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CaHRU and LIH Improvement Science and Research Methods seminar

Conducting systematic reviews of qualitative research studies

Patients' experiences and perceptions of GBS and its variants at diagnosis, discharge and during recovery

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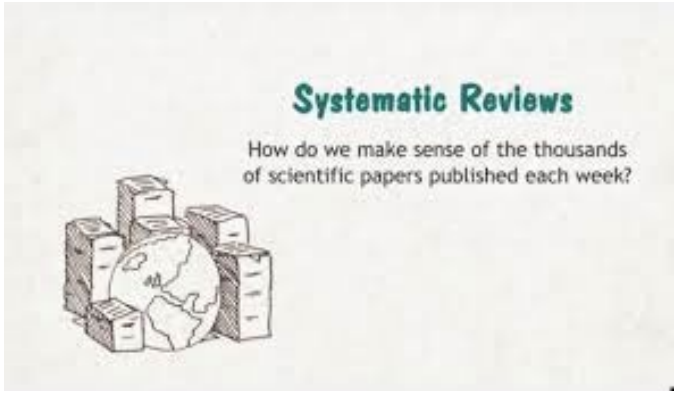
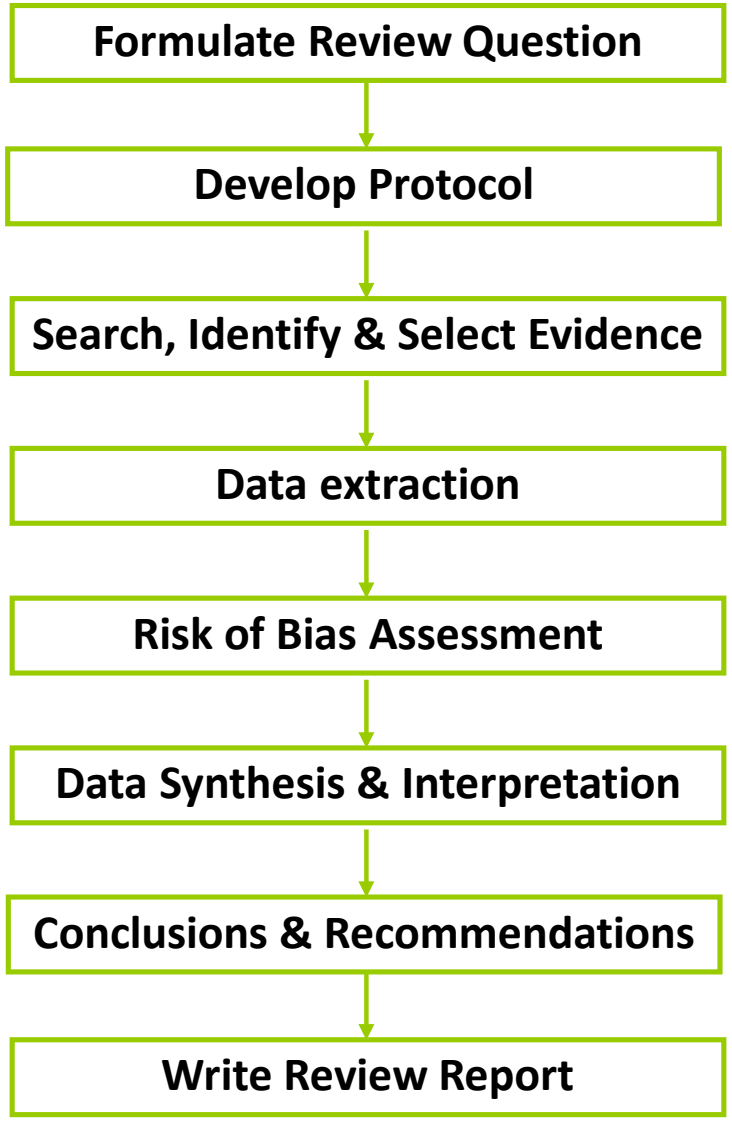
Systematic review of qualitative research studies

- Systematic Review:
  - A comprehensive, unbiased synthesis of many relevant studies in a single document using rigorous and transparent methods;
  - A scientific methodology that is reproducible and amenable to rigorous evaluation.

- Types of systematic reviews:
  - Quantitative systematic review & meta-analysis;
  - Qualitative systematic review;
  - Systematic mixed studies review;
  - Umbrella review.



Key stages in conducting a systematic review



Formulate review question

PICo

- **P**opulation
- Phenomena of **I**nterest
- **Co**ntext

Example

- What are patients' experiences and perceptions of GBS and its variants at diagnosis, discharge and during recovery?

Population | Phenomena of **I**nterest | **Co**ntext

Develop protocol

- The review protocol is the first major milestone of any systematic review
  - Provides a rigid, well-specified plan for how each stage of the review will be conducted – a roadmap;
  - Helps to avoid or minimise bias at each stage of the review – but only if followed rigidly;
  - Should be sent for external peer review, e.g. advisory group comprising researchers, practitioners, users, etc.;
  - Should be published, e.g. project webpage, research register, or peer-reviewed journal.

