



Palliative care in Jordan



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History:

Jordan Palliative care Initiatives (JPCI) was initiated in 2001 with the collaboration of Jordan Ministry of Health (MOH) and WHO Jordan.

Centres:

- KHCC is comprehensive cancer center
- Al-Malath foundation
- Al- Basheer Hospital

Improvements of Palliative care in Jordan:

- National Opioid quota has been increased
- Cost-effective morphine tablets are being produced
- Training courses have started to motivate health care professionals to take up palliative care as a profession.



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Aims and Objectives



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The aims of this systematic review were:

- To identify existing evidence about the experiences of communication in the care of children with palliative care needs.
- To appraise the research conducted in this area.
- To identify gaps in the literature in order to recommend for future related studies.

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3rd ICPCN, Durban, South Africa

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Method



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- Method: A mixed method systematic review of research on the experience of communication in the care of children with palliative care needs, conducted with **parents and health professionals** was undertaken.



Inclusion criteria



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Language	<ul style="list-style-type: none"> • Papers published in English
Year of publication	<ul style="list-style-type: none"> • The search was limited to studies conducted from 2000 onwards.
The design of the studies	<ul style="list-style-type: none"> • Primary studies: quantitative, qualitative, mixed methods
Phenomenon	<ul style="list-style-type: none"> • The study should contain information related to communication in the care of children with palliative care needs .
Perspective	<ul style="list-style-type: none"> • All perspectives: health professionals (i.e. physicians and nurses) and/or parents and/or children are included. Studies which report the perspectives of bereaved parents are also included.
Population	<ul style="list-style-type: none"> • Papers where the age of children is any range from birth to 18 years old.
Context	<ul style="list-style-type: none"> • Studies conducted in either specialised or non-specialised palliative care setting (i.e. home, hospital, hospice).
Publication status	<ul style="list-style-type: none"> • Published in a journal.
Quality of the studies (MMAT)	<ul style="list-style-type: none"> • Studies with scores > 25% (*).



Databases used for the review



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Name of database	No. of hits	Related papers	Title, abstract
CINAHL via EBSCO	290	70	Title, abstract, keywords
Cochrane	98	1	Abstract
PubMed	230	5	Title
MEDLINE (OVID) 1996 - Present	91	34	Title, abstract
Social Care Online	115	0	Title
Web of Science	89	25	Title
Scopus	371	70	Title
ProQuest	27	9	Title
Science-direct	1166	20	Title
Manual search (specialised journals, Google Scholar, ResearchGate, the reference list of potential papers)	80	35	Title, abstract.
Total	2477	269	



The search Terms used



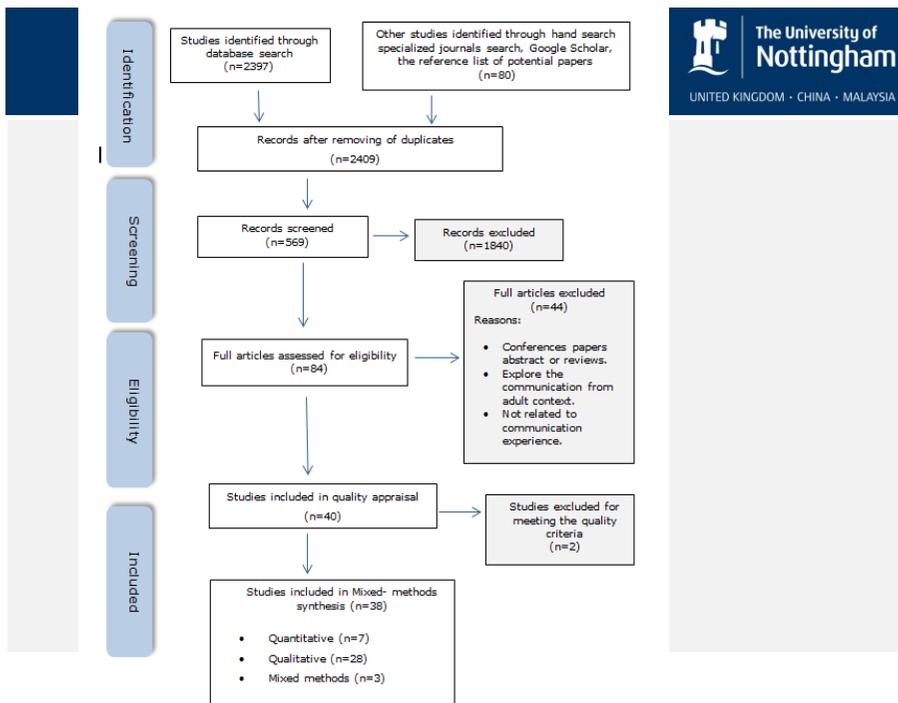
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1. Experience*	9. Nurs*	21. Child*	28. Palliative care	35. Communicat*
2. Perception*	10. Health care provider*	22. Juvenil*	29. Life threaten*	36. Interact*
3. Perspective*	11. Health	23. Pediatric	30. Life limit*	37. Contact
4. Meaning*	11. Health professional*	24. Paediatric	31. "End of life"	38. Conversat*
5. Narrative*	12. Health team*	25. "Young patient"	32. Incurable illness	39. Deliver*
6. Understand*	13. RN	26. Childhood	33. "Terminally ill"	40. Interchang*
7. Attitud*	14. Physician*	27. 20 OR 21 OR	34. 27 OR 28 OR	41. Talk*
8.1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7	15. Doctor*	22 OR 23 OR	29 OR 30 OR 31	42. Tell*
	16. Famil*	24 OR 25 OR	OR 32 OR 33	43. Disclos*
	17. Parent*	26		44. Announc*
	18. Mother*			45. 34 OR 35 OR
	19. Father*			36 OR 37 OR
	20. 8 OR 9 OR 10			38 OR 39 OR
	OR 11 OR 12			40 OR 41 OR
	OR 13 OR 14			42 OR 43 OR
	OR 15 OR 16			44
	OR 17 OR 18			46. 8 AND 20
	OR 19			AND 27 AND
				34 AND 45



