

Non-technical summary of research findings: A qualitative synthesis of the use of complementary therapies after a diagnosis of cancer

Introduction

People with cancer frequently use complementary and alternative therapies, such as massage, reflexology, herbal preparations and yoga. This research project aimed to understand more about why people with cancer seek these treatments and what benefits and problems they experience as a consequence. Over the last ten years there have been many studies about the patient's experience of complementary therapies. The aim of this research was to synthesise and integrate the findings from these studies, and to draw out key themes, to note gaps in the research, and suggest directions for future research

Method

There have been an increasing number of studies published in the last few years which identify and analyse the experiences of people with cancer using complementary therapies. These studies are a rich source of patient-centred information but the studies tend to be small-scale, and usually only draw on limited aspects of the wider body of research. The research team located all the relevant recent qualitative studies of the experience of using complementary therapies after a diagnosis of cancer. 26 relevant papers were found, and these were read by members of the research team, who identified main themes and compared themes from the different papers. We aimed to draw together the findings and analysis of all the relevant published work – highlighting the main themes from the results of each study and suggesting how these themes might fit together.

Key findings

Six key concepts have been identified, and linked together to understand patients' experiences of complementary therapies after a diagnosis of cancer.

Table: Key Concepts, brief description

Concept	Brief description
Connecting	Most people who use complementary therapies at this time experience an increased connection between themselves and practitioners, care-givers and other people with cancer, as well as helping a reconnection and integration of mind and body for themselves. This concept was divided into three main parts: a) Connecting with therapeutic provider. b) Connecting in a social group. c) Connecting individual mind and body (and spirit)
Control	The process of gaining a new sense of control – a “niche of choice” in the context of illness and invasive treatment - is central to many people's experiences of complementary therapies and encompasses a feeling of empowerment which patients attain over their illness, their treatment and/or their life generally.
Transformation	Some patients experience, through complementary medicine, longer term changes that indicate a fundamental shift in their perspective and world view – a process that some authors have described as transformation. The concept of Spirituality, as used in papers on which this synthesis is based, is very similar
Wellbeing	Other patients experience more pragmatic benefits from using complementary therapy. Many participants reported longer term improved well-being from learning or use of complementary therapies after cancer treatment was completed.
Polarisation	Respondents typically experienced complementary therapies and conventional medicine as two separate, unmixable entities. Patients felt unable to discuss complementary therapy choices with biomedical professionals, resulting in anxiety about mixing two systems in an integrated fashion.
Integration	Patients with experiences of an integrated service of complementary therapies and conventional medicine expressed overwhelmingly positive views of this.

These six concepts have been linked together into a “story” that accounts for cancer patients' experiences of using complementary therapies.

A story of the experience of using complementary therapies after a cancer diagnosis

The diagnosis of cancer has the potential to lead to distressing symptoms and treatment side effects, isolation, loss of control and biographical, emotional and physical disruption and distress. People who use complementary therapies at this time may experience an effect, usually beneficial, in all of these spheres, but this experience is influenced by the degree to which complementary therapies are integrated into their medical care at a structural level – in particular, whether they are offered a choice of therapies in a supportive environment, and whether they feel they can talk to conventional medical providers about their complementary therapy choices. Many people desire a degree of integration either in the form of integrative cancer services or directly from their medical practitioner being open to and knowledgeable about such therapies. Without this, when there is a degree of polarisation between conventional medicine and complementary therapies, the desired connecting up and reduction in isolation is limited. Nevertheless, many people who use complementary therapies at this time experience an increased connection between themselves and practitioners, care-givers and other people with cancer, as well as a reconnection and integration of their own mind and body (and spirit). This connection is closely associated with communication, both verbal and touch, and is often related to a preception of more balance and a sense of control. The process of gaining a new sense of control appears to be central to many people's experiences of complementary therapies and encompasses a feeling of empowerment that leads to people gaining, taking or surrendering control over their illness, their treatment and/or their life more generally. A relief from, or control over, symptoms of cancer and/or medical treatment may be experienced as a short term benefit that increases quality of life or feelings of wellbeing. In addition some patients may experience longer term changes that indicate a more fundamental shift in their own perspective, relationship to control, or spirituality – a process that some authors have described as transformation.

Conclusions

In relation to medical service provision, most patients in this study preferred integration of complementary therapies and biomedical treatment and welcomed biomedical practitioners who were interested in and non-judgmental about such integration. In relation to outcome measures for clinical trials, increased control, connection and communication were all important observed effects, alongside symptom relief and improved wellbeing.

Relevance to service users

The study demonstrates that for many patients, using complementary treatments after a diagnosis of cancer is a very positive experience. Participants particularly liked having time to develop a relationship with a therapy or treatment provider. Social aspects of treatments such as meeting other people in a similar situation were seen as a particular benefit. A common problem with using or considering alternative treatments was concern about whether conventional health carers would approve or whether this choice would put them in conflict with their doctor.

Relevance to Practitioners

The research highlights a need for increased opportunities for cancer patients to discuss alternative treatment options and experience integrated health care. The majority of patients in these studies used these treatments after a cancer diagnosis as complementary, not alternative, and often to deal with non-medical aspects of the disease – taking control, relieving symptoms, social interaction. Perceived polarisation between conventional medicine and alternative treatments was limiting patients' choices and causing anxiety. The benefits of time to develop a relationship with the alternative therapist, and to feel listened to, were particular motivations for seeking and using alternative treatments.

About the study

The research was conducted by a team led by Professor Nicky Britten at the Peninsula Medical School, University of Exeter, and funded by Dimpleby Cancer Care. The team members are: Dr Janet Smithson and Dr Charlotte Paterson, Peninsula Medical School, University of Exeter, Prof George Lewith, University of

Methodology chapter 2 Literature Search

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1. DEFINITIONS and TIMESCALE LIMITS

Definitions of CAM

The original plan, as outlined in the project protocol was to use the definition provided by NCCAM (in the US). This is a fairly inclusive definition of CAM which includes traditional Chinese medicine and Auyrveda, mind-body medicine including CBT, group support and spirituality. It also includes diet and supplements.