- The review protocol was registered with the PROSPERO International prospective register of systematic reviews (CRD42019122199) and is available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42019122199

Systematic review standards

- Reporting standards exist to guide review reports:
  - PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses);
  - PRISMA-ScR (PRISMA Extension for Scoping Reviews);
  - ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research);
  - Cochrane Handbook and MECIR (Methodological Expectations of Cochrane Intervention Reviews).

- We used the ENTREQ guidelines for enhancing transparency in reporting the synthesis of qualitative research.

ENTREQ checklist (Enhancing transparency in reporting the synthesis of qualitative research) *

No. Item	Guide questions/description	Reported on Page #
1. Aim	State the research question the synthesis addresses	Title & 5-6
2. Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	8-9
3. Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved)	6-7
4. Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	6
5. Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources	6-7
6. Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)	67 Appendix 2

Construct your search strategy

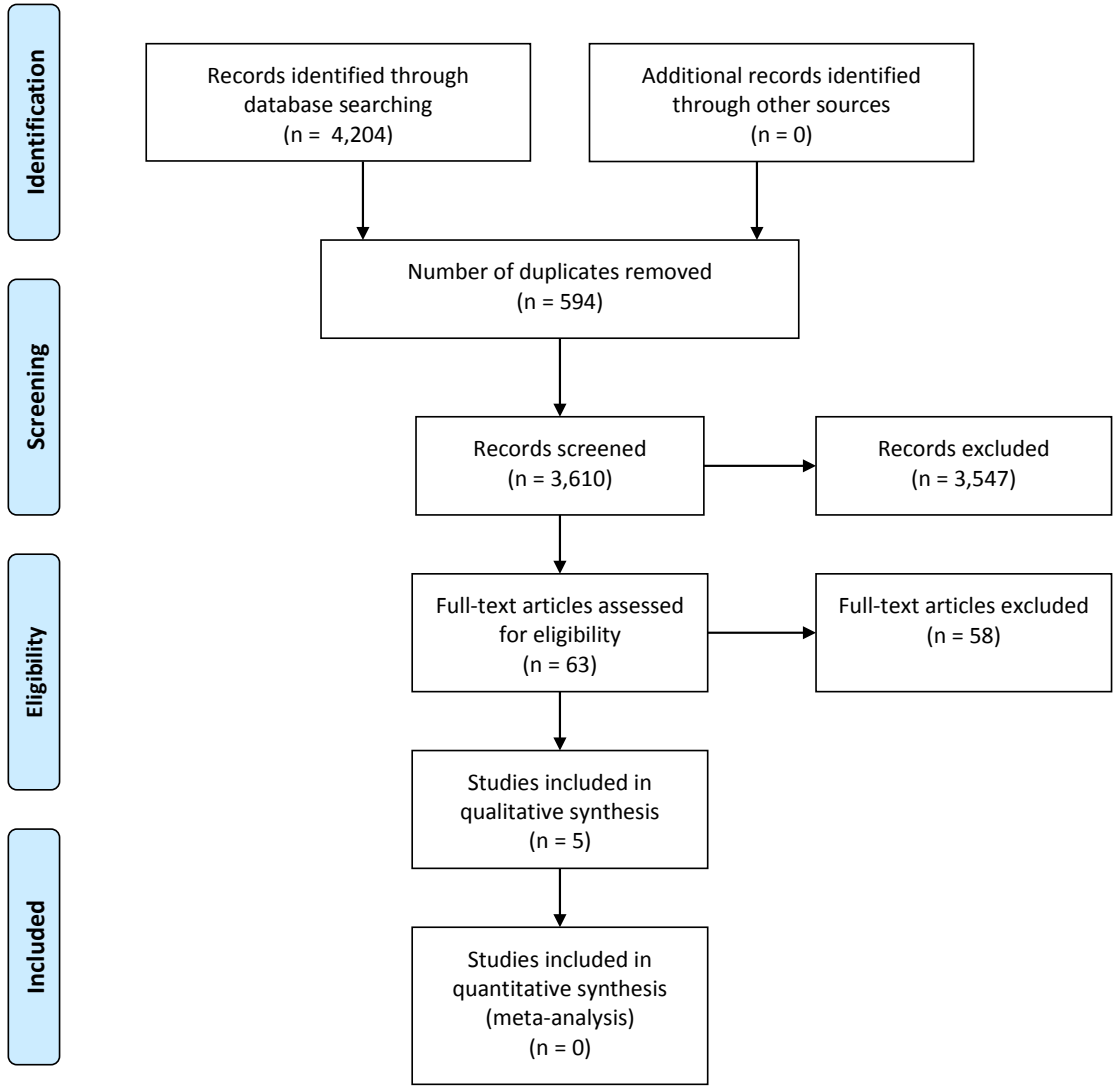
MeSH (Medical Subject Headings)

