

Awareness, understanding and attitudes of Italians regarding palliative care

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Summary. There are numerous difficulties encountered in the diffusion of palliative care (PC) in developed countries. A correct and widespread awareness of PC among the general public represents an important factor for its enhanced diffusion and use. The aim of this study is to verify the level of awareness of PC among Italians and their perception of the needs of patients with incurable illness. A random sample of 1897 adult subjects, aged 18 to 74 years, representative of the Italian population, was interviewed after stratification by gender, age (6 strata), education (3 levels), geographic area of residency (4 areas) and town of residency (4 dimensions). 59.4% of those interviewed had heard of PC, but only 23.5% of them believed that they had an adequate or precise idea of what PC is; 27% of them did not know or had a mistaken idea about the nature of PC. The most accepted perception was that PC alleviates pain and improves quality-of-life. The principal concerns attributed to incurable patients were: fear of suffering and of death, and the principal needs were perceived as: relief from pain and physical suffering. The primary needs of the family were identified in: medical and nursing care at home, followed by: care provided by volunteers and psychological support. The most appropriate care-setting for these patients was indicated as their home, possibly with the support of professional carers. In the case of children, the main concern indicated was that of being "separated" from family, friends, home and toys. Only 45.2% of interviewees thought that they knew a person who had experienced PC. In conclusion, the awareness of the Italian population of PC is scarce and often incorrect. In order to achieve a greater diffusion and better use of PC in our country, this awareness needs to be improved by appropriate intervention.

Key words: palliative care, public awareness, italian survey.

Riassunto (*Percezione, comprensione e attitudine degli italiani riguardo alle cure palliative*). Esistono numerose difficoltà nella diffusione delle cure palliative (CP) nei paesi occidentali. Un importante impulso al loro utilizzo è rappresentato da una corretta divulgazione e una diffusa conoscenza presso la popolazione. Lo scopo di questo studio è verificare il livello di consapevolezza degli italiani sulle CP e la loro percezione dei bisogni dei malati inguaribili. È stato intervistato un campione random di 1897 soggetti adulti (18-74 anni) rappresentativo della popolazione italiana, dopo stratificazione per genere, età (6 strati), istruzione (3 livelli), area geografica di residenza (4 aree) e grandezza della città di residenza (4 dimensioni). Il 59,4% degli intervistati aveva sentito parlare di CP; tuttavia, solo il 23,5% aveva una sufficiente o precisa idea di cosa fossero mentre il 27% non lo sapeva o ne aveva un'idea errata. La percezione più diffusa era che le CP servissero per alleviare il dolore e per migliorare la qualità della vita. Le principali paure attribuite ai pazienti inguaribili adulti erano quella della sofferenza e della morte, mentre i loro principali bisogni erano il controllo del dolore e della sofferenza fisica. I principali bisogni della famiglia erano invece l'assistenza medica e infermieristica domiciliare, seguita dall'aiuto dei volontari e dal sostegno psicologico. Il domicilio è risultato essere il luogo più appropriato dove assistere questi malati possibilmente con il supporto di personale sanitario professionale. Nel caso dei bambini inguaribili, la principale paura attribuita era quella dello "sradicamento" dalla famiglia, dagli amici, dalla casa e dai giochi. Solo il 45,2% degli intervistati ha dichiarato di conoscere qualcuno che ha intrapreso le CP. In conclusione, questo studio effettuato nel 2008, ha dimostrato che il livello di conoscenza degli italiani sulle CP è spesso errato o incompleto e ha evidenziato che, nel nostro paese è necessario accrescerne la conoscenza e la diffusione, ed implementarne l'utilizzazione attraverso interventi appropriati e dedicati.

Parole chiave: cure palliative, conoscenze pubbliche, indagine italiana.

INTRODUCTION

The broad utilization of palliative care (PC) not only depends on the number and quality of services provided by the healthcare system but is also heavily influenced by attitudes toward PC and levels of public awareness of its aims and positive benefits for patients.

