3 papers)</b>		
Palliative care trained respite staff (n=1)	90%	33
More nurses to conduct home visits/staff out-of-hours telephone service (n=2)	78-86%	32, 33

e.g. support from a PC nurse for patient care and coordination; PC trained nurse on after hours tel. service		
Greater access to equipment for home care to improve after hours PC service (n=1)	83%	33
Access to 24/7 call system to support patient care (n=1) e.g. to provide after-hours relief for GPs	79%	32
Access to multidisciplinary support essential to providing palliative care in a primary care practice (n=1)	78%	28
Access to 24/7 telephone advice from a PC specialist (n=1)	77%	32
Greater time available to provide care (n=1)	69%	28
More PC beds allocated in local hospitals (n=1)	54%	33
Additional care and treatment outside hospital to reduce avoidable hospitalisation at the end of life (n=1) e.g. early start of nursing care, initiation of night care services, treatment at home	28%	45
<b>Enhancing communication with PC services and professionals (n=2 papers)</b>		
Better communication and liaison between professionals (n=2) e.g. GP consulted about hospitalisation, clear information transfer to out-of-hours general practice	36-85%	30, 45
<b>Procedures, policies and laws (n=2 papers)</b>		
Templates to assist with referral to out-of-hours services (n=1) e.g. to transfer information about their patients' end of life care plans.	96%	29
Legislation to allow nurses to certify death (n=1)	58%	33

GP: general practitioner; PC: palliative care; PCP: primary care practitioner

<sup>a</sup>Very specific enablers related to this broad topic not reported given low rates of endorsement <15%.

## Discussion

This review builds upon previous research by providing an up-to-date and broad overview of the literature examining barriers and enablers to palliative care in primary care. Given that primary care practice is broad in scope, we chose not to restrict by disease focus. In general, it was difficult to compare the prevalence of barrier and enabler domains, given that some domains were assessed by many studies; while others received little attention. Nonetheless, the results provide insights into what has been assessed in the literature and how commonly issues and solutions are identified across the studies in which they were examined.

### ***Main findings***

More than half the papers included in this review reported lack of confidence in general, or in relation to specific tasks associated with palliative care, as barriers to the provision of such care. A lack of confidence was reported across many care areas including treatments, symptom management, and psychological and communication issues, reflecting the holistic nature of palliative care. Several other reviews have identified low confidence as barrier to the provision of quality palliative care in both primary and tertiary care settings.<sup>3, 48</sup> The availability of comprehensive training for primary care practitioners is likely needed to address issues of low confidence. This should include training at the undergraduate level as well as ongoing professional development opportunities. A 2013 review of US medical schools found a lack of palliative care integration into the education curricula.<sup>49</sup> Further, a recent review found that, despite the large number of training programmes being developed and evaluated for non-specialist healthcare providers, current evidence of their effectiveness is limited by poor reporting and weak methodology.<sup>50</sup> There is a need for future research to develop and evaluate robust training programmes that address confidence in providing palliative care in primary care settings. Such programmes should ideally include options for post graduate training as part of continuing professional development.

Barriers related to access, co-ordination and continuity, including issues related to poor communication with specialists and palliative care teams, were frequently endorsed in the literature. This finding is supported by a number of other studies, which have highlighted the need for primary care practitioners to have access to specialist and multidisciplinary support when caring for patients dying at home<sup>51</sup> and to have clearly negotiated roles within the healthcare team.<sup>52</sup> The lack of confidence and skills in palliative care reported by many primary care practitioners is likely to be compounded by a perceived lack of access to specialist support.

