

# Parental decision-making

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Are practices that promote effective decision-making in clinical settings being used when parents make decisions regarding their child who is D/HH?

Ann Porter  
HDR Candidate

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Kecman, E. (2018). Old challenges, changing contexts: reviewing and reflecting on information provision for parents of children who are deaf or hard-of-hearing. *Deafness & Education International*. doi:10.1080/14643154.2018.1506072

Porter, A., Creed, P., Hood, M., & Ching, T. Y. C. (2018). Parental decision-making and deaf children: a systematic literature review. *Journal of Deaf Studies and Deaf Education*, 295-306. doi:10.1093/deafed/eny019

## The study

To understand the extent to which the principles of shared decision-making and informed choice, recommended in the medical decision-making literature, have been implemented when parents make decisions related to their child's permanent bilateral or unilateral hearing loss.

### Supervisors

Griffith University

- Professor Peter Creed
- Associate Professor Michelle Hood

NAL

- Dr Teresa Ching

## Some definitions

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- information exchange
- deliberation
- implementation

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**Shared decision-making** - “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.”

(Elwyn et al., 2012).

<b>Informed choice</b>	<b>Decision-making process</b>	<b>Shared decision-making</b>
Information/knowledge	Information exchange	Two-way information sharing of best available evidence between clinician and parents.
Understanding of values/preferences	Deliberation	Clinician and parents discuss options and the importance parents place on the advantages/disadvantages of each option. Patient clarifying values with others.
Behaviourally implemented	Implementation	Shared decision – consistent with parents and clinician preferences.

# Present study

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## Systematic quantitative literature review (Pickering & Byrne, 2014)

- A method to systematically analyse existing academic literature to produce a structured quantitative summary of the field.



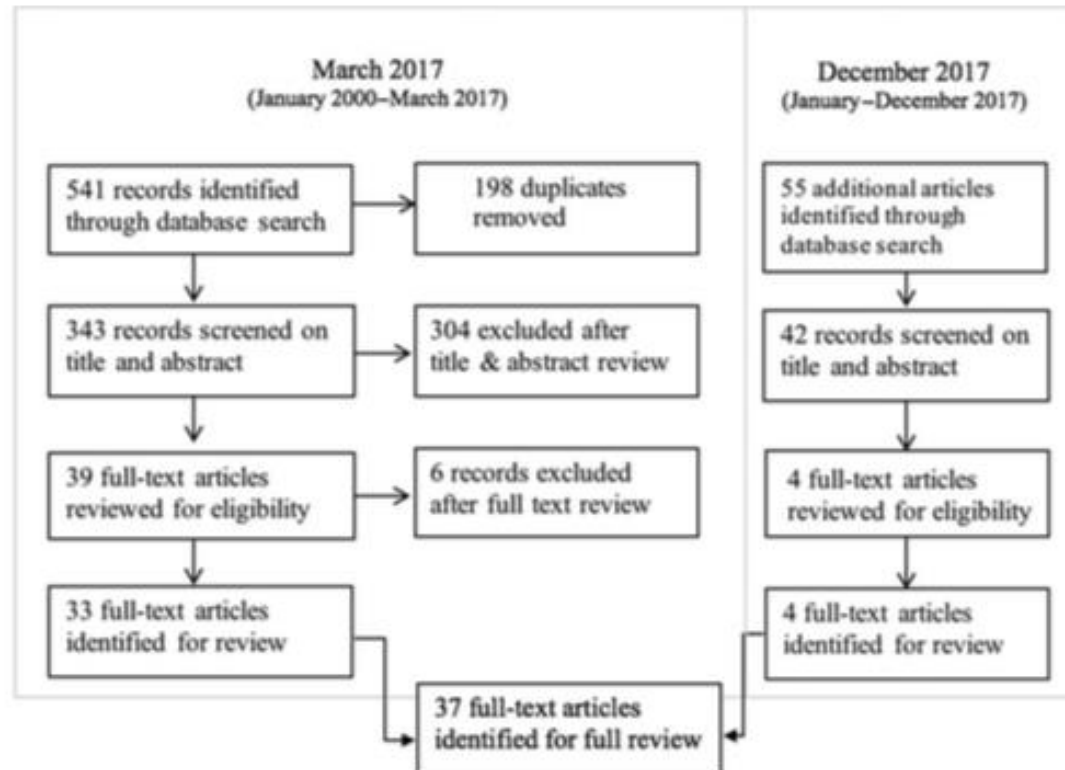
## Inclusion criteria

- **hearing parents** or caregivers of children who had a **bilateral or unilateral permanent hearing loss** and who made decisions on behalf of their child aged from **birth to 12 years** of age;
- include a proxy decision made on behalf of the child as a result of the child's hearing loss;
- examine **any component of the decision- making process**, (i.e., information exchange, deliberation or implementation), either explicitly or implicitly using **quantitative, qualitative, or a mixed methods approach**; and
- be **peer-reviewed papers** describing the results of original research published from **2000 to 2017**. Studies whose foci were decisions around genetic selection, reproductive choices, and genetic testing were excluded.