The World Health Organization defines PC as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [1]. PC is focused on caring, not curing; its goal is to provide the best possible quality of life, by ensuring the comfort and protecting the dignity of patients with life-threatening or life-limiting diseases and by providing support for their family members. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes investigations needed to better understand and manage distressing clinical complications. The WHO recommends PC also in children with life-threatening or life-limiting illness: “Paediatric PC is the active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not the child receives treatments directed to the disease” [1].

Despite evidence demonstrating its effectiveness and strong recommendations for its broad application, PC is still not widely available. Even today, only a small proportion of patients with incurable illness can actually access PC services. Many of them live and die in inadequate conditions, without relief from distressing symptoms, usually in a hospital setting and rarely at home. Multiple cultural, organizational, educational and economic reasons have given rise and have influenced the persistence of these shortcomings in patient care [2-10]. It is widely acknowledged that changes in attitudes and in the management of healthcare and social issues, accompanied by a correct diffusion of public information, can greatly influence the demand for and the use of PC services.

The purpose of this study was to examine the level of public awareness, understanding and attitudes of the Italian population regarding PC.

METHODS

The study was part of a larger survey carried out in the spring of 2008 on the attitudes and habits of the Italian population regarding a number of topics through a series of questions posed by staff from the Sociological Research Institute (Istituto di Ricerca Sociale GPF), specifically trained in the use of the questionnaire to guarantee homogeneity in its application.

The subjects for this study were obtained by random selection of a sample of 1897 individuals, aged 18 to 74 years, representative of the Italian population, after stratification for gender, age (6 strata), education (3 levels), geographic area of residency (4 areas) and number of inhabitants of the town of residency (4 dimensions).

All the subjects interviewed were asked to answer the following 9 questions (8 closed and 1 open):

- 1) *levels of awareness of PC*: choose among the following sentences the one that best corresponds to your level of awareness of PC: never heard of it; only know it by name; I have a vague idea; I have a reasonable idea; I have a clear idea (closed question; only one answer);
- 2) *perceptions of PC*: on the basis of what you know or believe, describe what you think that PC is (open question asked only to those who at least heard of PC; more than one answer allowed);
- 3) *the objectives of PC*: from among the following sentences, choose the one that, in your opinion, describes the aims of PC: I don’t know; it delays death; it accelerates death; it permits terminal patients to conduct an active life; it reassures the patient; it improves the quality-of-life of unwell people (closed question; only one answer);
- 4) *the worries of incurable patients*: what do you think are the principal concerns of a person who has been diagnosed with incurable illness? Select and put in order of importance (1st, 2nd, 3rd) three of the following: fear of pain; fear of death; fear of not being self-sufficient; fear of losing consciousness; fear of loneliness; fear of becoming disabled; fear of not having sufficient economic resources; fear of becoming a nuisance; I don’t know (closed question);
- 5) *the needs of terminal patients*: what do you think are the main needs of terminal patients nearing the end of their lives? Select and put in order of importance (1st, 2nd, 3rd) three of the following: relief from physical suffering; specialist medical care; medical and nursing care at home; support for the family carers; support from a psychologist; spiritual support; I don’t know (closed question);
- 6) *the needs of the families of terminal patients*: what do you consider to be the main needs of families caring for a terminally-ill family member? Select and put in order of importance (1st, 2nd, 3rd) three of the following: around the clock, specialist, medical care; nursing care at home; availability of voluntary carers; dedicated, residential centres; psychological support; bereavement support after the patient’s death; I don’t know (closed question);
- 7) *place of care*: in your opinion, which of the following is most appropriate care-setting for the care of terminally-ill patients: at home by family members; at home by professional carers; hospice; hospital; I don’t know (closed question; only one answer);

Table 1 | Composition of the sample of 1897 adult individuals interviewed. The sample reflects the general composition of the Italian population

Gender	Males	48.8%
	Females	51.2%
Age (Years)	18-24	9.8%
	25-34	21.0%
	35-44	20.7%
	45-54	18.1%
	55-64	16.1%
Level of education	65-74	14.1%
	Basic (5-8 years)	50.1%
	Intermediate (13 years)	37.2%
Geographic area of residency	Academic (17-19 years)	12.7%
	North-West	26.8%
	North-East	18.9%
	Centre	19.6%
Number of inhabitants of the town of residency	South and Islands	34.7%
	< 10 000	32.7%
	10 000-30 000	22.5%
	30 000-100 000	21.0%
	> 100 000	23.8%
Annual income (data not shown) has been subdivided in quintiles.		