Search ID	Search terms	Results
S1.	(MH "Guillain-Barre Syndrome") OR (MH "Miller Fisher Syndrome") OR (MH "Posterior Cervical Sympathetic Syndrome") OR "guillain–barré syndrome"	14,208
S2.	guillain-barre syndrome or gbs or Guillain-Barré	25,245
S3.	(MH "Polyradiculoneuropathy, Chronic Inflammatory Demyelinating") OR (MH "Guillain-Barre Syndrome") OR (MH "Polyneuropathies") OR (MH "Demyelinating Diseases") OR "chronic inflammatory demyelinating polyneuropathy (cidp)"	28,188
S4.	S1 OR S2 OR S3	45,850
S5.	(MH "Qualitative Research")	95,077
S6.	interview* or focus group*	1,599,805
S7.	experience* or perception* or attitude* or view* or feeling* or opinion* or reflection* or belief*	7,914,020
S8.	acute inflammatory demyelinating polyneuropathy OR aidp	1,070
S9.	S1 OR S2 OR S3 OR S8	46,272
S10.	S5 OR S6 OR S7	8,890,291
S11.	S9 AND S10	2,484

Truncation

Boolean operators (AND/OR/NOT)

PRISMA 2009 Flow Diagram



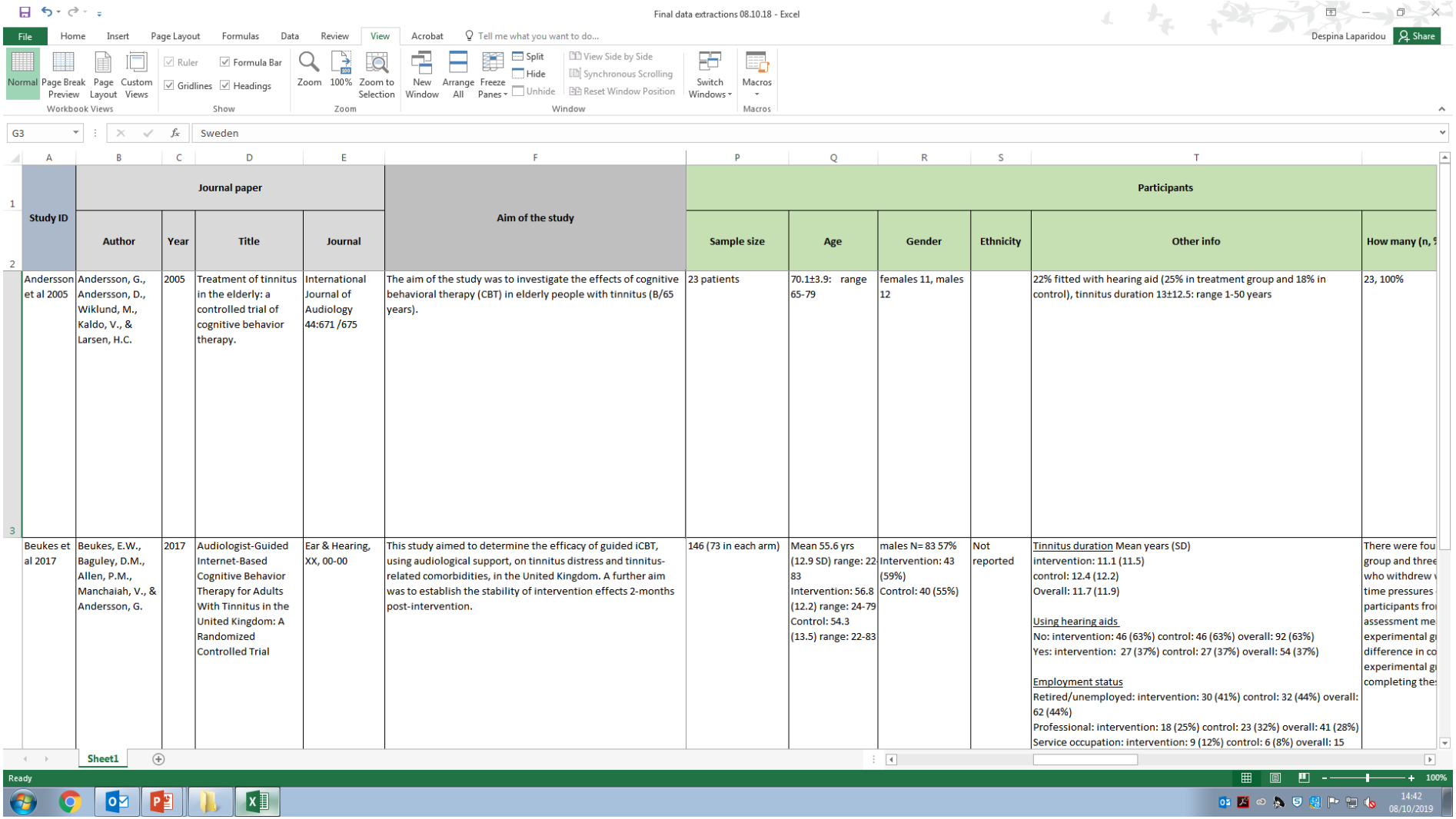
Data extractions

- Recording of information presented in primary studies

- Strike the right balance between reporting/recording too much or too little information

