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Cross-cultural differences in hospices. A retrospective study in Italy

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Summary. *Aim:* Increasing immigration in Italy poses challenges in providing cross-cultural palliative care (PC) and end-of-life (EOL) care. In this retrospective study we report the difficulties encountered by hospice operators caring for immigrant patients admitted to 16 hospices in Emilia Romagna from 2001 to 2011. *Materials and methods:* 327 immigrants were admitted in the study period (1.6% of total admissions). 379 hospice operators were surveyed regarding their experiences in cross-cultural encounters through a questionnaire. Answers were evaluated by the Mann-Whitney U test and chi-square test. 252 operators responded to the questionnaire (67% of total). *Results:* Relational aspects were the most frequent difficulties experienced by nurses during patient admission and hospitalization and by physicians during EOL. Language difficulties were reported by 75% of responders, regardless of their profession. Difficulties directly correlated with years of experience in a hospice (p=0.002). *Conclusions:* The results of this study suggest that hospice operators should learn how to deliver quality cross-cultural care. The problems encountered by both Italian doctors and nurses were most likely due to lack of teaching and training in cross-cultural communication and cultural competence. Immigrant patients admitted to Italian hospices are still few, but their number is expected to increase. Appropriate cross-cultural education should become mandatory for medical and nursing students as well as oncology and PC operators.

Key words: palliative care, hospice, end-of-life, cultural competence, communication

«Interculturalità in hospice. uno studio retrospettivo in Italia»

Riassunto. *Finalità:* La costante crescita del fenomeno di immigrazione in Italia pone innanzi a varie problematiche nel garantire cure palliative e di fine vita ottimali a pazienti nell'ambito di un contesto multiculturale. In questo studio retrospettivo abbiamo documentato le difficoltà rilevate dagli operatori degli hospice che si sono occupati di pazienti immigrati ricoverati in 16 hospice della regione Emilia-Romagna

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dal 2001 al 2011. *Materiali e metodi:* Trecentoventisette immigrati sono stati ricoverati nel periodo studiato, rappresentando l' 1,6% dei ricoveri totali. Trecentosettantanove operatori sono stati intervistati sulla loro esperienza con i paziente stranieri, attraverso un questionario. Le risposte sono state valutate attraverso il test U di Mann-Whitney e il test chi-quadro. Duecentocinquantadue operatori hanno risposto al questionario (67% del totale). *Risultati:* Le problematiche relazionali sono state quelle più frequentemente riportate dal personale infermieristico nella fase di ammissione e di ricovero e dai medici nel periodo di fine vita. Difficoltà linguistiche sono state riportate dal 75% degli operatori, indipendentemente dalla loro professione. Le difficoltà sono risultate essere direttamente correlate con gli anni di esperienza in hospice (p=0.002). *Conclusioni:* I risultati di questo studio suggeriscono che il personale degli hospice dovrebbe ricevere un training ed una formazione specifici per poter garantire cure ottimali anche nei confronti di pazienti con diverso background culturale. I problemi riscontrati sia dai medici sia dagli infermieri sono verosimilmente causati dalla mancanza di formazione nell'ambito della comunicazione e della competenza culturale. Il numero dei pazienti stranieri ricoverati negli hospice italiani è ancora esiguo, ma è destinato ad aumentare. Una adeguata formazione interculturale dovrebbe diventare d'obbligo per gli studenti di medicina e di scienze infermieristiche e per gli oncologi e gli operatori nel settore di cure palliative.

Parole chiave: cure palliative, hospice, cure di fine vita, competenza culturale, comunicazione

Introduction

As Western societies become increasingly multicultural, new challenges are emerging in the provision of optimal health care, especially palliative care (PC) where communication and existential matters assume the greatest importance (1). Caring for patients and families from diverse ethnic or cultural groups, whose beliefs, habits and way of communicating differ from the operators' own, requires knowledge, sensitivity and skills to understand and address all dimensions of patients' experience at EOL (2-6).

In the last decade a rising rate of immigration has been reported in Italy from North African, East European and Far Eastern countries. In Emilia Romagna, a central-northern Italian region, foreign residents comprise 10.7% of the overall population (7.1% in Italy as a whole). In the next 5 years, resident immigrants are expected to reach 20% of the general population in Italy (7). Non-resident immigrants are also likely to increase.

