

The role of the general practitioner in palliative care: a review

Marilyn Harney

Family medicine and palliative care are two specialities that share several important principles and have the needs of the 'whole person' at their core. For this reason, the general practitioner can provide an invaluable role in palliative care through the early identification of palliative care needs, care coordination and end-of-life decisions. Two online databases were used to search for scientific papers focusing on the role of family doctors in this growing speciality. These features, together with the challenges and barriers encountered by family doctors, are explored and discussed in detail in this review.

Marilyn Harney

MD MMCFD MRCGP(INT)

Department of Primary Health

Care,

Ministry of Health, Malta

harneymarilyn@gmail.com

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INTRODUCTION

Family medicine and palliative care are two specialities that share several important principles. **Family medicine** is the speciality that is responsible for providing comprehensive and continuing care to all individuals seeking medical advice, irrespective of gender, age and illness. Family doctors are often the initial point of contact for people in the health system, and aside from diagnosis and treatment their responsibilities include health promotion, disease prevention, palliation and patient empowerment.¹ An important characteristic of family medicine is the focus on the ‘person’, treating individuals as a ‘whole’ and seeing them in the context of their family, community and culture. Family doctors also have the privilege of building a unique relationship with their patients which further improves the quality of care provided.

Palliative care is the speciality that focuses on prevention and relief of suffering as a way of improving the quality of life of patients who are facing a life-threatening illness with a limited prognosis (not restricted solely to malignancy), by addressing the physical, psychosocial and spiritual needs, as well as providing support to their families.² This care is usually provided by a multi-disciplinary team.

Both family medicine and palliative care have the needs of the ‘whole person’ at their core, and two of their most marked characteristics are prevention and continuity of care. Taking into consideration these similarities, and with the reality of an ever-increasing ageing population and the burden posed by malignancy and other chronic conditions on the health of populations in developed countries³, the family doctor can provide an invaluable role in palliative care, the various features of which will be discussed in this review.

The terms ‘general practitioner’ and ‘family doctor’ are used interchangeably in the text.

METHOD

A search for scientific papers related to the various aspects of the role of the general practitioner in palliative care was done using two online databases, namely PubMed/MEDLINE and Google Scholar.

The keywords used in the search included: ‘family medicine’, ‘primary care’, ‘palliative medicine’, ‘palliative care’, ‘general practitioner’ and ‘primary palliative care’.

The titles and abstracts of the papers in the literature search results were reviewed and assessed for quality and relevance to the topic in question. Further papers were selected through citation searching, and eventually a final set of papers to be included in the review was chosen.

IDENTIFICATION OF PALLIATIVE CARE NEEDS

In everyday practice, palliative care is often started during the terminal phase of a life-threatening illness. Palliative care improves the quality of life of patients and their families by means of **early identification** of needs, followed by assessment and management², therefore identifying and dealing with issues early on, during routine visits by the family doctor, would be ideal. A number of tools have been developed to aid doctors in this process. These tools help in identifying patients’ needs at an early stage during the course of an illness, and thus developing a proactive palliative care plan. Family doctors are often patients’ initial and main medical contact point, and they also build a unique relationship with their patients over time. In view of this, the family doctor is in a distinctive position to use the consultation as an opportunity to start a discussion about this sensitive topic, which

patients often find difficult to bring up themselves.

Deciding when a palliative approach should be started is difficult, especially in the case of non-malignant diseases.⁴ The following is a summary of the tools which have been developed over the years for this purpose, and which are particularly adapt to be used in family medicine.

- **The 'surprise question'** was initially suggested for use by doctors as a rough initial indication in patients with advanced disease or progressive life-limiting conditions – *'Would I be surprised if the patient were to die in the next few months, weeks, days?'*⁵ The answer to this, based on the family doctor's intuition (derived from clinical, social and other factors that provide an overall picture of deterioration⁵), if in the negative should initiate thinking of possible measures to improve the patient's quality of life both at present and in the future, taking into consideration the likely deterioration in the condition. This question was however found to be of limited use in practice since doctors tend to overestimate the survival of their patients⁶, but is of benefit when incorporated in other tools. A recent study published in 2018 explored the value of adding a second question when the surprise question above is answered in the negative. The second surprise question *'Would I be surprised if this patient is still alive after 12 months?'* was found to be helpful by general practitioners (GPs) and appeared to contribute to more extensive and anticipatory palliative care planning.⁷
- **RADPAC (RADboud indicators for Palliative Care needs)** is another tool that can be used by family doctors to

identify patients who would benefit from a palliative care approach.⁶ It presents a set of indicators for patients with congestive heart failure, chronic obstructive pulmonary disease and malignancy. It is disease-specific, focusing on physical aspects, and lacks consideration of the psychosocial and spiritual domains. This tool does not include the 'surprise question'. Family doctors trained in the use of this tool have been found to be more sensitive in identifying palliative patients and providing a multidimensional palliative care approach.⁸