- Important data to extract:
  - Participants: demographic/disease characteristics, inclusion/exclusion criteria, sample size;
  - Study characteristics: aims, objectives, research questions, study design, setting, sampling method, data collection methods (e.g. interview, focus groups);
  - Data analysis: e.g. thematic analysis, interpretative phenomenological analysis, etc.;
  - Results: use NVivo software to facilitate analysis.

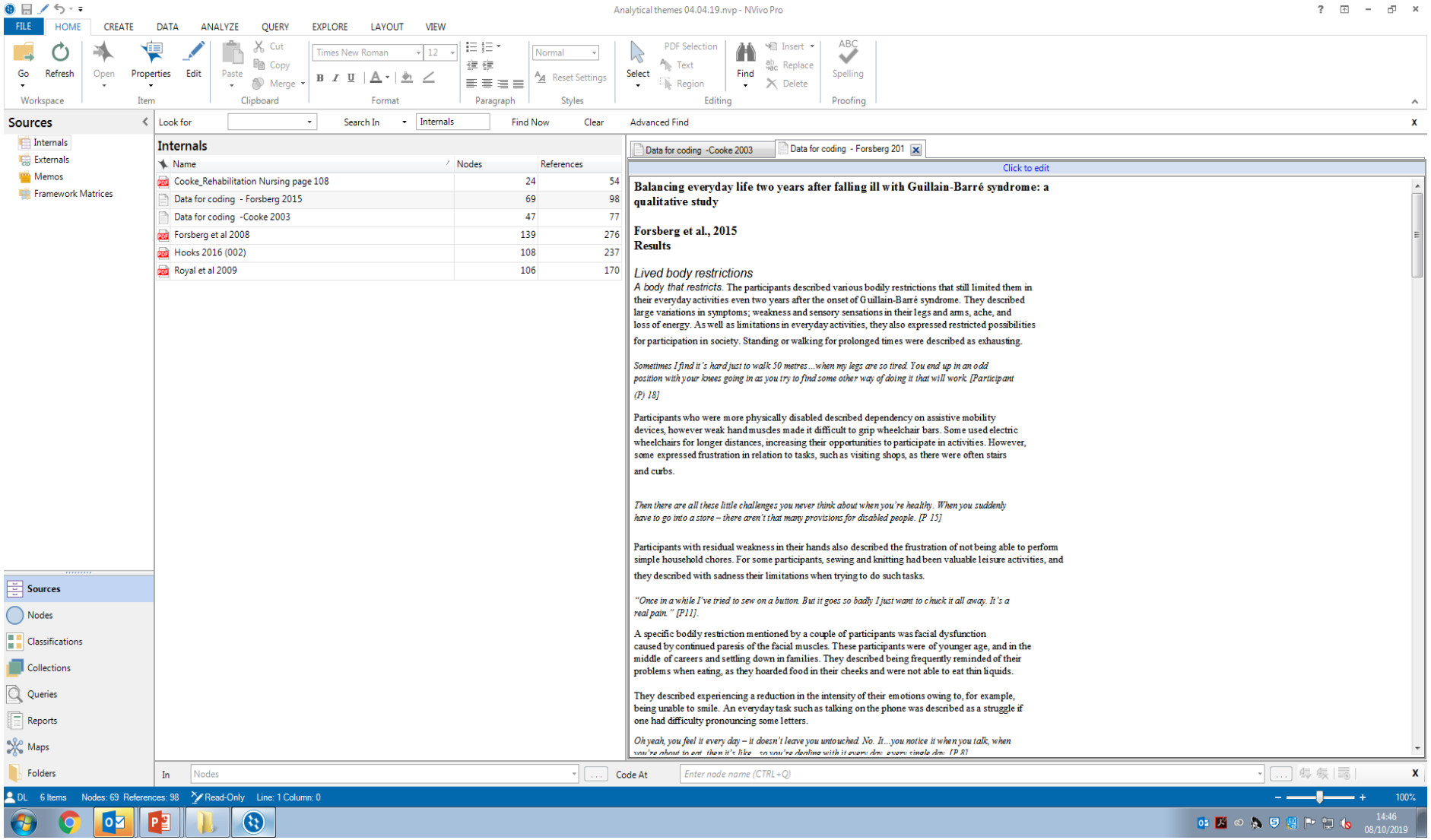
Data extraction



Final data extractions 08.10.18 - Excel

Study ID	Journal paper				Aim of the study	Participants					
	Author	Year	Title	Journal		Sample size	Age	Gender	Ethnicity	Other info	How many (n, %
Andersson et al 2005	Andersson, G., Andersson, D., Wiklund, M., Kaldo, V., & Larsen, H.C.	2005	Treatment of tinnitus in the elderly: a controlled trial of cognitive behavior therapy.	International Journal of Audiology 44:671 /675	The aim of the study was to investigate the effects of cognitive behavioral therapy (CBT) in elderly people with tinnitus (B/65 years).	23 patients	70.1±3.9: range 65-79	females 11, males 12		22% fitted with hearing aid (25% in treatment group and 18% in control), tinnitus duration 13±12.5: range 1-50 years	23, 100%
Beukes et al 2017	Beukes, E.W., Baguley, D.M., Allen, P.M., Manchaiah, V., & Andersson, G.	2017	Audiologist-Guided Internet-Based Cognitive Behavior Therapy for Adults With Tinnitus in the United Kingdom: A Randomized Controlled Trial	Ear & Hearing, XX, 00-00	This study aimed to determine the efficacy of guided iCBT, using audiological support, on tinnitus distress and tinnitus-related comorbidities, in the United Kingdom. A further aim was to establish the stability of intervention effects 2-months post-intervention.	146 (73 in each arm)	Mean 55.6 yrs (12.9 SD) range: 22-83 Intervention: 56.8 (12.2) range: 24-79 Control: 54.3 (13.5) range: 22-83	males N= 83 57% Intervention: 43 (59%) Control: 40 (55%)	Not reported	Tinnitus duration Mean years (SD) intervention: 11.1 (11.5) control: 12.4 (12.2) Overall: 11.7 (11.9) Using hearing aids No: intervention: 46 (63%) control: 46 (63%) overall: 92 (63%) Yes: intervention: 27 (37%) control: 27 (37%) overall: 54 (37%) Employment status Retired/unemployed: intervention: 30 (41%) control: 32 (44%) overall: 62 (44%) Professional: intervention: 18 (25%) control: 23 (32%) overall: 41 (28%) Service occupation: intervention: 9 (12%) control: 6 (8%) overall: 15	There were fou group and three who withdrew time pressures participants fro assessment me experimental g difference in co experimental g completing the

Data extraction



Risk of bias assessment

Critical appraisal focuses on:

- congruity between philosophical position adopted in the study, study methodology, study methods, representation of the data and the interpretation of the results;

- Critical appraisal tools enable you to systematically assess the trustworthiness, relevance and results of published papers;

- Two reviewers will independently assess risk of bias

Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2017

File Tools View Forsberg et al 2008 Data Extraction Form - Word

