The Concept of Palliative Care Practice among Iranian General Practitioners

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Abstract

Introduction: General Practitioners (GPs) have the main responsibility in medical and particularly palliative care provision in most of countries, though this is not the current case in Iran. Development of 'family physician' approach in rural and most of the urban areas in Iran, GPs will have the main role in care provision. There is no formal palliative care education during general medical training in the country so far. Regarding the increasing number of people in need of palliative care services, it is essential to assess GPs' knowledge about palliative care to develop special palliative care educational programmes.

Method: A cross-sectional questionnaire survey was conducted on general practitioners participated in a formal Continuous Medical Education programme, using three scales.

Results: 216 GPs returned the completed questionnaires. More than half scored their knowledge about palliative care as weak, which was significantly related to their previous experience in caring of a terminally ill patient (p=0.001). Less than one third stated their good ability to either assess or manage pain in end of life. Major gender differences were seen in different subscales such as communication with patients and carers, patient management, palliative care knowledge and skills, and psychological stress.

Conclusion: This study revealed a profound lack of knowledge and experience among Iranian general practitioners about palliative care which was mostly in more complicated areas rather than common symptoms relief.

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Introduction

The role of General Practitioners in health care provision for Iranians is rapidly increasing, particularly after the introduction of 'family physician' in rural areas and small towns. Traditionally in the current health system in Iran, people are free to go to either a GP or specialist and even a sub-specialist whenever they wanted, (1) however in the recent health reform GPs are becoming 'gate keepers' of the health system, where all referrals happen from the standpoint of a GP. In this circumstance, GPs warrant more training to deal with new tasks to meet the needs which exist in the population; most of these needs are not expressed.

Around 6 million annual deaths occur from cancer globally with the majority in developing countries, (2-4) with an increasing incidence rate in many developing countries. (5) According to the statistics from Ministry of Health and Medical Education, over 30000 deaths occur annually in Iran due to cancer with an incidence of over 70000 new cases. Palliative care as defined by the World Health Organisation is 'the active total care of patients whose disease is not responsive to curative treatment'.

Currently, cancer patients in Iran receive their care from either public or private tertiary hospitals and also day clinics, where special and sub-specialties provide medical care including diagnostic and treatment courses, however patients are discharged after any treatment course with a somehow simple instruction until the next treatment course. These patients usually do not receive any extra care such as nursing, consultation with their physician or satisfying other medical, psycho-social, physical or spiritual needs. There are scattered public or charity funded hospice and palliative care services round the country. In addition, although there is no accurate statistics indicating the proportion of cancer and other terminally ill patients die at their home in Iran, there is in some developed countries, increasing number of patients who die in the community, where

90% of the care delivered to patients is by GPs and primary care teams. (6)

While considerable variations in service provision do exist, this remarkable lack of palliative care services reflects a broad desire for the underlying principles and a widening of its scope. No longer concerned only with the terminal phase of an individual's life and committed to a form of holistic medical and psycho-social care that transcends biomedical and social models of health and illness, palliative care has been characterised as 'essentially creative and destructive' in relation to other kinds of medical specialisms and forms of service provision. (7) It comprises a mix of specialist services – those specifically catering for the needs of terminally or chronically patients, usually with cancer and general services, which meet the routine, day-to-day care requirements of patients.

General practitioners estimate palliative care as an important and valuable part of primary care. Nevertheless, they consider their coordinating role as a course with increasing obstacles. (8) Patients often appreciate the GP contribution to palliative care if the GP is accessible, endeavour to symptom relief, communicate with the patient and carer effectively and takes time to listen. (9) Pain, nausea, dysphagia, delirium, insomnia, anxiety, and depression were mentioned frequently as symptoms difficult to deal with in palliative care. (8) Also, psychosocial issues such as communication, bereavement, and defence mechanisms were subject to discussion in the focus groups. Ethical issues such as euthanasia were mentioned as the most complex subject in palliative care. (8) General practitioners can deliver effective medical care provided that an appropriate specialist support is available. (9)

Method

A questionnaire survey was conducted in one of Continuous Medical Education (CME) training courses specifically designed for GPs to assess their knowledge and attitude towards palliative care, using two previously administered questionnaires. Overall, 350 GPs attended in different sessions of this 4-day course and 216 agreed to participate in this survey.

