Italian Palliative Care Services: The Role of Patients’ and Professionals’ Views in Health Technology Assessment Scope Development

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Background: Palliative care services are growing, but vary across Europe. They can reflect different social needs, cultures, religious beliefs and legal contexts. However, there is a need to establish which models of service provision are most effective to support decision making. Health Technology Assessment (HTA) is a “multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner” [1]. Its aim is “to inform the formulation of safe, effective, health policies that are patient focused and seek to achieve best value” (1). The spread of HTA is worldwide nowadays.

At the moment HTA is sub-optimally equipped for the assessment of complex technologies. INTEGRATE-HTA is a new, innovative, three-year FP7 project [2]. It aims to develop methods to enable an “integrated” assessment of complex technologies. Palliative care is being used as a case study to test the methodology developed within this project.

Stakeholders are those who have interests in a system or issue. The engagement of stakeholders in HTA is widely recommended as it ensures that a large number of perspectives are considered. Nevertheless, stakeholder involvement in HTA processes is often under-developed and under-reported.

Aims: To identify stakeholder views of the key issues impacting on palliative care to inform the INTEGRATE-HTA project scope development. The present work focuses on the findings from participants in Italy.

Design: “Patient” (n=7) and “professional” (n=8) stakeholders aged ≥18 were enrolled as participants in qualitative research. They were directly approached by the local coordinator of the INTEGRATE-HTA Project. The study had the approval of the local Ethics Committee.

Semi-structured interviews, lasting approximately 45 minutes, were either conducted face-to-face or over the telephone. All interviews were audio recorded and notes were taken.

An adapted version of the EUnetHTA core model [3] supported the interviews to identify issues within the following 9 domains: Health problem and current use of technology (CUR), Description and technical characteristics of technology (TEC), Safety (SAF), Clinical effectiveness (EFF), Costs and economic evaluation (ECO), Ethical analysis (ETH), Organisational aspects (ORG), Social aspects (SOC), Legal aspects (LEG).

Responses were transcribed and thematically analysed using key-words or key concepts within each of the different domains. Thematic analysis identified some common issues.

Results:

• ensure that the non-cancer population also have access to palliative care services
• develop greater understanding about the harms of palliative care
• identify what effectiveness means for palliative care services
• provide training and support for family carers (also post bereavement)
• overcome communication difficulties with patients and carers
• ensure practitioners are adequately trained
• enhance recognition of palliative care as a speciality
• ensure easy (e.g. out of hours), equitable (e.g. to all groups) and timely (e.g. not restricted only to the last months of life) access to palliative care
• increase the availability of palliative care services, e.g. increase bed numbers
• improve the organisation of palliative care in terms of co-ordination of, communication & co-operation between services to ensure continuity of patient care
• reduce hospitalisation and increase home care
• improve patient and carer understanding of ethical issues (e.g. discontinuation of futile treatments)
• reduce the stigma of palliative care in society
• implement legislation regulating palliative care.

Conclusions: Interviewing lay and professional stakeholders with experience of palliative care allowed us to identify important topics and to assist the INTEGRATE-HTA project scope development. This engagement will ensure that perspectives of patients, families, carers, professionals will have due consideration within the HTA process.

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