In this article we present and analyse the results of a retrospective survey of the most common difficulties encountered by PC and EOL professionals in the clinical management of immigrant patients assisted by the Emilia Romagna Hospice network (ERHON).

Methods

The survey was conducted through a questionnaire administered to the personnel of 16 out of 19 hospices in Emilia Romagna (2 hospices did not reply; one was opened in 2011). All hospices opened in or after 2001, the last one in 2008. Hospice capacity ranged from 8 to 30 beds, with a mean value of 12 beds (8).

No validated questionnaire evaluating the difficulties of operators during their encounter with patients of different cultures existed in literature, so a specific questionnaire was designed by the authors (*Appendix*). The questionnaire, in the form of a semi-structured interview concerning experiences and difficulties within cross-cultural encounters, contained a section for all care team members and one for team leaders. The section for team members was designed to recognize the separate phases of assistance at which the main difficulties were encountered and the type of difficulties. In the questionnaire the duration of employment in hospices and the number of immigrants assisted by each operator were recorded.

Two hundred and fifty-two hospice operators (67% of the total number of operators in the hospices) completed the questionnaire. Among these operators 9 team leaders (5 physicians and 4 nurses) were identified from 9 hospices.

Table 1. Personal and professional data of the operators participating in the survey.

Profession	Number (%)	Sex: Male-Female	Mean age in years (range)	Mean time of employment in hospice in months (range)	Mean duration of experience in PC in months (range)
Physician	34 (13)	14-20	47 (32-67)	86.09 (3-180)	117.9 (10-300)
Nurse	106 (42)	13-93	38 (23-56)	55.9 (1-132)	65.6 (1-276)
Nurse assistant	82 (32)	10-72	46 (29-65)	59.5 (1-126)	61.7 (1-126)
Others	30 (12)	4-26	41 (23-64)	50.6 (1-120)	70.5 (5-264)
Total	252 (100)	41-211	42 (23-67)	60.41 (1-180)	72.02 (1-300)

Statistical analysis

Descriptive techniques were employed to estimate the frequency distributions of individual cases and related figures (minimum, maximum and mean values and percentiles). The Mann-Whitney test was employed for continuous variables to determine if the mean values for two groups of responders differed significantly. Multivariate frequency distributions of variables were analysed through Cross-tabulation; the Chi-square test was used to verify the significance of differences between observed values and those expected under the assumption of "statistical independence" among variables. Two threshold values were considered for a probability value "p" computed by statistical tests: a weak dependency for $0.05<p\leq 0.1$ and a strong dependency for $p \leq 0.05$.

Results

Out of 252 responders 41 were males and 211 females. Operators' ages ranged from 23 to 67 years, with a mean of 42 years (38 years for nurses and 47 years for physicians). Thirty-four operators (13% of responders) were physicians, 106 (42%) nurses, 82 (32%) assistant nurses. Of the remaining thirty, 13 (5%) were psychologists, 5 (2%) physiotherapists, 2 (0.8%) volunteers and 10 (4%) operators did not specify their role. (Table 1).

Hospice employment ranged from 1 to 180 months (15 years) with a median of 48 months (4 years) and the time of experience in palliative care ranged from 1 to 300 months (25 years), with a median of 60 months (5 years).

Two hundred and forty-two responders (96%) reported having assisted at least one foreign patient during their hospice work : 115 operators (about 47%) had cared for 1 to 5 patients, 84 operators (about 35%) for 6 to 10, 16 operators (about 7%) for 11 to 15, 17 operators (about 7%) for 16 to 20 and 9 operators for more than 20 (Figure 1).