The NHS CAM specialist library uses a list of CAM which is closer to the project teams' preferred definitions. This list includes Acupuncture, Aromatherapy, Chiropractic, Dietary and nutritional therapies, Herbal medicine, Homeopathy, Hypnosis, Massage, Meditation, Osteopathy, Reflexology, Yoga, but excludes spirituality, CBT, Group support, conventional diet and exercise.

Definitions of Qualitative research

For this study, the definition did not including content analysis, nor case studies of one patient, though a narrative analysis of one patient would be included.

Timescale for search

Implications of 10 year search timescale:

- Out of date nature of some early studies, and possibly of our findings. We can note the temporal differences in our analysis.
- Also need to be aware of the changing nature of cancer care over the decade, and changes in funding and publishing priorities.

2. SEARCH SPECIFICATION

A draft list of terms was been drawn up by the research team. The team consulted with several experts in this area – some with expertise in searching for cancer and CAM, some

for qualitative studies.

A trial search string was identified, as follows:

1. findings OR interview* OR focus group OR grounded theory OR ethno* OR phenomenolog* OR qualitative OR discourse OR discursive OR narrative

AND

2. cancer OR oncolog* OR tumour* OR tumor* OR carcinoma* OR malignan* OR neoplasm*

AND

3. complementary medicine* OR complementary therap* OR alternative medicine* OR alternative therap* OR integrative medicine* OR integrative therap* OR unconventional medicine* OR unconventional therap*

OR

supplements OR herb* OR homeopath* OR osteopath* OR acupuncture OR traditional Chinese medicine* OR mind-body therap* OR aromatherapy* OR reflexology OR massage OR naturopath* OR visualization OR meditation OR mind-body OR chiropract* OR mindfulness

3. PRACTICE SEARCHES

This trial search string was tested on the Pubmed database, adding the limits *English language only*, and *in the last 10 years*.

Modifications

We took out Tumor* Tumour* Herb* carcinoma malignan neoplasm and also integrative medicine integrative therapy, as these terms returned a large number of studies which were unrelated to our interests. We searched separately for herbal

This left us with the revised search string:

(findings OR interview* OR focus group OR grounded theory OR ethno* OR phenomenolog* OR qualitative OR discourse OR discursive OR narrative) AND (cancer OR oncolog*) AND (complementary medicine* OR complementary therap* OR alternative medicine* OR alternative therap* OR unconventional medicine* OR unconventional therap* OR supplements OR homeopath* OR osteopath* OR acupuncture OR traditional Chinese medicine* OR mind-body therap* OR aromatherapy* OR reflexology OR massage OR naturopath* OR visualization OR meditation OR mind-body OR chiropract* OR mindfulness OR phytotherapy)

Limits set were: last 10 years, English language only, Humans only, Adults only

4. ACTUAL SEARCH

3a) Search using 3 broad keywords – Cancer + CAM + qualitative

The databases ISI web of knowledge, ISI web of science, and Pubmed were searched for the 10 years immediately preceding the study; January 1998-December 2007.

The ISI web of knowledge returned 124 results for this search, of which 56 were saved to the Endnote database.

The ISI web of science returned 88 results, 3 of which were both new (not included by web of knowledge) and relevant, so added to the database.

The Pubmed search using these three broad terms returned 141 results, 14 of which were both relevant and not already covered by the web of knowledge and web of science searches.

So this provided 73 relevant references in the database.

3b) Exhaustive search using the refined complete search string

Then an exhaustive search was carried out in Pubmed using the terms decided on after the trial searches (above). This brought back **2057 articles** to be considered. See table 1 below for exclusion or inclusion decisions about these papers.

Many (80%) of these were eliminated by title alone – top line of table. Others (17%) were eliminated on reading the abstract, for the reasons (rows 2-6) in the table below. This left 57 articles (2.8% of the total search results) identified as relevant. Of these 25 were already in the database, so this process (3 days of searching) resulted in 32 new studies added to the database.

At the end of this we had 105 articles – so 32 new articles had been added to the 73 found by the less exhaustive search. All of the 73 found in the quicker search were replicated in the exhaustive search.

Table 1: Primary reasons for excluding or including papers obtained by this search N of articles=105		
	Judgement of article's relevance	%
1	Study eliminated as irrelevant by title alone	80
2	Study not qualitative (but relevant topic)	15
3	Study not mainly/totally about cancer	0.5
4	Study not about CAM	1
5	Abstract doesn't describe study/method adequately	0.25
6	Not a refereed journal article	0.25
7	Study relevant	3
	New study included which we didn't already have (2% of total articles reviewed)	
		100

Irrelevant articles obtained by this search strategy

Many studies the search is returning are, clearly from the titles, quantitative studies about about cancer with no link to CAM. The term “Visualization” led to inclusion of many papers about medical techniques called things like multi-planar visualization.

About half were rejected for not being relevant to the topic (e.g. visualization meaning x-rays, scans) and half for being right topic but quantitative. A few were rejected for being only about conventional diet and cancer, though there is overlap with the CAM-related diets so other diet articles were included. Similarly a few about conventional exercise were excluded.

Which new articles were found by the extensive search?

Many of the papers picked up in the extensive Pubmed search were nursing and complementary medicine journals - these were all (or nearly all) picked up in the forthcoming CINAHL search.

(the endnote papers should have where they were first found under Research Notes). So, we identified 105 relevant papers by searching Pubmed, ISI web of knowledge, ISI web of science.

Then I went through reading the abstracts again. Took out 10 which were quantitative (all from the first stage of the research). This left **95 papers**.

Implications of this search strategy.

Would we have got the same 95 from just doing the exhaustive search? I think so. More or less. Demonstrates the difference between the broad search and the exhaustive search (which took longer, of course, about 3 days).

5. NEXT STAGE OF SEARCH STRATEGY

At this point the articles were broadly categorised, see table below. There is some overlap between categories.