The tool was a battery of questionnaires comprising 3 main scales and a section for demographic questions. All scales passed a standard translation process from English to Farsi (forward and backward translations). The first tool evaluates respondents' knowledge (9 questions) and skills (8 items) during their medical education towards different aspects of palliative care, the second scale (Self Efficacy in Palliative Care Scale) consisting 22 items, assesses their skills in three components that are communication skills, patient management and multidisciplinary team working. (10, 11) 'Team working' component in SEPC in its original version had seven items, however the question 'appropriately referring palliative care patients to a lymphedema service' was deleted as there is no such a service in Iranian health system; patients who need this service will be treated in internal medicine wards. The last questionnaire (Thanatophobia Scale) consists of 7 questions in a 7-scale Likert type, which assesses the psychological stresses of palliative care on health professionals. (11)

Subscales were calculated in Self-efficacy in Palliative Care Scale in its three components: communication skills, patient management and multidisciplinary team working, by cumulating all variables in the same category. The same was done for the first tool, where two components were calculated as palliative care knowledge and skills. The last questionnaire produced one scale as psychological stress.

Considering the fact that WHO ladder for pain relief has a valuable role, (12) specially where a national clinical guideline is not available, 2 questions were added to find out what proportion of respondents are aware of such a guideline and to figure out how many GPs think if the WHO ladder is sufficiently useful for clinical practice. Added to this section, a table of seven analgesics was put to assess the GPs' familiarity with the most prevalent prescribed anti-pain medicines including morphine, NSAIDs, Fentanyl, Oxycodone, Buprenorphine, Tramadol and analgesic mouth wash.

There is at least one medical university in every 30 provinces in Iran, which holds the responsibility of health services to the provincial population. Moreover, 13 more medical universities exist in the capital (Tehran) and also small towns in a number of provinces, which all (except two medical universities belong to military forces) have a particular catchment area. The Iranian Ministry of Health and Medical Education has grouped these medical universities in three types (Type 1-3) according to the population under coverage, academic staff and education and research criteria.

Results

Overall 216 General Practitioner returned the completed questionnaires. Respondents graduated from 28 medical universities (out of the total number of 43 in Iran) with a mean medical experience of 8.25 years, half were male and mostly (70%)

Table 1: *Demographic characteristics*

		Female	Male	p-value
University	Main universities	59 (50%)	60 (50%)	P= ns
	Minor universities	29 (55%)	24 (45%)	
End of life care experience	Yes	39 (41%)	57 (59%)	P<0.01
	No	54 (60%)	36 (40%)	
Mode of practice	Public	41 (54%)	35 (46%)	P= ns
	Private	39 (46%)	45 (54%)	
	Charity and Welfare	9 (53%)	8 (47%)	
Palliative service for family members	No	40 (53%)	36 (47%)	p= ns
	Next of kin	19 (40%)	28 (60%)	
	2nd grade	34 (54%)	29 (46%)	
Mean graduation period (SD)		7.27 (6.1)	10.1 (9.27)	P<0.05
Mean medical experience (SD)		6.24 (5.2)	10.73 (9.7)	P<0.001

Table 2: *GPs' Knowledge and skills about palliative care*

	Female	Male	P value				
	Very good	Moderate	Weak	Very good	Moderate	Weak	
Concept of palliative care	8 (8%)	36 (37%)	52 (54%)	13 (14%)	36 (38%)	45 (48%)	Ns
How to assess cancer pain?	2 (2%)	20 (21%)	74 (77%)	6(6%)	25 (27%)	63 (67%)	Ns
Management of pain	3 (3%)	18 (19%)	75 (78%)	3 (3%)	38 (40%)	53 (57%)	<0.01
Management of dyspnea	13 (13.5%)	45 (47%)	38 (40%)	14 (15%)	58 (62%)	22 (23%)	0.05
Managing mood disorders	19 (20%)	56 (58%)	21 (22%)	17 (18%)	51 (55%)	25 (27%)	Ns
Managing nausea	26 (27%)	53 (55%)	17 (18%)	34 (37%)	47 (50%)	12 (13%)	Ns
Managing cachexia	11 (11%)	45 (47%)	40 (42%)	12 (13%)	49 (53%)	32 (34%)	Ns
Managing confusion	5 (5%)	32 (34%)	58 (61%)	10 (11%)	36 (39%)	47 (50%)	Ns
Managing constipation	22 (23%)	57 (59%)	17 (18%)	36 (39%)	43 (46%)	14 (15%)	Ns

graduated from the main universities (see Table 1 for more details).