- 8) *acquaintance of a person experiencing PC*: are you aware of at least one person from your circle of family, friends or acquaintances that has personally experienced PC? (closed question, yes/no);
- 9) *paediatric palliative care*: when the terminally ill patient is a child, what do you think are their principal concerns? Select and put in order of importance (1st, 2nd, 3rd) three of the following: fear of being taken away from his/her family; fear of no longer having other children to play with; fear of being away from his/her home and toys; fear of pain and physical suffering; fear of being alone, fear of being abandoned; fear of death; fear of becoming disabled, fear of not being able to walk anymore (closed question).

Annual income was also investigated and subdivided in quintiles.

Statistical evaluation of the results was performed by χ^2 analysis where applicable.

RESULTS

The profile of the sample of 1897 adult subjects interviewed is shown in *Table 1*. The sample composition was similar, and not statistically different, from that of the whole Italian population.

Figure 1 shows the distribution of the answers to the first question concerning levels of awareness of PC. More than 40% of the persons interviewed had never heard of palliative care and only 23.5% of them declared having an adequate or precise idea of what PC is. The distribution of individuals who had a reasonable or precise idea of the nature of PC was not uniform across the sample and was significantly different from that of those who had never heard of it or had no or only a vague idea about PC: women were more aware than men, as were individuals aged between 45 and 64 years, those with a higher level of education and living in the North-West or in the Southern regions and islands. Individuals with higher income were also overrepresented (*Table 2*).

The answers to the second question on the perception of PC varied and included sentences like: care that does not have a curative effect, care for terminal patients, care that can improve the final phase of life, care for patients who will not recover, it is not a real care since it does not cure. These answers could be assigned to 3 general categories: care that does not cure, care for terminal patients and care for patients that will not recover.

The answers to this question by subjects who declared to have a reasonable or precise idea of the nature of PC differed significantly from those of subjects who had a vague or no idea ($\chi^2 = 551.6$; $p < 0.001$). However, for both groups the prevalent identification of PC was with “the treatment of pain and improved of quality of life”.

The answers to the third question, on the purpose and aims of PC, are shown in *Figure 2*. Even with the help of some definitions, more than 27% of the people had no idea or had a wrong idea of the objectives of PC. On the other hand, the answer to this question, “PC improves the quality of life of incurable patients”, was the one most frequently indicated (38.7% of interviewed). This answer was not evenly distributed among the different strata of the sample: it was most frequently identified by individuals aged 25 to 54 years (41.5% vs 34.6% of other ages; $p < 0.02$) and by those

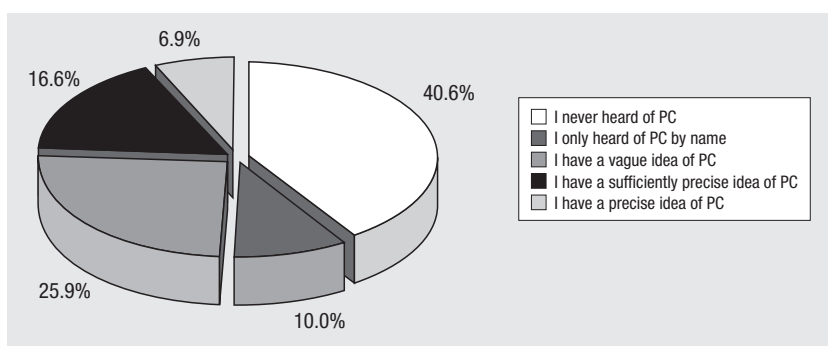


Fig. 1 | Level of knowledge of palliative care (PC). Answers to question no. 1: “Choose among the following sentences the one that best describes your level of knowledge of palliative care (closed question; only one answer allowed)”.