Table 2: Topic areas, broad categorisation	No of papers	%
Prevalence of CAM – who using it.	2	2
Patients’ use/perceptions/Experiences/beliefs of CAM during treatment	46	48
Patients’ perceptions/Experiences/beliefs of CAM after treatment	4	4
Outcomes/effects of CAM	4	4
Health care professionals’ perceptions/use of CAM	7	8
Communication about CAM, e.g. how/if patients talk about CAM to health professionals	8	9
Review of literature on qualitative cancer/CAM	1	

Decision making about CAM	18	19
Mostly speculative/theoretical	5	5
Total	95	100

Further database searching

Four further relevant databases were searched – CINAHL, Psychlit, Embase, and AMED.

Cinahl search

Using the same long search string as for pubmed, (limits last 10 years, English language, adults only), brought up 249 papers. This added 7 more references to the database (it also returned about 31 relevant references we already had).

CINAHL search string (the other three were very similar):

(findings OR interview* OR focus group OR grounded theory OR ethno* OR phenomenolog* OR qualitative OR discourse OR discursive OR narrative) AND (cancer OR oncolog*) AND (complementary medicine* OR complementary therap* OR alternative medicine* OR alternative therap* OR unconventional medicine* OR unconventional therap* OR supplements OR homeopath* OR osteopath* OR acupuncture OR traditional Chinese medicine* OR mind-body therap* OR aromatherapy* OR reflexology OR massage OR naturopath* OR visualization OR meditation OR mind-body OR chiropract* OR mindfulness)

Limits last 10 years, English language, Adults only.

Psychinfo search

Using the same long search string as for pubmed and Cinahl. This search brought up 755 new papers, of which 6 new references were added to the database.

AMED search (complementary medicine database). Used the Search terms here: (findings OR interview* OR focus group OR grounded theory OR ethno* OR phenomenolog* OR qualitative OR discourse OR discursive OR narrative) AND (cancer OR oncolog*). Didn't need the CAM terms as it's a CAM database. **Limits** last 10 years. English. Returned 1042 results. Only **two** of these were relevant new references not already obtained via other databases.

Scholar Google search

Did a couple of Scholar Google searches.

Narrative + cancer + alternative medicine. This search resulted in one relevant new reference.

Discursive + cancer + alternative medicine. Nothing new from that.

EMBASE search (complementary medicine database)

Same search terms and limits. This search brought up 377 refs. The search resulted in 1 new reference added to the database.

Searching the references of the articles shortlisted

Starting with the later papers, 04-07, the ones we have the full text and refs for. This took

most of a working day and gave 8 papers and 2 reports to chase up. Reading the abstracts resulted in 1 new paper added to the database.

Handsearching

It is generally recommended (ref) to do “handsearching” as well as database searching to ensure all relevant papers are located. In this study, despite a variety of handsearching techniques (asking relevant experts for suitable reference lists, checking the bibliographies of included papers, doing random searches, looking in relevant journals) there were no articles which fitted the project criteria but which had not been found by the exhaustive database search.

From these subsequent searches about 15 papers were added to the original 95 in the database, making 110 papers in the database.

6. CATEGORISATION AND ELIMINATION OF ARTICLES

Narrowing down of study focus

At this point (4 Feb 08) we had 110 papers in the database. We narrowed down the focus of our study to experiences of CAM after a diagnosis of cancer. We therefore divided the database into two – main database with 91 papers on patients’ experience of cancer and CAM (including decision-making, and reviews of literature. And a new database with 19 papers about communication about CAM, how health care professionals use/view/communicate about CAM, and how patients communicate about it to professionals.

In section 5 (above) Table 2 showed the main topic areas found in the literature search.

I assessed one third of the papers (the papers it was easy to access) on full texts. I categorized the full text articles first to get wider grasp of the issues (see separate document). Then I assessed the other two thirds on abstracts. We obtained the full text versions of any which were not eliminated at this point. Some of these articles were eliminated once the full text had been read. The results of this categorization process are shown in Table 3 below:

Table 3. Categorisation of articles*		
EXPER	Patients’ use/perceptions/ Experiences/beliefs of CAM	39
THEORY	Theory-building, no new data	3
SECOND	Secondary analysis of experiences of CAM	3
REVIEW	Review of literature on qualitative cancer/CAM	2
ELIM	See reasons in table 5 below	51
?	Need to see full text to decide	1

Total	99
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* Fuller details of the categorizing process including a table for each of the 99 considered articles is in the document “Categorising articles”.

Table 4. Main reason for eliminating at this stage	
Our topic is only one of several emerging themes	9
Mixed method/mainly quantitative/medical case study	12
Not about cancer or CAM (when read full text, abstract not always clear)	10
The “wrong sort of CAM”: spirituality, prayer, diet, exercise, psychotherapy, CBT, or traditional medicine in a traditional context.	12
Full text not in English	1
Report – relevant topic but not journal article	3
DECIS – About decision making with no data about experiences.	4
Total	51

Team decisions on “grey areas”

For articles with any doubt about inclusion, two members of the research team (JS, CP) looked together at the full texts (where available) or abstracts, and made a decision together. For those articles and areas which we were still unsure about, a further meeting took place in which the 3 team members made a final decision on the grey areas when all the database searches and most of the handsearching was complete.

Final decisions about inclusion or exclusion of marginal papers (29 Feb 08)

Decisions by NB, CP and JS were:

- Reports are out. Just peer-reviewed journal articles. 3 possible DOH reports eliminated.
- Definition of CAM in a different cultural setting. It was decided that these are traditional medicine in a traditional context so not the same thing as CAM.
- Art and music therapy. Excluded. As originally decided.
- Secondary analysis papers. 3 of these. Included as core papers, if they include qualitative data and analysis.
- Review and theory papers 5 papers. Excluded, but retained and we expect to come back to these once we’ve done an initial analysis of the data papers.

After these final decisions, we had 39 articles whose primary function was describing

qualitative research on patients' experience of using CAM. We also had 3 articles of secondary analysis on qualitative data in this topic.

We kept, but not in our core database, the details of the 5 highly relevant theory and review papers, also the 3 relevant reports our literature search had uncovered.