## Search strategy

- PubMed, PsycINFO, CINAHL, EMBASE, and World of Science.
- Reference lists of papers included in the review were also examined for any additional studies.
- Three variables were combined for each search
  - » terms for parent or caregiver,
  - » decision-making or choice behaviour, and
  - » D/HH or hearing loss
- Data management - EPPI Reviewer 4 software - developed at the EPPI-Centre at UCL Institute of Education, University of London, UK

# Search strategy



Two stage search and retrieval process

## Quality of studies

- Mixed Methods Appraisal Tool (MMAT)—Version 2011 (Pluye et al., 2011).
  - » quality criteria (usually 4) depending on whether it is qualitative, quantitative, or a mixed methods design.
  - » meets the criterion (rating = “yes”)
  - » does not meet the criterion (rating = “no” or “can’t tell”).

## Evidence synthesis

- NVivo 11 Software.
- An electronic version of each article was imported into NVivo for data extraction.
- Attributes of each paper (such as study design, focal decision, aspect of decision-making) were coded to provide a comprehensive quantitative summary of the papers.
- The results section of each paper was then broadly coded into the three phases of the decision-making process, (i.e., information exchange, deliberation, and implementation), for further analysis.

# Results

## Year of publication

<b>Year</b>	<b>N</b>	<b>Year</b>	<b>N</b>
2017	4	2008	3
2016	0	2007	0
2015	3	2006	1
2014	5	2005	1
2013	4	2004	1
2012	2	2003	4
2011	2	2002	0
2010	2	2001	0
2009	2	2000	3

# Results

## Country

Country	N	%
Australia	2	5.7
Canada	5	14.3
UK	8	22.8
USA	10	28.6
Others	10	28.6
TOTAL	35	100

# Results

Study design	N	Methodology	N
Quantitative descriptive	14	Self- administered questionnaires	10
		Researcher administered questionnaires	2
		Online surveys	2
Qualitative	20	Face-to-face interviews	15
		Telephone interviews	2
		Other	3
Mixed methods	3	Questionnaire followed by interviews with subset of respondents	3



# Results

Percentages of studies and MMAT ratings

Rating	All		Quantitative		Qualitative		Mixed	
	N	%	N	%	N	%	N	%
Met 0 of 4 MMAT criteria	—	—	—	—	—	—	—	—
Met 1 of 4 MMAT criteria	9	24.3	4	28.6	4	20	1	33
Met 2 of 4 MMAT criteria	9	24.3	4	28.6	5	25	—	—
Met 3 of 4 MMAT criteria	16	43.2	4	28.6	10	50	2	67
Met all 4 MMAT criteria	3	8.1	2	14.3	1	5	—	—
Total	37	99	14	100.1	20	100	3	100

# Results

Focal decision included

- Cochlear implantation (N=20)
- Bone anchored device (N=2)
- Cochlear implant brand (N=1)
- Communication modality (N=8)
- Oral bilingualism (N=3)

# Results

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## Information exchange

- Information provision (N=24)
  - » Source of information
    - Professionals
    - Other parents
    - Deaf adults
  
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- **Knowledge**
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  - » Adequacy of information
    - Enough
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    - Bias
    - Conflicting professional views

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- **Benefits and risks**
  - » Surgical risks - yes
  - » Other risks e.g. adverse social, psychological and language outcomes – no
  - » Parents not always open to exploring risks and potential negative outcomes

# Results

## Deliberation

- Exploring parental values
    - » i.e. “...detailed insight into the patient’s attitudes about the relative desirability of each of the possible benefits and harms – or attributes – inherent in each option.”
- (Llewellyn-Thomas, 2009)
- Value #1 – spoken language
  - Pressure on decision-making
    - » Pressure from professionals to make a particular decision
    - » Proxy decision-making – anxiety regarding making lifelong decisions on behalf of their child

# Results

## Implementation

- Retrospective – i.e. decision had been implemented
- Decision to implant – parents who implanted believed they had made the right decision
- Challenges with implementation of preferred option
  - » Funding
  - » Availability of services
  - » Communication modality preference of available provider

## Results

### Shared decision-making

- No studies explicitly explored shared decision-making



## In conclusion

- “In the context of the promotion of informed choice with families with deaf children, there remains a dearth of research that has paid close attention to styles of professional–parent interaction and facilitation in any way that is comparable with the fine-grained studies in other fields (Young et al., 2006).”

## Identified gaps

- Parent populations
  - » parents whose child has additional needs/unilateral hearing loss
  - » Parents with very low incomes and low literacy levels
- Shared decision-making
- Quality of research
- “Unbiased information” – what does this mean?

Thank you!

- Email: [ann.porter@griffithuni.edu.au](mailto:ann.porter@griffithuni.edu.au)