Time was also reported as a common barrier, with the time of providing home visits identified as a particular barrier for a majority of primary care practitioners. The provision of community-based palliative care brings with it a significant workload, with an expectation that primary care practitioners will provide support, not only for the physical and psychological needs of their patient, but also, their carer/family. This barrier may be exacerbated for the increasing number of primary care practitioners who work part time or those who feel that current remuneration levels are not commensurate with the value of the services provided.<sup>53-55</sup> It is important to note that lack of time has also been identified as a barrier to the provision of quality end of life care from the patient perspective, with patients perceiving that primary care practitioners lack time to listen to the patient; as well as patients lacking support to get accurate information on their care, for instance on available services or on how to manage symptoms and treatment side-effects.<sup>56</sup>

It is notable that many of the enablers reported across studies mirrored the barriers identified. For example, while skills and confidence were identified as common barriers; education, skills and experience were reported as enablers of care. In line with this, several studies have reported that factors such as greater experience, training, and older age<sup>31, 34, 37, 42, 44</sup> are positively related to confidence in palliative care delivery. This reinforces that access to training opportunities to ensure primary care practitioners gain experience in palliative care delivery are required to overcome this barrier.

Reported enablers also included diversifying the palliative care workforce with more nurses available to provide out-of-hours care, and more respite workers trained in palliative care,<sup>33</sup> as well as increasing access to multidisciplinary support and out-of-hours telephone support. These proposed solutions may be seen as advocating for more accessible, flexible and team-based models of care. Such recommendations may directly target barriers identified in relation to access, co-ordination and continuity. Team-based models and greater access to multidisciplinary support may also allow

for distribution of roles and responsibilities while maintaining a central role for the primary care practitioner, thus potentially addressing some of the barriers related to time identified across studies.<sup>52, 57</sup>

### ***What this study adds***

The range of barriers reported in this review is broad and includes issues related to individual primary care practitioners' knowledge, confidence and skills; as well as barriers related to the organisation of, and interface between, healthcare services. The scope of both barriers and enablers identified in the literature highlights the complexity of palliative care. Given the projected increases in demand for palliative care, there is a need to develop sustainable models of palliative care which overcome the barriers experienced by primary care practitioners. It is likely that interventions or models designed to improve palliative care delivery will need to address multiple barriers in order to have sustainable impacts on care. While enablers have been less well investigated in the literature than barriers, our findings have identified a range of enablers that could be used to inform the development of models of care to improve palliative care delivery in the community. The range of both barriers and enablers identified in the literature highlights the complexity of palliative care.

It was notable that many of the barriers and enablers had a wide range of prevalence values reported across studies. This likely reflects differences in, not only the study samples; the disease focus, but also in the framing of the specific questions to ascertain barriers and enablers. Most of the studies used study-specific surveys and few reported the use of frameworks to guide the development of the questions. Future research may benefit from the development of core questions or domains for assessing barriers and enablers related to palliative care. This would allow us to better assess similarities and differences in the barriers and enablers perceived by different groups of primary care practitioners. Similarly, the use of specific theories or frameworks in the

development of surveys may allow for greater consistency in the types of barrier/enablers assessed, and may aid in interpreting findings.

### ***Strengths and limitations***

Strengths of this review include the systematic methods used and the examination of methodological quality of included studies. Despite this, some limitations should be considered when interpreting the findings of the review. It is possible that our search strategy missed some relevant articles. However, given the comprehensive search strategy that was implemented, and the number of relevant studies located, the likelihood of this was minimised. The inclusion of articles published in languages other than English was beyond the scope of the review. This may mean that relevant evidence published in other languages has not been synthesised as part of this review. It is possible that inclusion of qualitative studies would have resulted in a broader range of barriers and enablers. Finally, some studies included in this review reported low response rates and were judged to have coverage bias. Unclear reporting of results was also judged as a risk of bias. This may influence the extent to which individual study results are generalisable, which in turn impacts on the generalisability of the review findings.

### **Conclusions**

Primary care practitioners experience a number of barriers to providing palliative care, which include difficulties across the following domains: skills and confidence; access, co-ordination and continuity of care; time and prioritisation of palliative care; patient and interpersonal; financial and policy; provision of care to culturally and linguistically diverse patients; and technology/equipment. The range of barriers reported suggests the need for training and the development of new models of care. It is encouraging that enablers were also reported across domains which mirrored many of the barriers. These enablers will provide useful insights for the development of palliative care models for primary care practitioners.