7. Conclusions and reflections on the Search strategy and findings

SUMMARY OF DATABASE SEARCHES

Search	Number of articles returned by automatic search string	Number of new articles added to database for serious consideration.	Articles in database
ISI web of knowledge. General search string, not the full one.	124	56	56
ISI web of science General again.	88	3	59
Pubmed, short string.	141	14	73
Pubmed exhaustive search.	2057	34	107
CINAHL search	249	7	114
PsychInfo	755	6	120
AMED	1042	2	122
EMBASE	377	1	123
Scholar google (not exhaustive.		1	124
Searching references of papers got		1 (3 if include reports)	125
From Colleagues' reference lists.		2 (3 if include report)	127

* note need to explain why did quick search for 1st three searches. To give idea of what numbers we were looking at.

Distribution of papers across the 10 year timescale

Using our search criteria (broadly speaking, qualitative research about adults' experiences of cancer and CAM use in papers written in English in the last 10 years), we found 115 papers from whole search. Out of these, 42 articles fitted our exact, narrowed-down criteria for inclusion in our meta-ethnography study.

Of the other papers which fitted the broad search categories (so they are qualitative studies relating to cancer and CAM), there were 21 papers focusing on communication about cam – between health professionals and patients, or health professionals' views of cancer and cam. There were 5 papers which were primarily reviews or theoretical models of qualitative studies of cancer and CAM. A further 73 papers were considered but not included in our meta-ethnography study because they were mixed method, or not primarily about patients' experiences of CAM, or the full text not being in English, or not fitting our exact CAM criteria, or being about communication or professionals' views or patient decision making rather than experiences of cam.

Year	No of papers in search results – papers broadly fitting search criteria	Eliminated, including cancercam	No of papers retained in our study – meeting exact study criteria
1998	111111	11	11
1999	111111	1	111
2000	11	1	1
2001	1111111111	11111	11
2002	11111111111	1111	1111
2003	1111111111111111	111111	11111
2004	1111111111111111	111111111	111
2005	1111111111111111	111111	11111
2006	1111111111111111	111111111	11111
2007	11111111111111111111111111111111	111111111	111111111111
TOTAL	115	73	42

Articles found which are broadly fitting search criteria.

1998-2002. First 5 years of period studied in project: 32/115 28%

2003-2007. Last 5 years of period studied in project: 83/115 72%

Articles found which fit our exact, narrowed-down search criteria.

1998-2002. First 5 years of period studied in project: 12/42 28%

2003-2007. Last 5 years of period studied in project: 30/42 72%

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- Aims of Data Extraction
- Quality Appraisal
- Design and Piloting of Data Extraction and Quality Appraisal sheets
- Data Extraction Exercise
- Overview of findings from Data Extraction exercise
- Conclusions and reflections on the Search strategy and findings

1. Aim of Data Extraction exercise

Reading the studies – repeated reading and noting of key concepts/metaphors/themes.
(from Campbell et al report. Also Noblit and Hare)

2. Quality appraisal

Based on team members' previous experiences of meta-ethnography studies, no quality appraisal was undertaken. From the perspective of a synthesis, the conceptual quality is viewed to be more important than the overall quality of a paper – so a poor quality paper, say with only a small sample, might contribute important concepts, or add to those found in a larger study. Prior to the Data extraction exercise, two screening questions were asked.

1. Is the research is relevant to the synthesis topic (cancer patients' or cancer survivors' experiences of CAM use)?
2. Does the paper report on findings from qualitative research including qualitative data analysis?

A quality appraisal sheet was drawn up and piloted in conjunction with the Data Extraction sheet. The intention was for papers not to be excluded on the basis of quality alone, if the research was relevant in terms of topic and methods used. (following Noblit and Hare's approach, also following reflections in Campbell et al 2002).

3. Design and piloting of the sheets

A data extraction sheet, and a quality appraisal sheet, were drawn up and piloted. Two of the team (JS and CP) piloted the first draft on two papers. There was then a meeting with 3 of the team (NB, CP, JS) after which the sheets were revised. The second draft was piloted by 4 of the team (NB, CP, JS and GL) on one paper. It was then revised further and this final version used on all 39 papers in the meta-ethnography.

Exclusion of papers after close reading and use of DE and QA forms

The papers chosen to pilot the DE and QA sheets on were marginal papers for the study. After the pilot exercise, 2 of the 3 piloted papers were deemed not to be suitable for inclusion in the study.

One (Ohlen et al) was excluded for being mainly about decisions (though there was a bit

of data about participants' experiences of CAM, the authors did not analyse or discuss this aspect of their results.

The second paper, (Arman and Backman 07) was excluded for being about cancer patients' experiences of life after cancer diagnosis, using CAM as a variable but not looking at the experience of CAM itself.

4. Data Extraction

Distribution of papers for Data Extraction

Distribution “strategy”

8. Each of the 39 papers was read for data extraction by JS, the full time researcher, and one of the other four team members (ME, GL, and CP).

We avoided people commenting on their own papers or ones they had been closely involved in.

Where papers were secondary analysis they were put to be read with the papers involving primary analysis of the same study.

After these constraints, the papers were assigned randomly in alphabetical order.

In the process of careful reading, another 13 papers were excluded for not fitting the project criteria outlined in chapter 2 (though their abstracts suggested they did). This left 26 papers for the study.

Inter-rater reliability

See document on this, add in here.

5. Overview of 26 papers still in study after Data Extraction exercise

- **Sample size:** Many studies small scale. 14 had samples of less than 20, 11 more than 20. One unspecified.
- **Cancer type:** 15 studies involved varied cancer types (often mostly breast cancer), 8 were just on breast cancer patients, 1 just on prostate, one on gynaecological cancers, one on liver cancer.
- **Gender balance:** 12 studies used all-women samples, and a further 6 used mostly (over 60%) women. 2 studies were on men. Only 4 of the studies were mixed with comparable numbers of men and women (40-60% men/women). Two unspecified.

CAM type:

- 14 studies were on Cam in general,
- 6 studies were on mind-body therapies (relaxation, yoga, meditation, visualisation, hypnotherapy, Johrei, guided imagery).
- 5 studies were on body-based therapies (massage, reflexology, acupuncture, aromatherapy)
- 1 study on Cytoluminescent therapy (injections + light therapy).