Table 2 | Comparison between the composition of the group of 446 adult individuals (23.5%) that declared to have a reasonable or precise idea of the nature of palliative care (PC) and the other 1451 individuals (76.5%) interviewed who had no or a vague idea of PC

		Those with sufficient or precise idea (%)	Those with no or vague idea (%)	p
Gender	Males	44.3	50.2	< 0.001
	Females	55.7	49.8	
Age (years)	18-24	7.2	10.6	< 0.001
	25-34	20.3	21.2	
	35-44	20.8	20.7	
	45-54	23.2	16.6	
	55-64	17.8	15.8	
	65-74	10.7	15.1	
Level of education	Basic	37.2	54.0	< 0.001
	Intermediate	39.9	36.4	
	Academic	22.9	9.6	
Geographic area of residency	North-West	29.2	26.1	< 0.001
	North-East	24.7	17.2	
	Centre	23.8	18.3	
	South and islands	22.3	38.4	
No. inhabitants of the town of residency	< 10 000	34.4	32.1	NS
	10 000-30 000	20.6	23.1	
	30 000-100 000	18.0	21.9	
	> 100 000	26.9	22.9	
Annual income (1 st quintile: lowest; 5 th : highest income)	5 th quintile	24.3	18.7	< 0.001
	4 th quintile	25.1	18.4	
	3 rd quintile	22.9	19.1	
	2 nd quintile	13.0	22.1	
	1 st quintile	14.7	21.7	

with higher income (42.7% in the 4th and 5th quintile vs 35.9% in the others; $p < 0.003$) and showed a significant correlation with the level of education (33.8% among those with basic education, vs 42.3% among those with intermediate education vs 47.5% among those with academic education; $p < 0.01$).

The answers to the fourth question are depicted in Table 3. Fear of physical suffering and fear of death were the principal concerns attributed to patients with incurable disease, followed by the fear of losing independence.

The answers to the fifth question, relating to the needs of terminal patients, are shown in Table 4. By far the most significant need attributed to patients in the terminal phase of their disease was: relief from

pain and distressing symptoms. The need for medical and nursing care at home was also deemed important as well as support for the family caring for the patient at home.

Concerning question number 6, on the needs of the family of terminal patients, medical and nursing care at home were indicated as the principal needs, but the availability of volunteer carers and a dedicated, residential centre for these patients were also considered important. Psychological support for the family was also indicated as a significant need (Table 5).

The answers to question number 7 indicated that the home is the preferred care-setting for incurable patients, cared for either by the family (45.6%) or by expert carers (28.7%); only 15.2% and 6.1% respec-

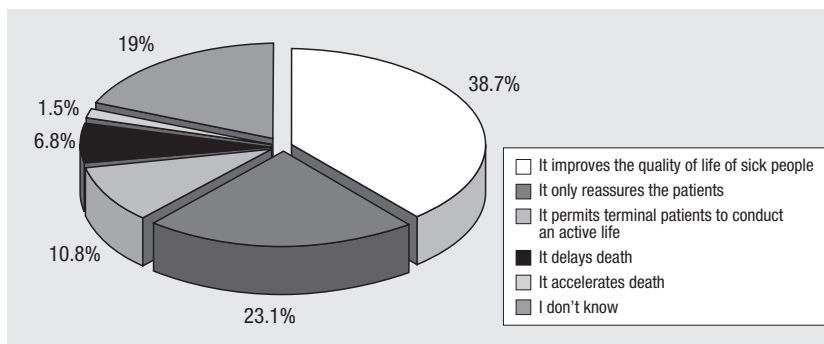


Fig. 2 | Purpose of palliative care (PC). Answers to question no. 3: "Choose among the following sentences the one that best corresponds to your opinion on what is the objective of palliative care (closed question; only one answer allowed)".