Through 2011, 326 immigrant patients had been admitted to the hospices. The number of foreign patients admitted during the years of activity at every hospice ranged from 6 to 46 patients (mean value 19.3). The average number of immigrant patients admitted to every hospice ranged from 0.9 to 5 patients per year (mean of 2). Immigrant patients constituted 0.8% to 2.6% of hospice patients across sites, with a median of 1.6% admitted from 2000-2011. Forty-nine percent of patients came from Eastern Europe (Albania, Romania, Moldova, Ukraine); 15% from Northern Africa (Morocco, Tunisia, Libya) 21% of patients came from Germany, France, Switzerland, Spain; 8 % from Central and Southern Africa (Cameroon, Ghana, Senegal, Ethiopia, Eritrea, Ivory Coast); 8% from Asia (China, India, Korea, Bangladesh, Pakistan). Less than 5% of

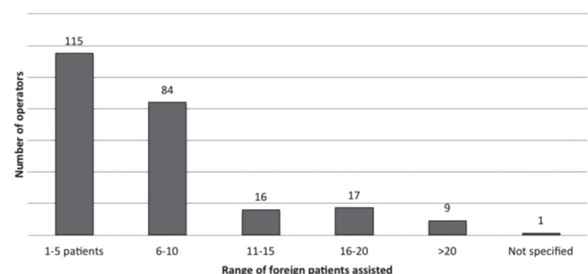

Figure 1. Number of foreign patients assisted in hospice by survey responders.

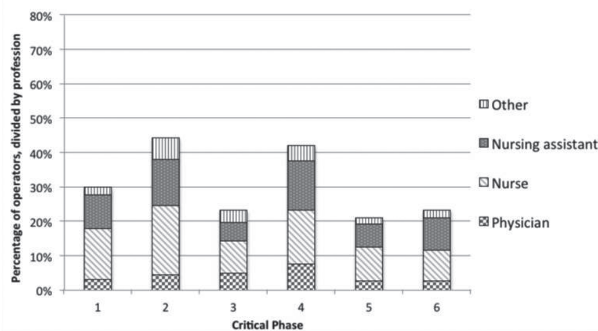

Figure 2. Percentage of operators finding difficulties in assisting immigrant patients. Critical phases: 1. Admission; 2. Hospitalization; 3. Discharge; 4. Death; 5. Grieving process; 6. None (Statistical analysis: see text).

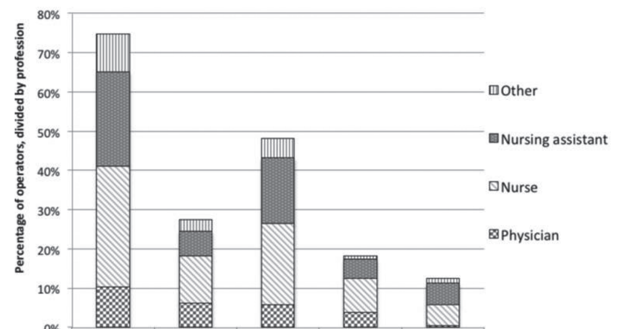

Figure 3. Percentage of operators finding difficulties in assisting immigrant patients. Critical areas: 1. Language barriers; 2. Identification of designated caregivers; 3. Relational aspects; 4. Patient's socio-economic status; 5. None (Statistical analysis: see text).

patients came from Central and Southern America or the Middle East.

Phases of assistance identified as critical

Out of 224 respondents to this specific question, 172 operators (about 77%) indicated difficulties in at least one critical phase of the assistance process: hospitalization (44%), death (42%), admission (30%), discharge (23%) and the grieving process (21%). A remarkable 23% of respondents claimed to have encountered no difficulties during any phase (Figure 2).

Admission was cited as critical by 35% of nurses and 29% of assistant nurses versus 22% of physicians; hospitalization was critical for 48% of nurses and 40% of assistant nurses versus 31% of physicians (p=0.080).

Discharge and death were considered critical by physicians (34% and 53%) more than by nurses (22% and 37%) and assistant nurses (16% and 42%) (p=0.080 and p=NS).

Assisting families during the grieving process proved difficult for about 20% of all professional categories.

Difficulties experienced in caring for foreign patients

Out of 241 respondents to this question, 211 (about 88%) reported having encountered difficulties in providing care to foreign patients in at least one area of patient management. Language barriers preventing effective communication were cited by 75% of responders. Other critical areas concerned relational aspects (48%), identification of designated caregivers within the family (27%) and patient's social problems (20%). Notably, 12% reported not having encountered any difficulties in these areas (Figure 3).