Methodology: a range of qualitative approaches

19 had a Grounded Theory/thematic analysis.

5 were Phenomenological.

2 Discourse analysis

2 Narrative analysis.

Grouping of papers by treatment type/stage of cancer

A. General experiences of general CAM.	8 in group.
B. Mind-body therapies,	6 in group.
C. Body-based therapies.	6 in group.
D. Palliative care/advanced cancer.	5 in group.
E. long term survivors/post treatment.	3 in group

10 provisional themes or groups of themes emerging from initial reading of CAM-synth papers.

1. Control
2. Positive experiences of CAM
3. Negative experiences of CAM
4. Social aspects of CAM
5. CAM as a consumer activity
6. The Battle against cancer
7. CAM as rational choice
8. CAM as part of holistic/wellbeing strategy
9. Integration with biomedicine
10. Separate spheres of CAM and biomedicine

These 10 theme groups are broken down into sub-groups, to be discussed in the next chapter.

6. Conclusions and reflections on the Search strategy and findings

Other themes/findings which don't immediately fit but need looking at

- Navigating through sea of information about CAM (A, E)
- Excusing doctors (B)
- Security of CAM context important (C)
- Close relationship between involvement/belief and quality of the experience (D, F)

- CAM can be used for more than one purpose simultaneously (D)
- CAM as harmless (E, F)
- CAM as natural (E, F)
- CAM works in different ways to biomed. More intuitive (E).
- CAM users not a fixed group, much shifting around (F)
- Gender differences – men prefer pills to touch therapies, etc (F)
- Markovic paper. Types of users (in life history, plus exper/stage of cancer). Linked to type of cam and how use it.

Table 1: Final 26 papers after Data Extraction decisions

Paper	Group	Keep in	QA rating	Sample size	% women	Cancer type	CAM	Methy
Angen	B	y	2-3	22	73	Varied	Mind-body. Yoga, medit, relax'n, visualis'n.	GT
Astin	A	y	2	67	100	Breast	general	TA
Bennett	B	y	2	8	100	Breast – returning	Johrei, self-hypnosis	IPA
Billhult 01	C	Y	3	8	100	7 breast, 1 rectal	Light massage.	Phen
Billhult 07	C	Y	2	10	100	Breast	Light massage	Phen
Bishop	G	y	2	43	86	Varied	general	DA
Brennan	B	y	3	6	Not known	Not known	Meditation	GT
Canales	A, F	y	2-3	66	100	Breast	General, massage / chiropractic	TA
Correa-velez	D	Y	2-3	39	44	Varied, advanced	General	TA/GT
Dunwoody	E	y	2-3	11	91	8 breast 3 bowel	Aromatherapy	GT/TA
Evans MEN	F	y	1-2	34	0	Varied	general	TA/GT
Gambles	C, D	y	2-3	34	97	Varied	reflexology	TA
Hok	D, G	y	2	1	0	Liver	General, esp herbal tea	NA
Humpel	A	y	2-3	19	Not stated	Varied, 10 breast	General	TA
Mackenzie	B	y	2	9	78	Varied, 4 breast	MBSR	GT
Markovic	A	y	2-3	53	100	Gynae	General	GT
Montbriand	A	y	2	8	88	Varied	General	Phen, ethno
Moore	B, G	y	4	?	100	Breast	Guided imagery	NA
Moss	D	Y	2	48	58	Varied, advanced	Cytoluminescent therapy	TA, mixed
Mulkins	A	y	2	11	55	Varied	General	TA
Partridge	G	y	2-3	8	100	Mostly ovarian, advanced	Especially acupuncture	DA
Ribeiro	A	y	3	6	100	Breast, tsurvivors	General, esp TCM and local healers.	TA/ethno.
Taylor	B	y	2-3	8	100	7 breast 1	Hypnotherapy,	TA

						colon	visualisation	
Verhoef	A	y	2-3	43	?	Varied	Integrative clinic	2ry, phen
Walker	C	y	2	16	100	Breast	Ear acupuncture	GT
Wong-Kim	E	y	2	30	100	Breast	General	GT

Methodology chapter 4. October version. Overview of the studies

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- 4.1 General purpose of the studies read
- 4.2 Brief overview of the 26 papers
- 4.3 Grouping the studies

4.1 General purpose of the studies read

In a broad sense, the general purpose of the studies read was to describe the experience of CAM among people diagnosed with cancer. However there were variations in the authors' aims. A number of studies were concerned with evaluating a particular course or therapy offered to a specific group of cancer patients. Other studies were more opportunistic, broader samples of people at varying stages and severity of cancer diagnosis (including long term survivors of cancer treatment) who had used CAM at some point, or considered using CAM. One study (Montbriand) was specifically looking at people who refused biomedical intervention for cancer.

Some of the studies were carried out by the teams who provided the service, though this was often not described very clearly in the papers, and there was a lack of reflexive analysis of this research interest.

Location: studies were all written up in English, so tended to be based in English-speaking countries. Several in the US (including two in Hawaii), in Canada, in Australia, Hong Kong. Sweden. (other countries).

26 papers were in the synthesis. Key features of these are summarised in table 4 (see end of document).

4.2 A brief overview of the 26 papers

Sample size: Many studies small scale. 14 had samples of less than 20, 11 more than 20. One unspecified

Cancer type: 16 studies involved varied cancer types (often mostly breast), 8 were just on breast cancer patients, one on gynaecological cancers, one on liver.

CAM type: 13 studies were on Cam in general, 7 were on a range of mind-body therapies (relaxation, massage, yoga, meditation, visualisation, MBSR, hypnotherapy, johrei/self-hypnosis, guided imagery). 5 studies were on body-based therapies (massage, reflexology, acupuncture, aromatherapy). One on Cytoluminescent therapy.

Methodology: Of those which stated a methodological approach, 9 said Grounded

Theory, 8 were variations of Thematic analysis (without explicitly referencing Grounded Theory) 5 were primarily some sort of Phenomenology. 2 Discourse analysis (though one was actually Thematic Analysis). 2 said Narrative analysis (again, one was actually Thematic Analysis).

