Case study: Qualitative evaluation of organisational models in palliative care

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Background

- At present, palliative care is a fairly widespread practice in developed countries. The way in which each country has developed and organized palliative care varies.
- The effectiveness and cost-effectiveness of palliative care programs and resources should be evaluated just as other health services are evaluated.
- However, identifying and applying appropriate criteria for the evaluation of palliative care involves a recognized challenge, mainly due to the vulnerability of terminal patients and their families and the complexity of their physical and psychological needs that are closely related to social and cultural dimensions.
- Therefore, the use of numerical indicators, valid for other services, has serious difficulties in palliative care.
- These are the reasons why this study is aiming to address the complementary but fundamental values that should be included in the evaluation of palliative care services.

Objective

To assess the quality of palliative care resources from the perspective of healthcare professionals, patients and families/caregivers in order to identify appropriate values for the design and evaluation of palliative care services.

Method options…

- Quantitative vs. semi qualitative vs. qualitative

- Primary study vs. Secondary study

Method

- We chose to do a systematic review of qualitative studies… why?
  - We had the opportunity: Large amount of literature produced previously in palliative care
  - We had an “excuse”: Resources needed for a primary study to achieve our goals was huge
  - We had a need: For health policy it could be more useful

Iterative Process

We began our adventure with some tools with us:

- A compass (team with experts in the field, and trained in the methods)
- A pair of binoculars (to search and find data)
- A sniffer dog (to identify what is relevant in the data to answer the research question)

Iterative Process

Along the adventure we needed to make decisions… which had to be:

- Justified
- Reasonable
- Transparent
- Inductive

Bearing in mind: Lincoln and Guba’ s

Techniques for establishing credibility

- Prolonged Engagement
- Persistent Observation
- Triangulation
- Peer debriefing
- Negative case analysis
- Referential adequacy
- Member-checking

Techniques for establishing transferability

- Thick description

Techniques for establishing dependability

- Inquiry audit

Techniques for establishing confirmability

- Confirmability audit
- audit trail
- triangulation
- Reflexivity

Three little tigers…

First tiger: Retrieving and searching

Where? Based on opportunity and iterative process

Medline, Cinhal, Evidence based medicine, Embase, Psycinfo, ISI web of knowledge, Index to Theses (Great Britain), Social Sciences Citation Index and Science Citation Index, Scopus, ASSIA and *IME*

When? Justify dates

From: 1990 (OMS definition of palliative care)

To: June 2006

How? We were lucky!!!

Search strategy developed by relevant researcher in the palliative care field (Davies & Higginson)

Plus

Filters for qualitative research

Which? Selection criteria

Studies on palliative care with a qualitative approach that allowed the clear identification of any of the healthcare resources in this area. Studies published in English, Spanish or French were considered

Search strategy example OVID-CINHAL
Palliative care in Cancer and…

1) exp Palliative Care/
2) exp Terminal Care/
3) exp Terminally Ill/
4) exp Attitude to Death/
5) exp Bereavement/
6) exp Right to Die/
7) exp Hospices/
8) exp Respite Care/
9) palliat$.tw.
10) Terminal$.mp. and (care or caring or ill$).tw. [mp=title, subject heading word, abstract, instrumentation]
11) Hospice$.tw.
12) Bereav$.tw.
13) Grief.mp. or griev$.tw. [mp=title, subject heading word, abstract, instrumentation]
14) (Attitude$ adj5 (care or caring)).tw.
15) (Support$ adj5 (death$ or dying)).tw.
16) exp Social Support/
17) (Spiritual$ adj5 support$).tw.
18) 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19) exp Neoplasms/
20) Cancer$.mp. or neoplasm.tw.
21) 19 or 20
22) 18 and 21

…Qualitative research filter modified

23) exp qualitative studies/
24) exp qualitative validity/
25) exp phenomenology/
26) exp phenomenological research/
27) exp action research/
28) exp ethnography/
29) exp ethnological research/
30) exp ethnonursing research/
31) exp content analysis/
32) exp thematic analysis/
33) exp field studies/
34) Qualitative.ti,ab.
35) (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).ti,ab.
36) (hermeneutic$ or phenomenolog$ or lived experience$).ti,ab.
37) (Grounded adj5 theor$).ti,ab.
38) (content analys$ or thematic analys$ or narrative analys$).ti,ab.
39) (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).ti,ab.
40) (meta-ethnog$ or metaethnog$ or meta-narrat$ or metanarrat$ or meta-interpret$ or metainterpret$).ti,ab.
41) (qualitative adj5 meta-analy$).ti,ab.
42) action research.ti,ab.
43) or/23-42
44) 22 and 43

Inclusion criteria

Participants

- Patients, caregivers or family who used palliative care services and/or professionals who attend terminal stage patients

Method

- Qualitative design and qualitative analysis.