Findings/Results (Primary Data Excerpts to be extracted into NVivo Software)

Risk of Bias Two reviewers will independently assess risk of bias within included studies using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2017).

	Yes	No	Can't tell	Support for judgement *(include direct quotes where available with explanatory comments)*	Location in text or source *(pg & ¶/fig/table)*
	(refer to these answers when discussing risk of bias)				
1. Was there a clear statement of the aims of the research? *Consider* • *What was the goal of the research?* • *Why it was thought important?* • *Its relevance*	☒	☐	☐		221
2. Is a qualitative methodology appropriate? *Consider* • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *IS qualitative research the right methodology for addressing the research goal?*	☒	☐	☐		
3. Was the research design appropriate to address the aims of the research? *Consider* • *If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?*	☐	☐	☒	It appears to be appropriate, but the authors do not comment on this	221
4. Was the recruitment strategy appropriate to the aims of the research? *Consider* • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	☒	☐	☐		221
5. Was the data collected in a way that addressed the research issue? *Consider* • *If the setting for data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?* • *If methods were modified during the study. If so, has the researcher explained how and why?* • *If the form of data is clear (e.g. tape recordings, video material, notes etc)* • *If the researcher has discussed saturation of data*	☒	☐	☐	Not clear if they reached data saturation, but many argue that data saturation would only be relevant for grounded theory	221
6. Has the relationship between researcher and participants been adequately considered? *Consider* • *If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions* *(b) Data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	☐	☐	☒		
7. Have ethical issues been taken into consideration? *Consider* • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around*	☐	☐	☒	Ethics approval obtained, but no further info given	221

Screens 5-6 of 8 140%

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Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2017

informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • *If approval has been sought from the ethics committee*					
8. Was the data analysis sufficiently rigorous? *Consider* • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	☒	☐	☐	However, if they had used a more open approach to the interviews (i.e. not an a priori framework), maybe they would have had an even more detailed analysis, with more themes, etc.	221
9. Is there a clear statement of findings? *Consider* • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researchers arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	☒	☐	☐		222 & 224
10. How valuable is the research? *Consider* • *If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?*	☐	☐	☒	Given that it is a qualitative study, I think it offers valuable insight into patients' experiences. However, this is not explicitly stated.	
• *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*					