Comments on the methods. The majority of papers used, or implicitly drew on, grounded theory techniques Many mentioned concepts from GT such as constant comparative analysis and saturation. A few studies talked about how many interviews they conducted until they reached “saturation”, however some of these did only about 8 interviews, casting some doubt on the authors' use of the concept of saturation. Saturation can be defined as “the researcher gathers data to the point of diminishing returns, when nothing new is being added (Bowen 2008: 140).

Gender balance:12 studies used all-women samples, and a further 6 used mostly (over 60%) women. 2 studies were on men. Only 4 of the studies were mixed with comparable numbers of men and women (40-60% men/women). Two unstated.

The main research aims of the studies in the metasynthesis

The studies generally fall into two categories. Evaluating a specific course or treatment (especially in groups B and C), or a general exploration of the experience of CAM use among cancer patients (either a specific subset of cancer patients, or in general). Some papers were primarily/also concerned with other issues. Many included consideration of decisions to use CAM or not (something we had excluded from this synthesis as a specific question to look at). One (Montbriand) was concerned with people who refused biomedicine. Only a couple of studies included people who chose not to use CAM (Bishop, any others?).

4.3 Grouping the studies

The papers were divided into 5 groups for comparative purposes, **according to their main research aims, and/or their sample.** See table 2 (end of document) for groupings.

- A. General experiences of general CAM. (8)
- B. Mind-body therapies (6).
- C. Body-based therapies (6).
- D. Palliative care/advanced cancer (5).
- E. Long term survivors/post treatment (3).

Comment by Advisory group member, David: There is an enormous difference in patients' experience within a specific diagnosis who are receiving different treatments; eg. adjuvant therapy, first line treatment for metastatic disease, second and further line treatment for metastatic disease, hormone therapy, chemotherapy, or radiotherapy. The palliative care/advanced cancer patients may not be having any of the thoses therapies at all at the time of their CAM, but their experience of CAM may also be influenced by their past treatments. Similar arguments apply to the survivor group.

A. General Experiences of general CAM

The 8 papers in this group had the research aim of describing experiences of CAM after a diagnosis of cancer. They had varied sampling methods but include participants at various stages of cancer, and all the studies were investigating a variety of types of complementary or alternative medicine. Two of the papers are of women only - Astin (2006) had a US sample of women with breast cancer, Markovic (2006) had an Australian sample of women with gynaecological cancers. One paper (Evans 2004) was of men only.

The other 5 papers were mixed in terms of gender and type and stage of cancer. Bishop (2004) analysed UK CAM users and non-users, at all stages and types of cancer. Humpel (2006), looked at experiences of CAM in general, across Australia, all stages and types of cancer.

Mulkins (2004), and Verhoef Mulkins (2005), were two papers on related studies of Integrative care of general CAM, in Canada, for people with all stages and types of cancer. Montbriand (1998), also studied experiences of a variety of CAM treatments in Canada, for people with all stages and types of cancer, but this sample was of "biomedical abandoners" - a rare group to study for this topic..

B. Mind -body therapies

The 6 papers in this group were evaluations of participants' experiences on specific treatment course of mind-body therapies. These included relaxation, massage, yoga, meditation, visualisation, Mindfulness Based Stress Reduction (MBSR), hypnotherapy, johrei/self-hypnosis, guided imagery. In these courses the participants learned specific techniques or behaviours to help them deal with the experience of cancer and associated treatments. Many of these groups were primarily women with breast cancer, at varied stages of the disease, and in various settings in different countries.

Mackenzie (2007) studied the experience of an 8 week Mindfulness based stress reduction programme followed by weekly drop-in sessions. Some had been attending for years. All participants had been diagnosed with cancer at least 4 years ago (so should they be also in the long term survivors group?)

Angen (2003) studied the impact of a Canadian psycho-social retreat programme (yoga, meditation, deep relaxation, visualisation and massage). Participants were mixed in terms of type of cancer and length/severity of illness. Some participants were metastatic.

Bennett (2006) studied women's experience of learning Johrei or self-hypnosis after the return of breast cancer and subsequent treatment.

Brennan (1998) looked at experiences of meditation classes in cancer therapy among Australian clients attending an oncology clinic

Moore (2000) looked at US women with metastatic breast cancer being taught to use guided imagery.

Taylor (2003) looked at UK women's experiences of a programme of hypnotherapy and CBT. Most were breast cancer patients, 1 had colon cancer.

C. Body-based therapies

The 6 papers in this group were evaluations of participants' experiences of a specific body-

based treatment (massage, reflexology, acupuncture, aromatherapy). There are similarities to the previous group as the papers study the experience of specific courses. Two of this group also fit into the palliative care/advanced cancer group.

Walker (2007) looked at the experiences of UK women with breast cancer undertaking a course of 8 sessions of ear acupuncture.

Dunwoody (2002) explored the experiences of UK (Northern Irish) cancer participants having a course of 6 sessions of aromatherapy.

Bilhult (2001 and 2007) considered the experience of 5 massage sessions in one study, and 10 in another study for Swedish breast cancer patients.

Gambles (2002) looked at experiences of a reflexology course in a UK hospice.

Partridge (2005) looked at US advanced cancer patients' experiences of acupuncture and other CAMs during cancer treatment.

D. Palliative care/advanced cancer

This group of 5 papers (including two also included in the body-based therapies) focussed on the seriously ill, mainly in palliative care, either in a hospice situation, or hospital care. These papers varied a lot in sample, and in focus. Three of the studies concerned specific CAM courses for patients in a cancer hospital or hospice. Two of these were body-based therapies - Gambles (2002) looked at experiences of a reflexology course in a UK hospice, and Partridge (2005) looked at US advanced cancer patients' experiences of acupuncture and other CAMs during cancer treatment. The third study (Moss 2003) investigated patients with advanced cancer undertaking a course of cytoluminescent therapy in Ireland. Many of these patients died during the 5 months treatment course.

Correa-Velez (2005) looked more generally at CAM use among patients with advanced cancer, in Australia, sampling from the cancer registry.