- **Gold Standards Framework – Prognostic Indicator Guide (PIG)** was developed in the UK and incorporates the 'surprise question' with a set of general and specific clinical indicators for decline in organ failure, dementia and frailty trajectories.⁵
- **Supportive and Palliative Care Indicators Tool (SPECT)** is based on a combination of general indicators and disease-specific assessment criteria. It was developed in Scotland⁹ and the 'surprise question' is not part of this tool as the authors feel it can delay appropriate early palliative care intervention.¹⁰
- **NECPAL CCOMS-ICO (NECPAL: Necesidades Paliativas)** tool was developed in Spain, is based on PIG and SPECT, but has been adapted to a Latin-Mediterranean clinical and cultural context. Of particular note are the inclusion of the request of the patient or family for palliative support as one of the criteria, as well as psychosocial domain, frailty and any progression of functional and nutritional decline.¹¹

- **Early identification tool for palliative care patients** was developed in North America. It incorporates the use of the 'surprise question' together with a set of general indicators for decline and parameters for advanced stages of illness.¹²
- **The 'quick guide'** was developed in London and provides simple guidance for daily clinical practice. It makes use of the 'surprise question' together with a set of

general indicators of decline, hospital admissions, weight loss, comorbidities and burden of illness.¹²

A comparison of the four main identification tools available is illustrated in Table 1. SPICT appears to be the most validated, accessible and comprehensive tool available to general practitioners; it is also straightforward, making it easy to use irrespective of the level of experience of the physician in palliative care.¹³

Table 1 Comparison of tools available for identification of palliative care needs

	RADPAC	GSF - PIG	SPICT	NECPAL
Primary care	✓	✓	✓	✓
Secondary care			✓	✓
Surprise question		✓		✓
Patient choice/request			✓	✓
Target patient group				
- Cancer	✓	✓	✓	✓
- COPD	✓	✓	✓	✓
- Heart failure	✓	✓	✓	✓
- Others*		✓	✓	✓
General indicators				
- Age		✓		
- Functional status	✓	✓	✓	✓
- Weight loss	✓		✓	✓
- Hospital admissions	✓	✓	✓	✓
- Other	✓		✓	✓
Specific indicators for:				
- Cancer	✓	✓	✓	✓
- COPD	✓	✓	✓	✓
- Heart disease	✓	✓	✓	✓
- Kidney disease		✓	✓	✓
- Liver disease			✓	✓
- Neurological disease (inc. MND, PD, MS)		✓	✓	✓
- Dementia/Frailty		✓	✓	✓

RADPAC: RADboud indicators for PAlliative Care needs; **GSF-PIG:** Gold Standards Framework – Prognostic Indicator Guide; **SPICT:** Supportive and Palliative Care Indicators Tool; **NECPAL:** Necesidades Paliativas; **COPD:** Chronic Obstructive Pulmonary Disease; **MND:** Motor Neurone Disease; **PD:** Parkinson Disease; **MS:** Multiple Sclerosis; *Others: Kidney disease, Neurological disease, Frailty/Dementia/Stroke

Shaded rows indicate features common to all the four tools.

Even though these tools are available, studies in Europe have shown that these are rarely used in the identification of palliative care needs, and currently this practice is largely based on the family doctor's clinical judgement, information received from the hospital¹², observation of increase in patient dependency and information from family members.¹⁴

COORDINATING CARE

Family doctors will often have a coordinating role in palliative care.¹⁵ This includes the important management of symptom complexity: dealing with the psychosocial and spiritual symptoms for which specific skills need to be developed¹⁵, in addition to the physical symptoms. GPs are capable of delivering satisfactory symptom control¹⁵ but there is room for improvement in this aspect especially when dealing with pain management.¹⁶ Non-acute issues might need to be gently explored by the family doctor, as the patients and families often do not readily discuss these in an attempt not to bother the doctor, and as they often believe the doctor's role is more focused on dealing with acute problems. On the other hand, family doctors might also avoid such discussions about palliative care needs because they are uncomfortable approaching the subject and because of fear of taking away the patient's hope.¹⁷

Upon identification of the palliative care needs, the family doctor can plan and coordinate care by involving other professionals as required and facilitating use of services in the community which might be beneficial, such as loan of equipment. Collaborating with specialist teams in palliative care results in improved outcomes for patients.^{15,18}