END OF FORM

(*PLEASE ENSURE ANY NOTES INCLUDING THE REQUIREMENT OF CORRESPONDENCE FOR FURTHER STUDY INFORMATION ARE COPIED TO PAGE 1*)

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Risk of bias assessment

Table 3. Critical appraisal/quality assessment of studies

Study	CASP01	CASP02	CASP03	CASP04	CASP05	CASP06	CASP07	CASP08	CASP09	CASP010
Cooke & Orb, 2003	●	●	●	●	●	●	●	●	●	●
Forsberg et al., 2008	●	●	●	●	●	●	●	●	●	●
Forsberg et al., 2015	●	●	●	●	●	●	●	●	●	●
Hooks, 2015	●	●	●	●	●	●	●	●	●	●
Royal et al., 2009	●	●	●	●	●	●	●	●	●	●

Data synthesis & interpretation

- Approaches to Qualitative Synthesis:
  - Thematic synthesis - our approach;
  - Narrative synthesis;
  - Realist synthesis;
  - Content analysis;
  - Meta-ethnography;
  - Meta-aggregation.

BMC Medical Research Methodology

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Research article

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Methods for the thematic synthesis of qualitative research in systematic reviews

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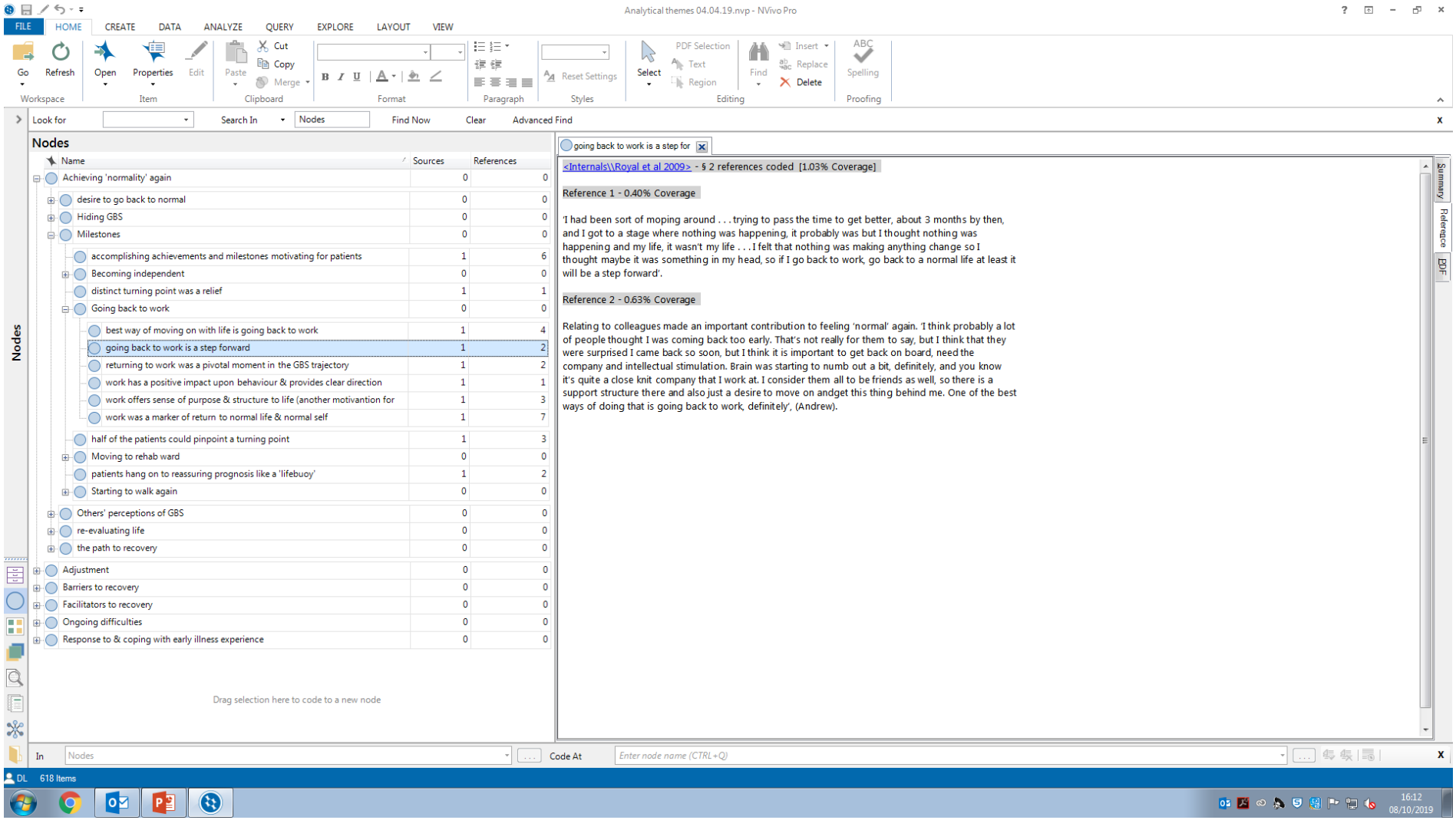
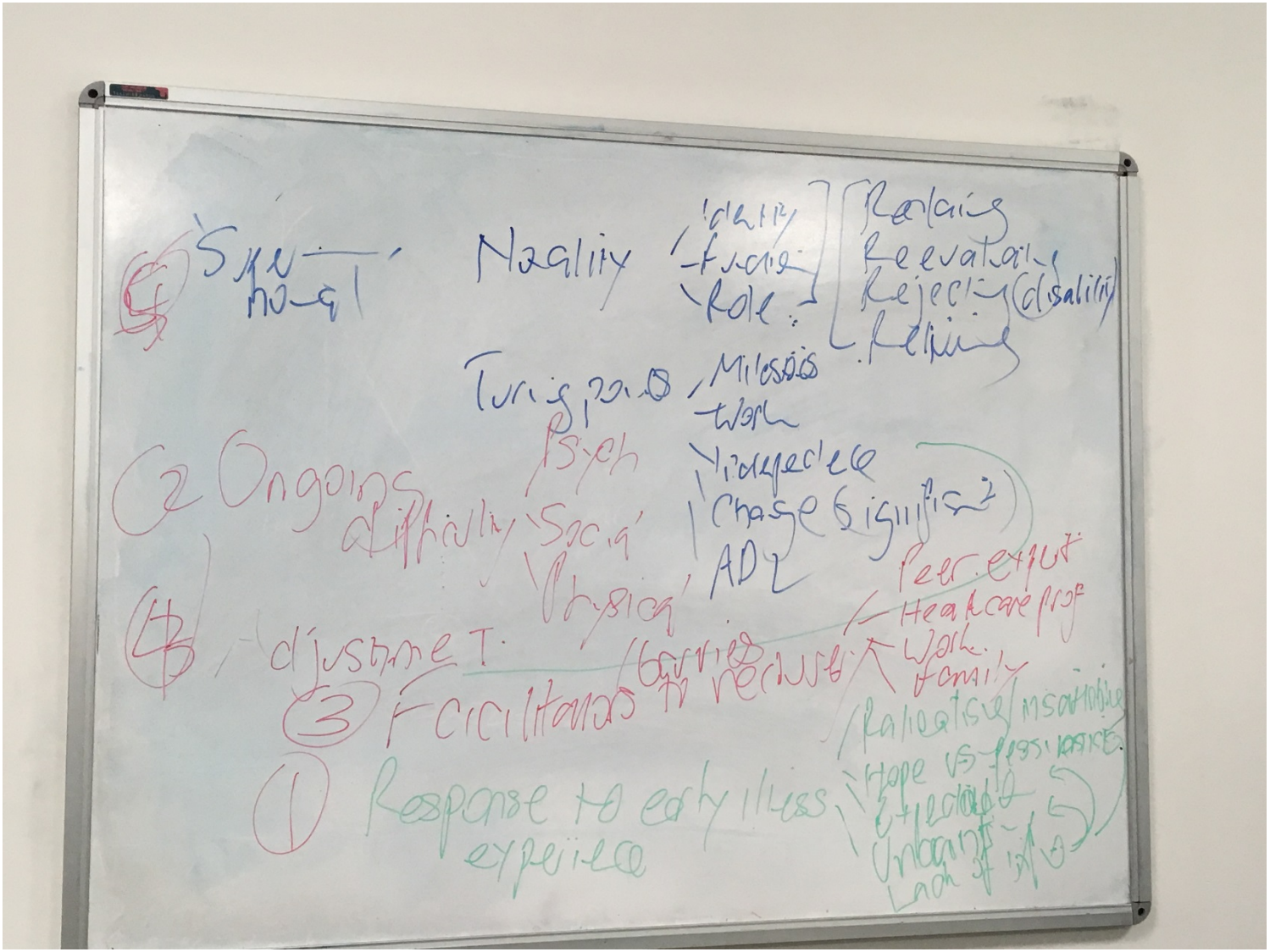
Data synthesis & interpretation