Hok provided a specific narrative account of one terminally ill Swedish liver cancer patient (who died, and the narrative is provided by the spouse).

E. Long term survivors/post treatment

This group of 3 papers concerned studies of people who were no longer considered to have cancer, and their reflections and experiences of CAM use both at the time of their cancer treatment, and subsequently. (details of each). Wong-Kim (2007) looked at (Chinese-born and US-born) women's beliefs about CAM use for pain management in breast cancer, among women who were no longer actively undergoing treatment. Ribeiro (2006) looked at Hawaiian women's experiences of CAM use for breast cancer, in a group of women who were mainly post-treatment. Canales (2003) investigated US breast cancer survivors' uses of CAM. These three studies therefore are looking at similar issues, among US women breast cancer survivors, but in different areas of the US and with different ethnic groups.

Table 4. Key features of studies

Paper	Sample size	% women	Cancer type	CAM	Data collection
Angen et al (2003)	22	73	Varied	Mind-body. Yoga, meditation, relaxation, visualisation.	Focus groups
Astin et al (2006)	67	100	Breast	General	Focus groups
Bennett et al (2006)	8	100	Breast – returning	Johrei, self-hypnosis	Interviews
Billhult and Dahlberg 2001	8	100	7 breast, 1 rectal	Light massage.	Interviews
Billhult et al 2007	10	100	Breast	Light massage	Interviews
Bishop and Yardley (2004)	43	86	Varied	General	Focus groups
Brennan and Stevens (1998)	6	Not stated	Not stated	Meditation	Interviews
Canales and Gellar (2003)	66	100	Breast	General, massage /chiropractic	Focus groups and interviews
Correa-velez et al (2005)	39	44	Varied, advanced	General	Interviews
Dunwoody et al (2002)	11	91	8 breast 3 bowel	Aromatherapy	Focus group (1)
Evans et al (2007)	34	0	Varied	General	Interviews
Gambles et al (2002)	34	97	Varied	Reflexology	Open-ended questionnaire
Hok (2007)	1	0	Liver	General, especially herbal tea	Interview (1)
Humpel and Jones (2006)	19	Not stated	Varied, 10 breast	General	Interviews
Mackenzie et al (2007)	9	78	Varied, 4 breast	Mindfulness Based Stress Reduction (MBSR)	Interviews and 1 focus group
Markovic et al (2006)	53	100	Gynaecological	General	Interviews
Montbriand (1998)	8	88	Varied	General	Interviews, 1 longitudinal case study, 1 focus group
Moore and Spiegel (2000)	Not stated	100	Breast	Guided imagery	Not stated
Moss (2003)	48	58	Varied, advanced	Cytoluminescent therapy	Open-ended questionnaire
Mulkins and Verhoef (2004)	11	55	Varied	General	Interviews
Partridge et al (2005)	8	100	Mostly ovarian, advanced	Especially acupuncture	Interviews
Ribeiro et al (2006)	6	100	Breast	General, especially TCM and local healers.	Interviews
Taylor and Ingleton (2003)	8	100	7 breast 1 colon	Hypnotherapy, visualisation	Interviews
Verhoef and Mulkins (2005)	43	?	Varied	Integrative clinic	Interviews and focus groups
Walker et al (2007)	16	100	Breast	Ear acupuncture	Focus groups
Wong-Kim and Merighi (2007)	30	100	Breast	General	Interviews

Table 2: Group members 26 papers

<p>A. General experiences of general CAM. Astin Bishop Evans Humpel Markovic Montbriand Mulkins Verhoef Mulkins</p>	<p>B. Mind-body therapies Angen Bennett Brennan Mackenzie Moore Taylor</p>	<p>C. Body-based therapies Bilhult 01 Dunwoody Bilhult 07 Gambles* Partridge* Walker</p>
<p>D. Palliative care/advanced cancer Correa-velez, Gambles* Hok Moss Partridge *</p>	<p>E. Long term survivors/post treatment Canales Ribeiro Wong kim</p>	

2. in 2 groups

Chapter 5 Findings: key concepts

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5.1 The process of determining key concepts

The stages of a meta-ethnography study, though generally outlined in sequence, are commonly acknowledged to be an iterative process, similarly to much qualitative research. The process of identifying key concepts, translating the concepts, drawing out 3rd order concepts, and building theory all proceeded in cycles/consecutively.

The project researcher had made (see chapter 3) an initial summary of the key concepts/metaphors/ themes emerging from the 26 papers remaining in the study. The 26 data extraction sheets were converted into an Atlas-ti programme, including the key themes and concepts located by both readers of each paper. Then the initial themes which were located by the project researcher and others in the teams were linked to the relevant data extraction concepts – usually 2nd order concepts by the authors, occasionally 1st order concepts (quotes by the participants). Then a series of “concept maps” was devised (using the Atlas-ti network function) to show the links between the themes and concepts, including overlaps, converging and contrasting themes. This initial list of themes were considered, juxtaposed and reworked in a process of discovering the relationships between the concepts and the studies.

The primary aim of this synthesis was to understand more about what benefits and problems people with cancer experience when using complementary or alternative medicine. From the analysis of the themes in this data set, what are the main areas of benefits people hope for from CAM, do they find they achieve them. What are the problems or drawbacks of their experiences with CAM?