Ensuring continuity of care is an important feature, especially by liaising with hospital doctors and the specialist palliative care team, as well as the family.¹⁹ Family doctors tend to be involved more during the early stage of diagnosis/referral and the terminal stage of care, leaving a "vacuum" in the middle of the disease trajectory which if not addressed possibly leads to sub-optimal treatment and unnecessary admissions to hospital.²⁰ Indeed, doctors in primary care have an important role to play and should be there for patients throughout the whole course of the illness.²¹ Communication between specialists and GPs during and after hospital admissions is important for doctors to be aware of any changes or developments, and to emphasize the valuable role the family doctor has in the holistic management of the patient in the community.²²

The family doctor needs to be sensitive to the 'unspoken needs' of patients and their families, patiently being there for them and providing them with the time and space to talk about their fears and concerns, while acknowledging that this might be a difficult and challenging journey for them. Providing emotional support to family members and helping them deal with anticipatory grief is another important role, which should also be extended to the relatives after the patient's death as they go through the bereavement process.²³

Good communication between the family doctor and the patient is of utmost importance. A number of issues might affect this, including when patients are unwilling to know their diagnosis or prognosis and when relatives put pressure not to fully disclose information to the patient.²⁴ There should be frequent reassessment of patients' ideas regarding disclosure of information, and care

should be tailored accordingly.²⁵ A high level of communication skills is needed in dealing with these situations.²⁴

Family doctors can influence and prevent hospital admissions at the end of life by carefully anticipating possible scenarios, discussing them with patients and relatives, planning and giving advice accordingly.²⁶ Relatives and caregivers need to feel supported by the family doctor, especially through the doctor being accessible during emergencies while being able to take decisions and shoulder responsibility.²⁶ Hospital referrals may also be affected by patient and family factors, such as requests for referral by patients who feel 'safer' in a hospital environment, or relatives feeling that they cannot provide the necessary care at home. Improving holistic community palliative care by early referral, communicating with patients and supporting caregivers, are important aspects which help to reduce admissions to hospital and decrease the number of hospital deaths at the end of life.²⁷⁻²⁸

END-OF-LIFE DECISIONS

Family doctors are often faced with challenging end-of-life issues, which include informing patients about their diagnosis and prognosis, discussing their preferred place of care, withholding or withdrawing treatment and symptom control.^{24,29} The family doctor, as well as the patient might be reluctant to start discussions about such issues, however doctors should use their privileged position to initiate and facilitate these sensitive discussions while helping patients prepare for death.²⁴ The question 'How long have I got?' is commonly asked and might be difficult for the doctor to answer, especially in view of uncertainty and fear of over- or underestimating the length of survival, which

might in turn be a source of distress for relatives or carers.^{24,30} Prognostic indices such as the Palliative Prognostic Score may help family doctors reach a more accurate prediction.³⁰ Discussions about prognosis can also be challenging for the doctor when the patients and/or relatives are in denial and fail to accept that the end-of-life is near, and this might make it more stressful for the GP to make decisions regarding the palliative care needs of the patient.²⁴ Even though most patients (approximately 75%) would prefer to die at home, the majority die in hospitals or nursing homes, with only about 30% dying at home.³¹ Carers of patients who died in their 'preferred place' were significantly more satisfied with the care provided by their family doctor.¹⁶

Withholding and withdrawing treatment and intensification of analgesia are options that most GPs would consider in their management of palliative patients, and discussion of these issues with patients was found to be related to doctors having received some form of training in palliative care.³²⁻³⁴ This is in contrast to palliative sedation, which GPs were in general uneasy with, as they felt abuse of this could result in euthanasia.³⁵⁻³⁷ Euthanasia and physician-assisted dying is a very broad subject and constantly changing especially in view of developments and changes to legislation. Studies have shown that the majority of GPs in the UK, Malta, Italy, Belgium, Australia and New Zealand would be reluctant to perform euthanasia, even if this is legal.^{35, 38-41} This is in contrast to the situation in the Netherlands where euthanasia is legal, and the majority of these procedures are performed by GPs.⁴² Having been exposed to training in palliative care and working with palliative patients was found to significantly affect doctors' views resulting in a lower chance of considering

euthanasia.^{32,38,39} This could possibly be due to doctors feeling more confident in effectively managing symptoms and keeping patients comfortable at the end of life.

Since 2012, a hospital trust in the UK has developed a two-day course for healthcare professionals called 'Transforming End of Life Care'. This was found to be useful by participants, including family doctors, and was noted to be a source of increased self-rated confidence, competence and knowledge in end-of-life care.⁴³ Similar initiatives in other countries might prove to be beneficial, especially for GPs to gain skills in dealing with this often challenging period in their patients' lives.

There is a lack of legal and moral guidance for GPs when it comes to end-of-life decisions³⁵ and developing guidelines or protocols in this regard would facilitate this difficult process for doctors.