No differences were found among professional categories with regard to difficulties concerning language, relationships and social issues. Physicians, more than other hospice operators, reported difficulty in identifying designated caregivers (p=0.040). Those who indicated the relational area as most critical encountered these difficulties with 74% of patients, 71% of family members and 34% of designated caregivers within the family. When asked whether problems concerning culture, religion or spirituality had emerged, about 47% of responders (14 missing data) answered affirmatively.

Team leaders' perspectives

Nine team leaders (5 physicians and 4 nurses) from 9 out of 16 hospices responded (seven hospices did not specify their team leader). Differences in answers to the common section provided by team leaders and other hospice operators were not statistically significant.

When asked whether they had requested any expert consultation to solve difficulties or help with patient and family management, 7 team leaders reported

Table 2. Correlation between difficulties and months of employment in hospice (Mann-Whitney U test).

	One or more problems during the assistance	None	One or more problems in critical areas	None
Months of employment in hospice (mean ± ds)	67.07 ± 38	49.31 ± 43	64.57 ± 39	48.87 ± 42
Problems *vs* none (p value)		0.002	0.026	

consulting a cultural mediator, 7 a family leader, 3 a religious minister and 2 a community leader. When asked to rate the contribution of patients' and families' socio-economical status (SES) with regard to potential difficulties, 6 out of 9 found SES not to be important, while for 3 SES was highly relevant.

Six team leaders had been asked by fewer than 25% of patients or families if they might return to their native country to die, 1 by 50%, 2 by none. Requests seemed to be prompted by logistic and economic problems of dying in Italy (6/9) and by patients' or families' unawareness of prognosis (4/9). Eight team leaders believed that most patients did not make such a request due to difficulty in obtaining adequate care or proper medication in their native country.

Team leaders were questioned about whether or not they had found adequate solutions to difficulties in caring for patients from different ethnic and cultural backgrounds admitted to their hospices. Seven out of 9 reported having found a solution, the nature of which was unspecified as our survey was only meant to assess team leaders' engagement in problem-solving.

Experience of hospice operators

As reported in Table 1, hospice operators' experience was measured as time of employment in hospices. The mean value for time of employment in hospices was about 60 months. The number of foreign patients cared for by each operator increased with the time of employment in hospices.

Operators who had encountered difficulties in one or more phases of foreign patients' hospital stay had worked in hospices longer than those who did not report any problems (67 versus 49 months respectively)(p=0.002) (Table 2).

Similarly, those who had encountered difficulties in one or more areas of their relationship with foreign patients and families had also worked in hospices longer than those who did not report any problems (64 versus 49 months respectively) (p=0.026).

Discussion

In Western countries cultural diversity poses numerous challenges when it comes to providing equal health care (1, 2, 6, 9). US studies show that cultural diversity of both patients and health providers results in increasing opportunities for discord between clinicians, patients and their families based on different cultural values, beliefs, practices and ethical standards. Patients find difficulty in navigating through our Western health systems and are often denied access to adequate cancer and palliative care. Oncology and PC professionals need to acquire cultural competence to provide optimal care and advocacy for their patients (10).

Today, most immigrants in Italy are healthy and young due to sociodemographic factors. In the future, however, their number will increase, as will the age of long-term immigrants, and more immigrants will be cancer sufferers *(Dr. S. Candela- Department of Public Health, Reggio Emilia, personal communication).* The consequence of this migratory flux could amplify problems in delivering PC and EOL care for people with different cultures in Italy as in other Western countries. The present study is the first research carried out in Italy on this issue. It focused on difficulties that arose during hospitalization of immigrant patients in 16 Emilia-Romagna hospices from 2001 to 2011. The percentage of legal immigrants is higher in this than in other Italian regions, and illegal immigrants are also present (7). Despite the inevitable bias due to the retrospective nature of our study and the limited

number of patients, our results shed light on the presence, frequency and nature of some of the difficulties encountered by hospice operators in caring for immigrant patients and help us identify areas of weakness in which to improve (11-15).

This study shows that many hospice operators in Italy report difficulties in understanding the needs of foreign patients and their families during the communication process.