## **Declarations**

### **Authorship**

MC: conceptualisation, review of abstracts and papers, quality rating of studies, writing of first draft

AZ: conceptualisation, review of abstracts and papers, data extraction, quality rating of studies

MF: data extraction, revising/drafting paper

JB: data extraction, revising/drafting paper

AH: data extraction, revising/drafting paper

BR: conceptualisation, revising/drafting paper

### **Funding**

This work was supported by a Strategic Research Partnership Grant (CSR 11-02) from Cancer Council NSW to the Newcastle Cancer Control Collaborative (New-3C); and infrastructure funding from the Hunter Medical Research Institute (HMRI). A/Prof Mariko Carey is supported by a National Health and Medical Research Council (NHMRC) Boosting Dementia Research Leadership Fellowship (APP 1136168). Dr Jamie Bryant is supported by a NHMRC-ARC Dementia Research Development Fellowship (APP1105809). Dr Megan Freund is supported by a NHMRC Translational Research in Practice Research Fellowship (APP 1132839).

### **Conflicts of Interest**

The Authors declare that there are no conflicts of interest.

### **Data Sharing**

Not applicable.



## **Acknowledgements**

The Authors wish to thank Ms Briony Johnston for her assistance with manuscript preparation.

## References

1. Sepúlveda C, Marlin A, Yoshida T, et al. Palliative care: the World Health Organization's global perspective. *Journal of Pain and Symptom Management* 2002; 24: 91-96.
2. Carmont S-A, Mitchell G, Senior H, et al. Systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care. *BMJ Supportive & Palliative Care* 2017; bmjspcare-2016-001125.
3. Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. *Palliative Medicine* 2002; 16: 457-464. DOI: 10.1191/0269216302pm573oa.
4. Quill TE and Abernethy AP. Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. *New England Journal of Medicine* 2013; 368: 1173-1175. DOI: 10.1056/NEJMp1215620.
5. Gomes B and Higginson IJ. Where people die (1974—2030): past trends, future projections and implications for care. *Palliative Medicine* 2008; 22: 33-41.
6. Christensen K, Doblhammer G, Rau R, et al. Ageing populations: the challenges ahead. *The Lancet* 2009; 374: 1196-1208.
7. Phillips JL and Currow DC. Cancer as a chronic disease. *Collegian* 2010; 17: 47-50.
8. Deeks SG, Lewin SR and Havlir DV. The end of AIDS: HIV infection as a chronic disease. *The Lancet* 2013; 382: 1525-1533.
9. Ferris FD, Bruera E, Cherny N, et al. Palliative cancer care a decade later: accomplishments, the need, next steps—from the American Society of Clinical Oncology. *Journal of Clinical Oncology* 2009; 27: 3052-3058.
10. Department of Health and Human Services. Health service use at the end of life and projection of palliative care in Victoria. Available at the department's website <<https://www2.health.vic.gov.au/palliative-care>>. 2016.
11. Etkind S, Bone A, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine* 2017; 15: 102.
12. National Health Service. 2010 to 2015 government policy: end of life care. London: National Health Service, 2015. <https://www.gov.uk/government/publications/2010-to-2015-government-policy-end-of-life-care> (accessed 6 April 2018).
13. Zealand). MoHN. The New Zealand palliative care strategy. Wellington, New Zealand: Ministry of Health, 2008.
14. Health. NMo. The NSW Government plan to increase access to palliative care 2012-2016. Sydney: NSW Ministry of Health, 2012.
15. Gardiner C, Gott M and Ingleton C. Factors supporting good partnership working between generalist and specialist palliative care services: a systematic review. *British Journal of General Practice* 2012; 62: e353-e362.
16. Slort W, Schweitzer BP, Blankenstein AH, et al. Perceived barriers and facilitators for general practitioner–patient communication in palliative care: a systematic review. *Palliative Medicine* 2011; 25: 613-629.
17. Brazil K, Galway K, Carter G, et al. Providing optimal palliative care for persons living with dementia: A comparison of physician perceptions in the Netherlands and the United Kingdom. *Journal of Palliative Medicine* 2017; 20: 473-477. DOI: <http://dx.doi.org/10.1089/jpm.2015.0274>.
18. Lam M, Lam H, Agarwal A, et al. Barriers to home death for Canadian cancer patients: A literature review. *Journal of Pain Management* 2017; 10: 107.
19. Fernando J, Percy J, Davidson L, et al. The challenge of providing palliative care to a rural population with cardiovascular disease. *Current Opinion in Supportive and Palliative Care* 2014; 8: 9-14.