Table 3 | Answers to question no. 4: Fears of incurable patients. What do you think are the principal fears of a sick person who has no chance of recovery? (closed question; indicate 1st choice and also 2nd and 3rd choice)

	1 st choice (%)	2 nd -3 rd choice (%)	Total (%)
Fear of pain	33.3	39.7	70.0
Fear of death	40.9	24.1	65.0
Fear of not being self-sufficient	10.8	41.4	52.2
Fear of loneliness	4.0	26.3	30.3
Fear of becoming invalid	3.4	20.0	23.4
Fear of not having sufficient economic resources	2.4	15.7	18.0
Fear of becoming displeasing	1.1	8.1	9.2
I do not know or other answers	4.1	-	4.1

Table 4 | Answers to question no. 5: needs of incurable patients. Among the following, indicate the most important need of a sick person at the end of his/her life; also indicate the one that you would put in 2nd place (closed question)

	1 st choice (%)	2 nd choice (%)	Total (%)
Reduce physical suffering	59.7	11.8	71.5
Special medical assistance around the clock	14.0	26.4	40.4
Medical and nursing assistance at home	8.5	23.3	31.8
Support for the family that assist him/her	5.1	18.2	23.3
Support by a psychologist	6.5	9.5	16.0
Religious support	3.1	7.8	10.9
I do not know	3.0	-	3.0

tively indicated the hospice or the hospital as the preferred setting.

Question number 8, asked if the subjects knew anyone from among their friends or family members who had experienced palliative care: 54.8% of the interviewed affirmed not knowing anybody that had experienced PC; however, it is likely that this figure represents an overestimation due to the poor awareness of the nature of PC by those interviewed.

Question number 9 is concerned with the fears of children with incurable illness as perceived by adults. The results show that the main concern attributed to children is that of being “uprooted” from their family, friends and home. This predominates over the fear of

pain or physical suffering and fear of death (Table 6). The fear of being abandoned was also present.

DISCUSSION

Awareness and perception of Palliative Care (PC) among the Italian population is inadequate; less of 60% of adults had heard of PC, but only 7% of them believed that they had a precise idea and another 16% thought that they had an adequate idea of what PC is.

Awareness of PC was more diffused among women, middle-aged people, those with a higher income, a higher level of education and residing in the North-West and the South of Italy.

Table 5 | Answers to question no. 6: family needs of a terminal patient. Among the following needs indicate the most important one for the family members that assist a sick person in the terminal phase of his/her life; also indicate the one that you would put in second place (closed question)

	1 st choice (%)	2 nd choice (%)	Total (%)
Special medical assistance around the clock	28.8	15.8	44.6
Nursing assistance at home	24.3	20.3	44.6
Volunteers for shifts of assistance	9.3	21.0	30.3
Special structure to admit the patient	10.6	18.0	28.6
Support by a psychologist	16.0	10.6	26.6
Religious support	6.4	6.6	13.0
Support after the death of the patient	1.1	4.3	5.4
Do not know	3.4	-	3.4

Table 6 | Answers to question no. 9: paediatric palliative care. When the sick person with no chance of recovery is a child, indicate among the following fears the one that you think is the principal one and also the one that you would put in second and third place (closed question)

	1 st choice (%)	2 nd -3 rd choice (%)	Total (%)
Fear of being away from parents and family	29.1	42.5	71.6
Fear of not being able to stay with other children	17.7	38.5	56.2
Fear being away from home and his/her toys	5.2	35.2	40.4
Fear of pain, of physical suffering	16.8	22.7	39.5
Fear of becoming invalid	3.4	20.0	23.4
Fear to be alone, to be abandoned	8.3	29.0	37.3
Fear of death	13.6	9.7	23.3
Fear of becoming invalid, not able to walk	3.4	9.6	13.0
I do not know	5.9	-	5.9

The majority of the people interviewed were not able to define PC in his/her own words. There was a tendency to identify PC with treatment of physical pain and also with treatments aimed at improving quality-of-life, but some people also gave the definition of PC as an “alternative” therapy or some sort of psychological support, almost a placebo. However, the connection of PC with the care of incurable patients, as care not aimed at curing the disease but only at relieving its symptoms, was relatively frequent.