Only 12 percent of respondents rated their knowledge about palliative care as excellent or very good, while more than half scored as weak or less, which was significantly related to their previous experience in caring of a terminally ill patient (p=0.001). Less than one third stated their good ability to assess pain and a little bit more were able to manage pain in end of life. Earlier practice again had a major impact on GPs' knowledge towards assessment and managing pain in cancer patients (p<0.01). GPs' experience in caring end of life patients significantly affected their ability to assess patients palliative care conditions. Major gender differences were seen in different subscales such as communication with patients and carers, patient management, palliative care knowledge and skills, and psychological stress. Surprisingly in the latter, female GPs stated less stress in facing end of life patients than males (p=0.001). There was no sex difference in team working subscale.

Medical universities were grouped in two as 'main' (Type-1) and 'minor' (Type 2-3) according to the size of medical schools and their experience in training medical graduates. No statistically significant difference was seen in various subscales of the three questionnaires in the two types of medical universities.

There was no missing item in the first tool and on average 21 respondents did not complete the SPEC fully and 27 GPs (12.5%) missed the third scale.

Reliability

The 'palliative care in medical education' tool has two components (knowledge and skills), the Self Efficacy in Palliative Care Scale has three sub-scales

Table 3: *Statistical features of the questionnaires*

Tools	Subscale	No. of items	Missing	Skewness (SE)	Chronabach's alpha
Palliative care knowledge & skills in medical education	Palliative care knowledge	9	0	-0.14 (0.17)	0.81
	Patient management skills	8	0	-0.45 (0.17)	0.81
Self Efficacy in Palliative Care Scale	Communication	8	17	-0.55 (0.17)	0.92
	Management	8	21	-0.89 (0.17)	0.90
	Team working	6	25	-0.34 (0.18)	0.91
Thanatophobia	Physicians' stress	7	27	-0.15 (0.18)	0.83

Table 4: *Differences between sub-scales*

Subscale	Mean (SD)		P value	Familiar with the concept of palliative care		P value	Experience in end of life care		P value
	Female	Male		Good	Weak		Yes	No	
Palliative care knowledge	3.36 (.48)	3.2 (.49)	<0.05	2.7 (.45)	3.3 (.44)	<0.01	3.1 (.46)	3.4 (.47)	<0.001
Patient management skills	3.5 (.57)	3.2 (.59)	<0.001	2.9 (.66)	3.4 (.55)	<0.05	3.2 (.59)	3.6 (.54)	<0.001
Communication	3.4 (0.69)	3 (.71)	<0.001	2.9 (.76)	3.2 (.74)	<0.05	3 (.71)	3.4 (.7)	<0.001
Management	3.35 (0.7)	3.1 (.63)	<0.05	2.9 (.7)	3.2 (.74)	<0.05	3 (.67)	3.4 (.6)	<0.001
Team working	3.1 (0.8)	3.2 (.77)	Ns	2.8 (.9)	3.23 (.79)	>0.05	3.1 (.75)	3.3 (.84)	0.01
Physicians' stress	3.85 (1.6)	4.5 (1.26)	0.001	4.4 (1.3)	4.1 (1.5)	Ns	4.5 (1.3)	3.8 (1.5)	0.001

and Thanatophobia scale has only one component. Internal reliability in various sub-scales were calculated using Chronabach's alpha (Table-3), which varies between 0.81 ('palliative care knowledge' and 'skills') and 0.92 (communication).

Team working sub-scale comprised of six items, which were 'ability to work in a team', 'referring to physiotherapist', referring to occupational therapist', 'referring for complementary medicine', 'referring to psychiatrist', 'referring to spiritual advisor'. If the last item was deleted in internal reliability analysis, an even higher figure could be obtained (Chronabach's alpha =0.92). SEPC had the highest internal reliability amongst the three tools administered in this study.