20. Oishi A and Murtagh FE. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals. *Palliative Medicine* 2014; 28: 1081-1098.
21. Aromataris E and Munn Z. Joanna Briggs Institute reviewer's manual. The Joanna Briggs Institute, 2017. Available from <https://reviewersmanual.joannabriggs.org/>. 2018.
22. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine* 2009; 151: 264-269.
23. Peters DH, Garg A, Bloom G, et al. Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences* 2008; 1136: 161-171.
24. Clemens KE, Kumar S, Bruera E, et al. Palliative care in developing countries: what are the important issues? *Palliative Medicine* 2007; 21: 173-175.
25. Munn Z, Moola S, Lisy K, et al. Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. *International Journal of Evidence-Based Healthcare* 2015; 13: 147-153.
26. Elo S and Kyngas H. The qualitative content analysis process. *Journal of advanced nursing* 2008; 62: 107-115. 2008/03/21. DOI: <http://10.1111/j.1365-2648.2007.04569.x>.
27. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews: A product from the ESRC methods programme. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.178.3100&rep=rep1&type=pdf>, accessed 7th May 2019. 2006.
28. Hong TC, Lam TP and Chao DVK. Barriers facing family physicians providing palliative care service in Hong Kong - A questionnaire survey. *Hong Kong Practitioner* 2013; 35: 36-39+44-51.
29. Kiely F, Murphy M and O'Brien T. Information transfer to out-of-hours co-operatives: a survey of general practitioners' views in relation to palliative patients. *BMJ supportive & palliative care* 2013; 3: 405-411. DOI: <http://dx.doi.org/10.1136/bmjspcare-2012-000281>.
30. Low J, Vickerstaff V, Davis S, et al. Palliative care for cirrhosis: A UK survey of health professionals' perceptions, current practice and future needs. *Frontline Gastroenterology* 2016; 7: 4-9. Review. DOI: <http://dx.doi.org/10.1136/flgastro-2015-100613>.
31. Magee C and Koffman J. Out-of-hours palliative care: what are the educational needs and preferences of general practitioners? *BMJ Supportive & Palliative Care* 2016; 6: 362-368. DOI: <http://dx.doi.org/10.1136/bmjspcare-2014-000764>.
32. Malik S, Goldman R, Kevork N, et al. Engagement of Primary Care Physicians in Home Palliative Care. *J Palliat Care* 2017; 32: 3-10. DOI: <https://dx.doi.org/10.1177/0825859717706791>.
33. Tan HM, O'Connor MM, Miles G, et al. GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved: a mixed methods study. *BMC Palliative Care* 2009; 8: 13. DOI: <https://dx.doi.org/10.1186/1472-684X-8-13>.
34. Becker G, Momm F, Gigl A, et al. Competency and educational needs in palliative care. *Wien Klin Wochenschr* 2007; 119: 112-116. Comparative Study. DOI: <https://dx.doi.org/10.1007/s00508-006-0724-9>.
35. de Graaff FM and Francke AL. Barriers to home care for terminally ill Turkish and Moroccan migrants, perceived by GPs and nurses: a survey. *BMC Palliative Care* 2009; 8: 3. DOI: <https://dx.doi.org/10.1186/1472-684X-8-3>.
36. Dunlay SM, Foxen JL, Cole T, et al. A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. *Palliative Medicine* 2015; 29: 260-267. Empirical Study; Quantitative Study. DOI: <http://dx.doi.org/10.1177/0269216314556565>.
37. Giezendanner S, Jung C, Banderet HR, et al. General practitioners' attitudes towards essential competencies in end-of-life care: A cross-sectional survey. *PLoS ONE* 2017; 12 (2) (no pagination). DOI: <http://dx.doi.org/10.1371/journal.pone.0170168>.
38. Groot MM, Vernooij-Dassen MJFJ, Verhagen SCA, et al. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliative Medicine* 2007; 21: 697-703. DOI: <http://dx.doi.org/10.1177/0269216307083384>.