Physicians said they encountered more difficulties than other hospice operators during the patient's dying phase, whereas nurses and assistant nurses found managing admission and hospitalization to be the most difficult phases. In Italy, the latter are mostly involved in the practical management of patients, from providing special meals according to cultural habits, to delivering same gender personal care, dealing with large families, often overcrowding the patient's room and tending to speak on behalf of their sick relative, as well as finding appropriate space for patients to use for praying, gathering or expressing grief (16-19).

For physicians, communication about death and dying is rendered more difficult by cultural and language barriers (20-22). Though Italian physicians are used to differences between Northern and Southern Italian regions in disclosure, patient awareness and choice of place to die, the cultural perceptions, expectations and practices of foreign immigrants at EOL pose additional challenges (9, 23, 24).

Almost 50% of our hospice operators reported difficulties in facing cultural, religious or spiritual aspects of EOL care for foreign patients. Remarkably, team leaders claimed that a solution had been found in the majority of the cases (7/10). This information must be interpreted with caution, however, since our survey did not require respondents to specify either the nature of the problem or the solution found.

Probably one of the most important problems is language. As the majority of immigrant patients spoke non-European languages that are not taught in Italian schools, difficulties did not correlate with the various operators' education. The problem of the language barrier is not easy to solve. In most cases, family or community members were involved in translating medical information. Studies confirm, however, that relatives and friends often translate selectively what doctors or nurses say, due to lack of health literacy or in order to protect the patient from painful information (1,15). By contrast, the use of professional interpreters may be perceived as breaching cultural norms or endangering privacy. Oncologists and PC professionals must therefore learn how to include interpreters in the team and to include them alongside patients and families as cultural mediators who can help solve difficulties and not only to be simple translators of the language (2, 3, 16).

One unexpected result of our study is that the percentage of operators finding difficulties in caring for immigrant patients and families was higher among those who had more experience in hospices. While the reliability of this result is limited by the low number of immigrant patients admitted to the hospices in Emilia-Romagna during the study period, these data suggest that operators with more experience may be more sensitive in perceiving difficulties and more honest in reporting them. Yet they may lack adequate teaching and training in how to handle such difficulties. Studies show that specific training can be more influential than experience when it comes to increasing operators' ability to care for patients from different cultures (6, 25-32).

Many operators reported the need to acquire specific cross-cultural communication skills at EOL. In Italy, education in palliative medicine has been a historical lacuna in medical and nursing curricula. Some universities have started courses on PC and communication, but they are still not mandatory and are usually brief and unsystematic (33-35).

Appendix

1. Name and last name (not mandatory)						
2. Job						
3. Place and date of birth						
3a. If you were not born in Italy, how long have you been living here?						
4. In which hospice are you employed?						
5. How long have you been working in this hospice?						
6. How long have you been working in Palliative Care?						
7. During your experience in hospice have you taken care of foreign patients by birth, residence, or with a different cultural background than yours?						
8. How many times has this occurred?	Never	1-5	6-10	11-15	16-20	More than 20
9. Have you experienced any problems in one or more stages of the process of care?	Admittance	Hospitalization	Discharge	Death	Grieving process	None
10. Were there problems in any of these areas?	Language	Identification of caregiver	Relationship	Social	None status	
11. If you have had any relational problems, with whom have they occurred?	Patient	Caregiver	Family	Others (specify)		
12. What matters have you had problems about?						
13. During the assistance were there any problems concerning culture, religion or spirituality?	Yes	No				
14. What skills do you think are needed to achieve the best care for patients of different cultures?						
Questions to be answered only by each hospice team leader:						
15. Was any of these counsellors' advice needed?	Minister of religion	Family leader	Community leader	Cultural mediator	Others (specify)	None
16. Were the patient and family's possible social issues relevant during the process of care?	Not relevant	Not very	Very	More relevant than other problems		
17. How many patients asked to return to their native country?	None	<25% of the patients	50%	>75%		
18. Was this related to any of these problems?	Unawareness of prognosis	Logistical problems	Economical problems	Difficulties in providing care in the native country	Difficulties in getting medications	Others (specify)
19. Which strategies were adopted to deal with these issues?						
20. Could you find a solution ?	Yes	No				
21. If not, why so?						

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