- The quality of the studies was assessed using the **Mixed-Method Appraisal Tool** (MMAT-version 2011) (Pluye, 2011; Pluye et al., 2009)
- This tool is valid and reliable for assessing the quality of mixed-method studies (Pace et al., 2012)





Data extraction

- The extracted data included: author, year, context and setting, study aim, design, sampling strategy, data collection methods, and key findings for each study.



Inductive thematic analysis

- All findings were manually coded in order to initiate the initial categories, which were discussed between authors. Then, after reading and re-reading the categories, we organised and consolidated them into meaningful condensed themes

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Communication with children about illness and impending death.

- **Adopting protective approach**

- Parents do not often wish to discuss death with children, and find this topic difficult, painful and hard to touch upon in any detail (Van Der Geest et al., 2015; Dangel et al., 2000)



- **Reasons:**
- This was to protect them from the **emotional burden** and **loss of hope** that might result from such discussions (Gaab et al., 2013).
- Some caregivers hesitated to raise the topic of death as they did not want to tell their children in a bad way, or **transfer bad news** to them, especially when they perceived that their children already understood all of the necessary information and had no need for further discussions.



- Some parents aimed to **protect their children from the pain and anguish** that might have resulted from extinguishing their hope for a cure (Van Der Geest et al., 2015)
- Another parents had **a sense of fear** regarding the **child's response**, and was afraid of preventing the child from enjoying the last days of their life (Van Der Geest et al., 2015)
- Parents and primary caretakers did not discuss death with their children, who went on to die in hospice care. The perspectives were that the children were **too young to understand death**, that there was **a lack of time**, that **having such discussions was difficult**, fear of the children's reaction, and **the refusal of the children themselves to talk about it** (Dangel et al., 2000)



Communication with children about illness and impending death



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- Some parents avoided discussing death with their children because **they were in denial** (Zelcer et al., 2010)
- The parents were afraid they might **destroy their children's hopes of a cure**, despite the children's high awareness of the advanced nature of their illness, and having the major role in guiding their parents in preparing them for death.
- Family caregivers reported that they experienced **difficulty in breaking bad news**, perceiving that they **lacked the skills needed to inform their children in an appropriate way, without the help of health professionals** (Gaab et al., 2013b).



The Role of Culture



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- Conservative cultures demonstrate collusion behaviours in terms of keeping patients unaware of their diagnosis, as these cultures often believe that telling the patient the truth will **deprive the patient of hope**, thereby adding to their distress (Seth, 2010).



Greek Culture



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- It is common in Greek culture not to inform children about their diagnosis; rather, information about poor prognoses and the imminent death of child patients is communicated exclusively between physicians and parents, who usually attempt to adopt a protective approach with their children (Papadatou and Bellali, 2002; Papadatou et al., 2001).
- Greek nurses could therefore face difficulties when children who have no awareness of their diagnosis ask questions about their diseases and prognoses.



Indian culture



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- In India, Seth (2010) found that the majority of families (65%) did not want their children, who were receiving chemotherapy, **to be informed about their diagnosis.**
- In addition, the majority of them (60%) asserted that their children should not be told about **the adverse effects of their treatment, especially the long-term outcomes.**
- This is in keeping with an identified Indian cultural characteristic that parents are **very unwilling to deliver bad news to their children, and attempt to delay the process as much as possible** (Seth, 2010).



The indigenous (Maori) tradition



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- A few primary caregivers were encouraged to speak with their children with the aim of preparing them for death.
- This was partly due to the indigenous (Maori) tradition in New Zealand whereby parents are encouraged to investigate concepts related to death with their children (Gaab et al., 2013).



Jordanian culture



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- Jordan's conservative culture does not support revealing cancer diagnoses to children (Arabiat et al., 2011).



The perspective of parents

- Using medical language (Kastel et al., 2011; Contro et al., 2002; El Halal et al., 2013; Davies et al., 2003)
- Receiving mixed messages (Contro et al., 2004; Contro et al., 2002; Kastel et al., 2011)



- Responding to difficult questions
- Conflicts with families
- Inadequate communication skills



Future studies



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- It is evident that there is a requirement for a multidisciplinary approach to research, which will provide those who work with children with appropriate evidence on a daily basis (Downing et al., 2015).
- Communication is a spontaneous and continuous social interaction that needs to be observed as a process in the field rather than as isolated individual experiences (Using a variety of data collection methods).



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Thank you For Your Attendance



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Any Questions?