39. Hirooka K, Miyashita M, Morita T, et al. Regional medical professionals' confidence in providing palliative care, associated difficulties and availability of specialized palliative care services in Japan. *Japanese Journal of Clinical Oncology* 2014; 44: 249-256. DOI: <http://dx.doi.org/10.1093/jjco/hyt204>.
40. Le B, Eastman P, Vij S, et al. Palliative care in general practice: GP integration in caring for patients with advanced cancer. *Aust Fam Physician* 2017; 46: 51-55.
41. Rhee JJ, Zwar N, Vagholkar S, et al. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *Journal of Palliative Medicine* 2008; 11: 980-985. Research Support, Non-U.S. Gov't. DOI: <https://dx.doi.org/10.1089/jpm.2007.0251>.
42. Schweitzer B, Blankenstein N, Willekens M, et al. GPs' views on transfer of information about terminally ill patients to the out-of-hours co-operative. *BMC Palliative Care* 2009; 8 (no pagination). DOI: <http://dx.doi.org/10.1186/1472-684X-8-19>.
43. To THM, Tait P, Morgan DD, et al. Case conferencing for palliative care patients - A survey of South Australian general practitioners. *Australian Journal of Primary Health* 2017; 23: 458-463. Review. DOI: <http://dx.doi.org/10.1071/PY16001>.
44. Winthereik A, Neergaard M, Vedsted P, et al. Danish general practitioners' self-reported competences in end-of-life care. *Scandinavian Journal of Primary Health Care* 2016; 34: 420-427.
45. De Korte-Verhoef MC, Pasman HR, Schweitzer BP, et al. General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed-method study. *Palliative Medicine* 2014; 28: 949-958. DOI: <https://dx.doi.org/10.1177/0269216314528742>.
46. Silvoniemi M, Vasankari T, Vahlberg T, et al. Physicians' self-assessment of cancer pain treatment skills--more training required. *Support Care Cancer* 2012; 20: 2747-2753. DOI: <https://dx.doi.org/10.1007/s00520-012-1396-9>.
47. Plat FM, Peters YA, Giesen P, et al. Availability of Dutch General Practitioners for After-Hours Palliative Care. 2018: 0825859718766947.
48. Visser M, Deliens L and Houttekier D. Physician-related barriers to communication and patient-and family-centred decision-making towards the end of life in intensive care: a systematic review. *Critical Care* 2014; 18: 604.
49. Horowitz R, Gramling R and Quill T. Palliative care education in US medical schools. *Medical education* 2014; 48: 59-66.
50. Brighton LJ, Koffman J, Hawkins A, et al. A systematic review of end of life care communication skills training for generalist palliative care providers: research quality and reporting guidance. *Journal of pain and symptom management* 2017.
51. Groot MM, Vernooij-Dassen MJ, Crul BJ, et al. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliative medicine* 2005; 19: 111-118.
52. Crawford GB and Price SD. Team working: palliative care as a model of interdisciplinary practice. *The Medical Journal of Australia* 2003; 179: 32.
53. Australian Department of Health. GP Workforce Statistics – 2001-02 to 2016-17 (data accessed 11 September 2018). <http://www.health.gov.au/internet/main/publishing.nsf/Content/General+Practice+Statistics-1>.
54. Meier DE and Beresford L. Billing for palliative care: An essential cost of doing business. *Journal of palliative medicine* 2006; 9: 250-257.
55. Partridge AH, Seah DS, King T, et al. Developing a service model that integrates palliative care throughout cancer care: the time is now. *Journal of Clinical Oncology* 2014; 32: 3330-3336.
56. Michiels E, Deschepper R, Van Der Kelen G, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliative Medicine* 2007; 21: 409-415.
57. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *Journal of pain and symptom management* 2003; 25: 150-168.