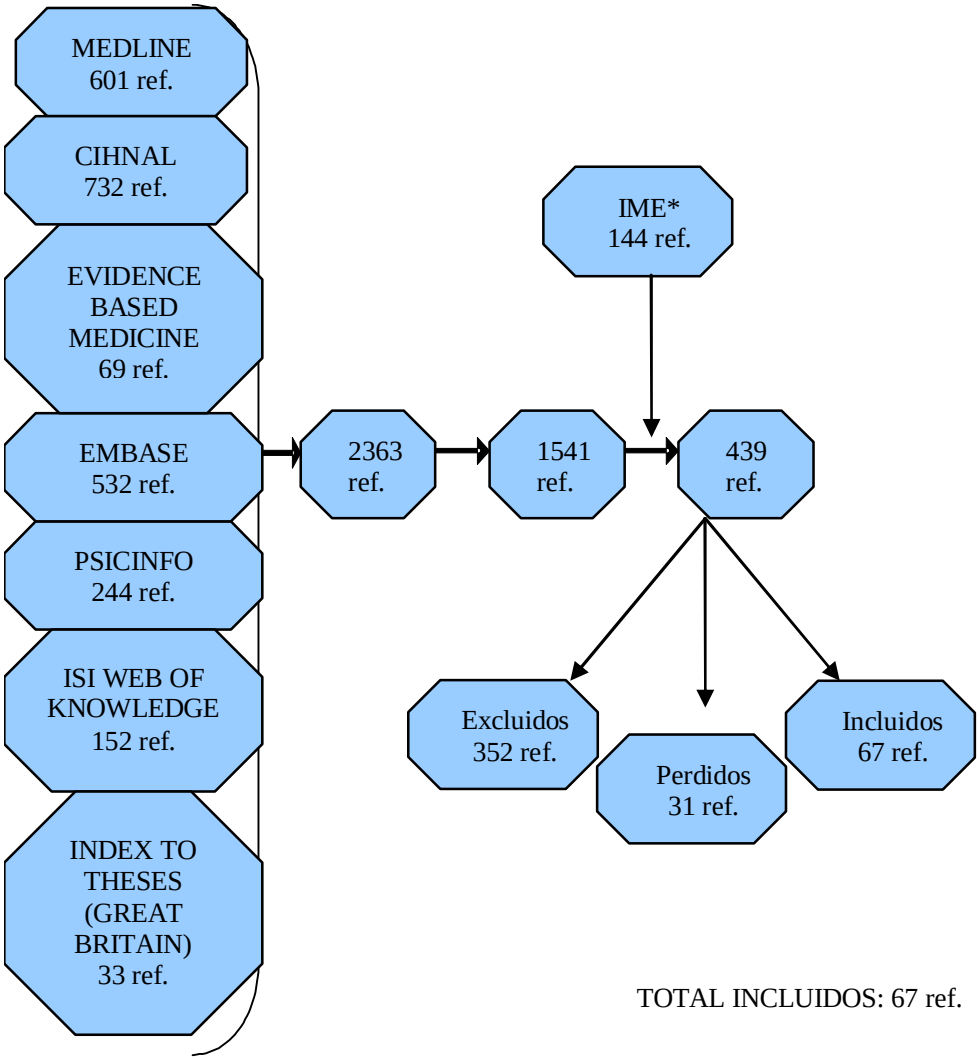
Data

- Opinions, perceptions, values or experiences related to palliative care services.