CHALLENGES AND BARRIERS FACED BY FAMILY DOCTORS

Family doctors might feel that they are not knowledgeable enough when dealing with palliative care patients.^{15,24,44-46} This might stem from the fact that exposure to such patients is infrequent, and therefore they would feel less comfortable prescribing certain medications such as high doses of opiates, or using certain equipment such as a syringe driver, which are otherwise not commonly used in everyday practice.⁴⁵

Family doctors may have to deal with feelings of helplessness and might also struggle emotionally when dealing with patients with a terminal illness, whom they have known for a long time, as well as their relatives.^{15,23,24,44} This exposure to painful emotions highlights the possible lack of coping skills of doctors

when faced with death and suffering. Several studies have shown that family doctors provide excellent educational support and are involved in pain management, but tend to lack in providing emotional, social and spiritual support to patients.^{15,20,47}

The multidisciplinary team is a key characteristic of palliative care, and the fact that many family doctors usually work alone might be a challenge in delivering this care.²³ Liaising with specialist palliative care services available is important, and if possible having discussions with the team about individual patient care and issues would be ideal. In the absence of specialist palliative services, such as in rural areas, the GP is seen to take more the role of leading and managing palliative patients.⁴⁸ This might indicate that simply referring patients to specialist palliative services is resulting in family doctors being less involved and experienced in the care of their palliative patients.

Dealing with palliative care patients is often demanding, and family doctors would often be required to be available out-of-hours, dealing with emergencies as they arise and carrying out home visits.^{24,44,49} Guidelines are lacking in palliative care, and in this always-evolving speciality family doctors need to keep up-to-date with new knowledge and advances, which might be a challenge for busy practitioners.^{23,44,49}

There appears to be a big demand for improved and extended medical training in palliative care as shown by a number of studies with doctors in different countries, including Australia, Belgium, Sweden, Italy, Malta, Denmark and Switzerland.^{15,32,33} Incorporating palliative care as part of the post-graduate family medicine specialization programme has been found to be an effective way of teaching, as well as causing a positive change in

attitudes towards end-of-life care.⁵⁰ Palliative care is incorporated in most GP vocational training programmes worldwide, however studies have found that lack of time and patient exposure were common barriers to providing effective training, and it was suggested that training should focus more on specific needs which were relevant for GP trainees, including addressing ethical issues, using a syringe driver, managing dying patients in the community and self-care.^{51,52} GP trainees' confidence in palliative care was found to improve after their rotation which they found useful in terms of developing communication skills and improving knowledge of managing symptoms at the end-of-life.^{15,53} A study in Canada however showed that most of the trainees were discouraged from incorporating palliative care in their everyday practice as after seeing it being carried out by specialised physicians the trainees did not feel confident in their ability to manage such patients independently.⁵³ This highlights that training should be modified to address the particular needs of the trainees and focus on improving their confidence in areas which they can eventually put into practice, by involving them in the care of patients being managed by specialist teams and giving them the opportunity to learn by experience.¹⁵ The Primary Palliative Toolkit developed in 2015 also highlights the need for promotion of palliative care training.⁴⁵ A number of learning opportunities are available for doctors, including conferences, e-learning modules and courses. The European Certificate in Essential Palliative Care is an 8-week distance learning course, aimed at healthcare professionals, and is available in the UK, Ireland and Malta. It has been found to improve confidence in the management of palliative care patients, which confidence is sustained over time.⁵⁴ A study by Reed et al.

demonstrates evidence of improved confidence in management of symptom control, communication skills and a holistic approach towards patients in candidates who had completed this course.⁵⁴

CONCLUSION

In high-income countries, about 70% of deaths are due to advanced cancer and other chronic conditions¹¹ and the increase in demands on the service is one of the main reasons why the role of family doctors in palliative care is becoming more important.

Several adjectives can be used to describe the family doctor's role in palliative care, including 'team leader', 'guide', 'supporter', 'coordinator', 'interpreter', 'co-morbidity manager' and 'gatekeeper'.⁴⁶ The GP should be the key person to manage and coordinate care, and this role can be improved by facilitating communication with specialists and providing training opportunities.⁴⁶

Palliative care is considered to be one of the best parts of the job of a family doctor, and acting as a 'reference point' by simply explaining what is going on is particularly reassuring for patients.^{16,44} When given appropriate training in the important skills of communication, leadership and empathy, the family doctor can feel empowered to provide an invaluable service to patients and families during this very delicate period in their lives.

In his General Practice textbook, John Murtagh brilliantly summarizes the role of the family doctor as follows:

'The GP is the ideal person to manage palliative care for a variety of reasons—availability, knowledge of the patient and family, and the relevant psychosocial influences. A key feature is the ability to provide the patient with independence and dignity by managing

palliative care at home. Someone has to take the responsibility for leadership of the team and the most appropriate professional is a trusted family doctor.'⁵⁵

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