Data synthesis & interpretation



Thomas & Harden (2008) Thematic synthesis

Analytical themes	Descriptive themes	Parent codes	Quotes
From uncertainty to hope	Rationalising symptoms & misattributing diagnosis	Attributing GBS to stress	"…one participant attributed the onset of GBS to severe stress, so became diligent about limiting his responsibilities at work."
		Fears of having cancer or MS	"Some also described a fear of having a better-known disease such as cancer or multiple sclerosis."
		Initially attributing symptoms to fatigue, medication, infection, etc.	"A few persons tried to ignore the strangeness of their bodies, but others came up with explanations such as being tired or overworked."
		Initially ignoring symptoms	"At first, these strange sensations were ignored but after a couple of days the feelings of illness increased."
		Misdiagnosis by healthcare staff	"This participant went to the physician's office for care. The physician's office called for emergency support and transport because they felt this participant was having a stroke."
	Participants were eager to find out what's happening to them/Relief about diagnosis	Relieved to be admitted to hospital	"Glad that I'd arrived someplace where somebody could help me. Relieved a little bit. I guess when I was admitted to the hospital that they were glad they didn't send me home…and after the ICU experiences, I began to awake and learn more about what I had."
	Prognosis	Relying on the promise of recovery	"The concern of having a very serious disease and the fact of a prolonged recovery was becoming a realization, while others in the same situation still continued to rely heavily on the prospect of a positive prognosis."
		Some received more pessimistic prognosis	"For instance, a few persons received a more pessimistic prognosis early in the course of disease."
		Some were sad & disappointed re the long recovery	"A couple of persons described a growing awareness soon after the diagnosis, that recovery would take a long time and that this made them disappointed and sad."
	Uncertainty	Uncertainty	"The uncertainty was overwhelming for many and affected their whole lives."
	Need for information	GBS info reassuring	"Frank information about the course of disease made many persons feel secure, even when the paralysis increased. They knew that the paralysis could affect their respiratory muscles and that mechanical ventilation could be necessary."

Present results- Evidence table

Table 2. Study characteristics

Study	Study aims	Sample	Method of data collection	Method of data analysis
Cooke & Orb, 2003; Australia	To "examine the perspectives of patients with Guillain-Barré syndrome during their recovery phase"	Purposive sampling of 5 participants (3 male, 2 female) admitted to the hospital with a diagnosis of GBS; discharged from hospital in the last 2 years Ages: 28-67 years	Semi-structured individual interviews with open-ended questions	Constant comparative method
Forsberg et al., 2008; Sweden	To "describe experiences of falling ill with GBS, with the focus on the onset of disease, the diagnosis and the illness progress during hospital care"	The study population (35 participants: 22 male, 13 female) was identified in a previous multicentre study, including eight hospitals. Participants were approached 2 years after illness onset. Ages: 20–78 years	Individual interviews	Content analysis
Forsberg et al., 2015; Sweden	To "describe experiences of disability in everyday life and managing the recovery process two years after falling ill with Guillain-Barré syndrome"	The study population (35 participants: 22 male, 13 female) was identified from a previous longitudinal study. Participants were approached 2 years after illness onset. Ages: 22-80 years	Semi-structured individual interviews	Content analysis
*Hooks, 2015; USA	To "gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome"	Individuals, from eight different states, with a prior self-identified diagnosis of moderate to severe GBS. The sample (recruited through	Semi-structured individual interviews	Content analysis

Present results- Main themes

Table 4. Analytical and descriptive themes

Analytical theme	Descriptive themes
Theme 1: From uncertainty to hope	• Initial strange sensations • Rationalising symptoms & misattributing diagnosis • Participants' eagerness to find out what's happening to them • Uncertainty • Healthcare professionals' lack of knowledge and experience with GBS • Need for information about GBS • Prospect of a positive prognosis • Hope of recovery
Theme 2: Feeling lost in a changing life	• Experience of physical symptoms • Loss of identity • Dependency, vulnerability and feelings of helplessness • Feelings of shame and embarrassment • Psychological responses to GBS • Effects of GBS on family life • Difficulties with re-assuming social lives • Experiencing work-related difficulties
Theme 3: Fractured care	• Lack of continuity of care • Lack of person-centred care at hospital • Feeling not listened to by healthcare staff • Communication issues with healthcare staff • Feeling that needs are not being met by healthcare staff • Lack of publicity about GBS

Our systematic review- Conclusions

- Exploring this literature has enabled us to:
  - Identify how patients may need extra support to cope better with their recovery;
  - Identify ways that healthcare professionals and services can help facilitate further such a recovery.

- One of the most important areas that needs to be addressed is the lack of knowledge about GBS among the majority of healthcare professionals.

- One factor that positively influenced management and eventually outcomes was having a positive attitude and thinking towards recovery.

- Being diagnosed with and surviving GBS was a life-changing experience for all participants.

Disseminate findings

- Failing to disseminate research findings is unethical, and the protocol should detail precisely a dissemination strategy:
  - How will you disseminate the findings? Where will you publish?
    - Project report to GAIN charity
    - Peer-reviewed journal
    - Conferences
  - Who is your intended audience?
    - People diagnosed with GBS & their relatives/carers
    - Healthcare professionals
    - Social services

- Manuscript currently in preparation (Social Science & Medicine)

References

- Aromataris, E., & Pearson, A. (2014). The Systematic Review: An Overview. The American Journal of Nursing, 114 (3), 47-55.
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Thank you for listening!