Hierarchy applied for exclusion of abstracts and full text

1. Do not focus on health care services for patients in terminal stage (-735)
2. The design and / or analysis is not qualitative (-284)
3. Pediatrics (-84)
4. Only address symptom management and not related to health services (-408)
5. Languages other than English, Spanish or French (-10)
6. The study is prior to 1990 (-11)
7. Does not evaluate specific palliative care service (-48)
8. Not original article (-6)
9. The information published on the results is not relevant to the study (-9)
10. The published information is insufficient (-4)

Selection



TOTAL INCLUIDOS: 67 ref.

Second tiger: quality appraisal

Relevance and level of analysis was evaluated but no study was excluded for this reason

1st question: is this study relevant for my objective? (see exclusion criteria 9.)

If yes,

2nd question: Is there any reason for poor credibility of the results?

Third tiger: Data analysis-Synthesis

- Included studies were grouped according to the perspective addressed:
  - professionals, patients or family/caregivers
- For each perspective, the studies were categorized by the type of health care resource included.
- The Ritchie & Spencer framework was used to synthesize of studies.

Big amount of studies included… Is this good or bad?

Tabla 4. Clasificación estudios incluidos			
Perspectiva D.asistencial	Profesionales (N=30)	Pacientes (N=26)	Cuidadores-familiares (N=34)
Hospice	3	6	7
Hospital	5	1	1
Enfermeras Macmillan	3	1	0
Enfermera especialista en oncología hospitalaria	1	1	2
Centros de día especializado en cuidados paliativos	1	3	0
Atención comunitaria-primaria de servicios en domicilio	15	11	21
Servicios especializados de cuidados paliativos	2	5	3
Centro Oncológico	0	0	1

STOP

- Was this so straight forward? No
- Process of deciding what was the best method to synthesize the results keeping in mind our goal.
- Changing from metaethnography to applying a method for analysis of qualitative primary studies looking at the papers like “original data” TO ANSWER OUR RESEARCH QUESTION … something like doing secondary analysis

More decisions coming…

Differences between studies….

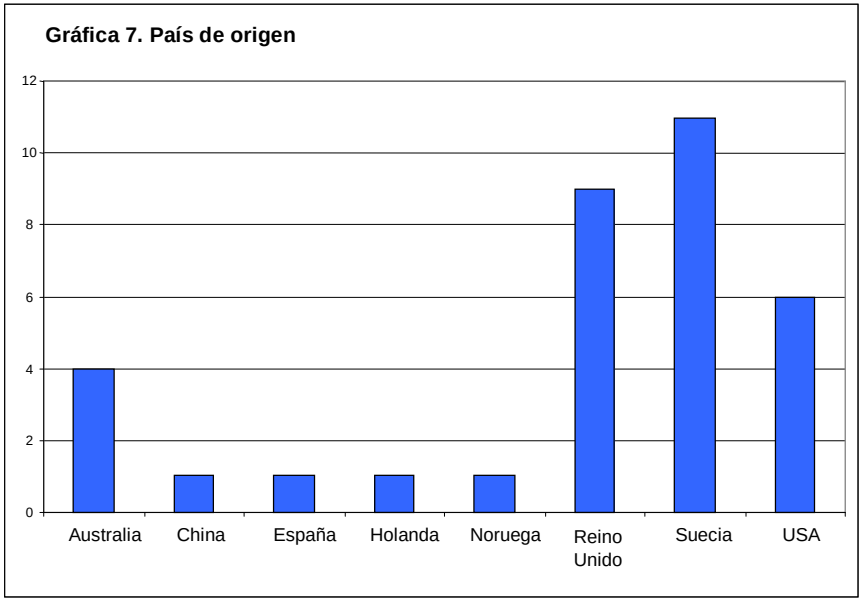
CUIDADO DOMICILIARIO			
REF	**PARTICIPANTS**	**METHOD**	**DATA COLLECTION TECHNIQUE**
Sorbye 1990 (95) Noruega	14 (14/15) **pacientes:** 7 hombres, 8 mujeres 9 vivían con su cónyuge 3 solos 2 con un hijo/a. Rango edad: 28 - 80 Familiares y enfermeras de 15 pacientes cáncer (13) y no cáncer (2)	Estudio cualitativo	Observación participante de 83 visitas a hogares de 14 pacientes. Entrevista estructurada
Athlin 1993 (78) Suecia	**20 (20/29) familiares** 5 cónyuges 3 hermanos/as 11 hijos/as 1 cuñado Rango edad: 20-51 8 miembros del personal: 1 enf atención primaria 2 enf asociadas 2 enfermeras tituladas 2 enf ayudantes 1 médico Cáncer.	Fenomenología (Colaizzi & Spiegelberg)	Entrevistas abiertas (25 con los parientes y 17 con el personal)
Wilson 1999 (120) Reino Unido	**14 cuidadores-familiares**	Estudio cualitativo	Entrevistas semiestructuradas