Even with the help of definitions (both correct and incorrect) less than 20% of the interviewed were able to correctly define PC; the most prevalent definitions were that PC can improve quality-of-life and reassure terminal patients. Here again, gender, socio-economic and educational factors seemed to influence the ability to provide a correct definition.

The two main concerns of adult, terminal patients were identified as: fear of pain and suffering, and fear of death. In the case of children, adults believed that the most prevalent fear was that of being “uprooted”: of being separated from parents, friends, home and toys. This prevailed over fears of physical pain (probably only attributed to acute interventions) and that of death (a difficult concept to be understood by a child).

Coherent with the concerns attributed to incurable patients, the major need identified was that of relief from pain and distressing symptoms. The need for effective care at home by professional carers, either physicians or nurses, was also considered important.

The need for care at home with the support of professional carers was also believed to be equally important for the family, immediately followed by the help and support of volunteers or the admission of the patient to a dedicated centre.

For the vast majority of those interviewed, the best care-setting for an incurable patient was his/her home, with care provided either by the family members or by professional carers. There was however a significant minority (21%) that believed that the patient is better cared for in hospice or in hospital. This option was indicated more frequently by people

with a higher income or residing in the North-West, despite the fact that in Italy the greatest number of PC services and hospices are located in the North-East of the country.

A few studies similar to this have been performed in Italy and other countries on smaller groups of subjects [2-10]; however, they suffer from severe selection biases and therefore are not representative of the entire population. Our method of sampling guarantees that the results of our survey can be projected, with a reasonable approximation, to the whole population of Italy.

Generally, the results of our study do not differ substantially from those of the literature, which have all shown an inadequate, although variable, awareness of PC among the general public [2-10]. Furthermore, our results indicate that gender, age, economical and educational level, as well as area of residency, are significant factors for enhanced awareness of the nature and aims of PC. These factors are also important for the indication of where adult patients with incurable disease are best cared for. There seems to be two different attitudes: on one hand, there is a population who is economically well-off, residing in the North of the country, who expect technically advanced, “less personal” care, away from the family in a dedicated centre; and on the other, a less wealthy and more “grassroots” population, residing in the South of Italy, who believe that patients should not be separated from their home and family.

This difference in attitudes may also reflect the different distribution of hospices in Italy. There are over 150 hospices in the country (mostly dedicated to adult patients with terminal cancer and only one dedicated to children with incurable illness), which are prevalently located in the Centre-North of Italy.

Inadequate awareness and perception of PC may have an important impact on its use by incurable patients and their families. In fact, public awareness and attitudes may influence the entire system from access and use to palliative care services to health-care policy and service provision for the patients and their families. Furthermore, mass-media representation of the end-of-life phase and of dedicated

services provided for terminal patients both reflects and influences social attitudes. By establishing low expectations for quality-of-life, these attitudes may impair the understanding of the positive benefits of PC and act as barriers between PC services and the patients and their families during the terminal phase of illness [11].

Rather than pursuing palliative treatments aimed at improving quality-of-life and protecting the dignity of incurable patients, the scarce awareness and poor perception of PC directs patients and families to medical interventions in specialized centres which are usually oriented towards intensive, curative treatments.

A number of initiatives aimed at improving this state of affairs can be envisaged, such as: public awareness campaigns, legislation, economic investments etc., but the literature on the effectiveness of these and other kinds of interventions is scarce.

The Italian Parliament has recently passed legislation that regulates the provision of palliative care and pain management for adults and children with incurable illness. This new legislation has been am-

ply discussed and publicised by the mass media. It will be interesting to replicate our survey to evaluate if this important event has contributed to improving awareness and the perception of palliative care in the Italian population.

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Conflict of interest statement

The Authors declare that there is no conflict of interest.

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