Validity

Face and content validity of all three questionnaires were proved during translation process and preparing the battery to be administered in the main phase of the survey. Moreover, construct validity was confirmed where all components had statistically significant correlation with the GPs' knowledge about the concept of palliative care and also their experience in end of life care. Table-4 demonstrates that physicians with an experience in terminal care had scored higher in all components, except psychological stress in which experienced physicians had less stress when confront terminally ill patients. In contrary, less experienced general practitioners scored less in the first two tools, which indicates the convergent validity of these scales.

Pain management

GPs were asked about WHO instruction for pain management called as 'WHO pain relief ladder', which involves a range of analgesics in palliative care for cancer patients. Only about one fifth (22%) were aware of WHO strategy for pain relief and about the same proportion (20%) were in favour of applying this step-ladder in the country and 23% were against the efficiency of this strategy; the rest (57%) had no opinion in this regard.

General practitioners' knowledge about major pain relief medicines were assessed in a Likert scale

format. Main pain relief drugs were included in this section. Physicians rated their knowledge about NSAIDs, morphine, Tramadol and mouth washes as good to excellent in more than 74% of cases, however their familiarity with Fentanyl, Oxycodone and Buprenorphine were at lowest respectively (more than 50% expressed their weakness).

Discussion

Development of palliative care services is an urgent need for all nations who suffer from lack of these services, especially in developing world and Iran, where cancer among other chronic diseases are prevalent. (2, 13)

General practitioners in the recent reform in health delivery system in urban areas will play a substantial role as the gate keepers and first contact with patients. Unfortunately there is no formal palliative care education during general medical education in the country. These data will help health policy makers and professionals to develop specific curriculums to acquaint GPs and medical students with the concept of total care at the end of life.

General practitioners usually tend to miss symptoms that are not treatable by them or which are less common. (9) Similarly, GPs in this study, were more confident to manage common medical symptoms like nausea, constipation, mood disorders and dyspnea, nevertheless, they expressed profound weakness towards the essentials of end-of-life care such as assessment of pain, management of pain, management of confusion and knowledge about the concept of palliative care. This is mainly due to the fact that medical education in Iran is mostly symptom oriented rather than providing a holistic care. Lack of knowledge about palliative care among GPs is similarly found in other developing countries. (14)

Referring to a clergy for spiritual care is odd in caring of a terminally ill patient in Iran. This is highly due to the religious context among Iranians, where families and friends play the role of ministers in Christianity. All relatives and fellows pray for the patient, support him or her spiritually and also accompany the patient in worships. Setting a systematic approach, however, has been proposed to support Iranian terminally ill patients spiritually. (13) Establishment of such specialist palliative care services, which formally involve GPs in the first line of contact, may be an effective method of improving GP palliative care skills and performance of the specialist services roles which in turn lead into improvement of functional outcomes, patient satisfaction, effective use of resources, improving effective physician behaviour in other areas of medicine and providing a better quality of life.

The questionnaires administered in this study were all valid and reliable to be used in other surveys. SEPC and Thanatophobia reached almost the same internal reliability to Masson and Ellershaw's study. (11) Layout of the pack of questionnaires may play a role in increasing missing items of the tools, as there was no missing data in the first tool compared with 27 missings in the last scale, however, the Thanatophobia sounds a bit harder to understand and complete as it deals with psychological stress during palliative care for inpatients and also has a seven-scale format.

No statistically significant difference was seen in various subscales of the three questionnaires in the two types of medical universities. This indicates that a universal lack of knowledge among GPs exists, which is not vary between Type-1 and other medical universities. A holistic and general educational reform, thus, is required to enhance GPs capabilities to deal with palliative care patients and their informal caregivers.

This study could be more improved if the GPs attended in short term training in the field of palliative care and followed after a while to evaluate the impact of training course on their knowledge, attitudes and practice.

In conclusion, this study revealed a profound lack of knowledge and experience among Iranian general practitioners about palliative care which was mostly in more complicated areas rather than common symptoms relief. Complementary palliative educations and CME workshops tailored for GPs, changes in medical curriculum, providing multidisciplinary specialist support and palliative medicine specialist training programmes may play important roles in improving the current palliative care services for the ever increasing demand of Iranian population.

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