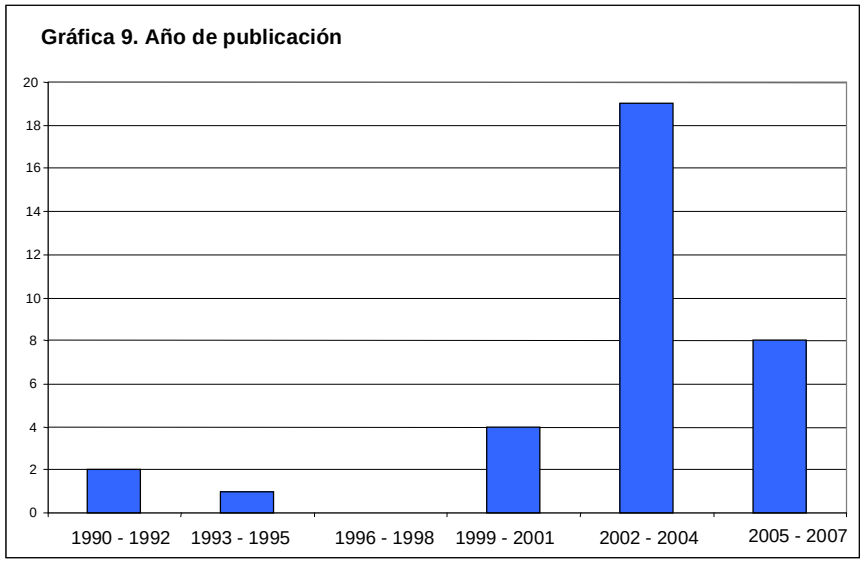
Different perspectives in the same paper

Different methods

Different data collection techniques

Different years, countries…





- Different type of results…
- … some more descriptive
- … some more interpretative

- Are these differences a problem or an added value?

- … it is a challenge
- ….but probably added value…

Results

- First part: thick description of the categories identified

- Second part: List of dimensions based on the first part of the analysis

Lets see one example…

Health care professionals perspective

- Physical Symptoms control as a priority
- Training requirements to achieve physical symptoms control
- Coordination between hcp is very important to achieve control of symptoms
- The care objectives need to be clear
- Psychological support needed
- Emotional support needed
- Spiritual suffering support needed
- Sexuality
- Familiar environment and social support
- Need to recognize family and patient as a unit of care
- Special importance for communication and information
- Consequences over hcp when working with terminal stage patients

Dimensions

1. General dimensions (list of 17 questions)
   - Information and communication (list of 8 questions)
   - Preparing for agony (list of 7 questions)
2. Physical dimension (list of 13 questions)
3. Psychological dimension (list of 8 questions)
4. Spiritual dimension (list of 9 questions)
5. Socio-familiar dimension (list of 19 questions)
   - Work related (list of 2 questions)
   - Financial (list of 2 questions)

Here comes Reflexivity….

Is “WHO” important?

- *Vinita Mahtani, Inmaculada Gonzalez and Concepcion Garcia applied selection criteria to abstracts check in pairs (Experience in qualitative research)*
- *Vinita Mahtani Chugani and Analia Abt. Analyzed data for synthesis. T*riangulation (*Experience in qualitative research)*

- *Miguel Angel Benítez del Rosario.* Peer debriefing (expert in palliative care and experience with qualitative research)

External reviewers:

- Jose M. Comelles. For methods

- Maria Teresa García Baquero Merino. For palliative care. Applicability-Usefullness

Full text available in Spanish

http://www2.gobiernodecanarias.org/sanidad/sescs/index.php?option=com_content&task=view&id=222&Itemid=42&lang=es

I hope I have brought up more questions than answers for you….

Thank you very much

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