5.2 Findings

Key concepts emerging

6 key concepts, or themes, represented in a table (Table 2, below). These varied according to the treatment type/stage of illness. The 26 studies were divided into five treatment/stage groups (due to the categories we used, three studies were in two groups):

- A. General experiences of mixed CAM. N=8
- B. Experiences of Mind-body therapies. N=6
- C. Experiences of Body-based therapies. N=6
- D. Experiences of those with advanced cancer/palliative care. N=5

E. Experiences of long term survivors of cancer. N=3

Table: Key Concepts, brief description, differences by stage/treatment group

Concept	Brief description	Differences by stage/treatment group
Connecting	Most people who use complementary therapies at this time experience an increased connection between themselves and practitioners, care-givers and other people with cancer, as well as a reconnection and integration of mind and body. This concept was divided into three main parts:	
	a) Connecting with therapeutic provider	Particularly strong in Group C body-based therapies and group D Palliative care/advanced cancer. Present in group A. Did not emerge in group B mind-body therapies, or group E long term survivors.
	b) Connecting in a social group	Present in all groups, particularly strong in the Body based therapies group (C).
	c) Connecting mind and body (and spirit)	Particularly strong in groups A and B (mind-body therapies). Didn't emerge in groups C and D.
Control	The process of gaining a new sense of control – a “niche of choice” in the context of illness and invasive treatment - is central to many people’s experiences of complementary therapies and encompasses a feeling of empowerment that leads to people gaining, taking or surrendering control over their illness, their treatment and/or their life generally.	The codes related to the theme of control were most prevalent in the General (A) and Mind-body (B) groups. They were much rarer in the Body-based (C) and Long term survivors (E) groups, and the concept of Control was non-existent in the advanced cancer group (D).
Transformation	Some patients experience, through complementary medicine, longer term changes that indicate a fundamental shift in perspective – a process that some authors have described as transformation. The concept of Spirituality, as used in papers in this synthesis, is very similar	Themes to do with Transformation were more common in groups A and B, and rare in the other three groups. (this was also the case for themes about fighting cancer).
Wellbeing	Other patients experience more pragmatic benefits from CAM use. Many participants reported the longer term improved well-being from learning or use of CAM therapies after cancer treatment was completed Quality of life was a concept referred to in four papers as a 2 nd order concept.	This concept occurred in all the groups but was particularly strong in group C (body based therapies) and group D (Advanced cancer/palliative care) – in contrast to the weak occurrence of higher order outcomes (Transformation, spirituality) in these groups.
Polarisation	Respondents typically experienced CAM and biomedicine as two separate, unmixable entities. Patients felt unable to discuss CAM choices with biomedical professionals, resulting in anxiety about mixing two systems	Came out strongly in our General group A and Mind-body therapy group B, and were virtually non-existent in the Body-based therapies (C) and in the Palliative care/advanced cancer.
Integration	Patients with experiences of an integrated service of CAM and biomedicine expressed overwhelmingly positive views of this.	In contrast to Polarisation, the Integration theme was distributed fairly evenly across the five groups.

Each of these 6 key concepts is elaborated on in the following sections, including

translation grids to demonstrate the relationships between the concepts. The format for each of the concepts follows the same pattern:

- Summary of concept, definitions, use in these studies
- Concept considered by the different treatment/stage groups
- Translation grids for the concept, by treatment/stage group

5.2.1 Control

Summary: *CAM as a way taking back control over life at a time of disruption*

From the studies in this meta-synthesis, it is clear that many patients use CAM in a variety of ways, but, generally, as ways of feeling more in control of the situation they are in – either in terms of taking/having control over their treatment, the progression of the illness, or of having some control over symptoms of the illness or the biomedical treatment, such as nausea or pain.

It seems that a particular benefit of CAM is the way it enables patients to take control of, or negotiate within, a small area of their own health and treatment, having some choice in what's happening. A “niche of choice”, as one participant put it. This is important as, in the majority of cases, participants did not want to take charge of their biomedical treatment, but they did want an area of their life and treatment which they could take charge of.

In our data extraction exercise, we located various aspects of control as one of the most commonly occurring themes in the 26 papers in the study. However, there was little elaboration or definition of the terms used in the papers. Most authors who highlighted the theme of control did not go beyond a basic mentioning of the term, or picking up on participants using it. One of the few examples of describing what they mean by control was by Mackenzie et al “Self control refers to patients developing ability to control their own behaviours. It requires patients to pay attention to the results of their behaviour and make corrective adjustments as needed”.

1. Under-definition and lack of theorising of terms

As in the wider literature, concepts of control are often bandied about without going into any details about what they cover. However, this meta-study does provide some elaboration – little bits in some papers, which together build up a coherent picture. The notion of control is important to the participants in this study particularly because of the loss of control experienced by having a serious illness and invasive treatment. CAM is important to many as a means of taking control, especially in terms of negotiating a small area of one's own health and treatment, having some choice in what's happening. A niche of choice.

The control grid (see end of document) shows how the term, and related terms (empowerment, agency) is used across all the studies in our meta-study.

2. CAM as a niche of control

A small area in which they can take charge, make choices and decisions. Negotiate. Particularly important in situation where loss of control is one of the main features.

Being able to negotiate the finer details of treatment was important, and this was how participants in various of the studies used the concept of Feeling in Control, or being in control, etc. In many of the studies the talk about control was related to this niche of health, small area of choice. I think this is quite useful to pick up on, that CAM is important to cancer patients as a way of taking control in small areas, and mostly they don't want to take control over their whole treatment or major decisions about the cancer treatment, but they do appreciate small areas of control. Bishop and Yardley (04) find this.

“(participants) negotiated a limited area of their health within which they took agentic decisions to use complementary medicine ...individuals worked to avoid constructing themselves as fully responsible and accountable for their health, negotiating their position through delineating domains of expertise. The negotiation of domains of expertise and responsibility was facilitated by the use of complementary medicine alongside orthodox medicine, which allowed participants to share overall responsibility with orthodox medical professionals.”

3. Control contrasted with....

In some of the examples given above, taking control is (sometimes explicitly by the participant, sometimes implicitly by the participant, and sometimes explicitly inferred by the authors) contrasted with not feeling in control of pain before CAM, and with leaving control to the health professionals. These are the two most common contrasts in the data set (see grid for some more details here). In Moore and Spiegel, control is contrasted with a question of spoiled identity due to diagnosis of cancer. So control is about recovering control own identity.

4. Surrendering control as an empowering activity

Our meta-study has examples of Surrendering control, conceptualized by the authors as an empowering activity (Mackenzie, Moore, Montbriand). This fits in with the idea that the dominant metaphors of Taking Control etc can be in fact disempowering to participants, limiting the acceptable ways of thinking and talking about their experiences.

5. Normative assumption that Control is good

There is a normative assumption, or dominant discourse, in nearly all the papers studied here, that control is a good thing. This is reflected in the wider literature on cancer, coping, etc. We need to consider our research team's assumptions on this and other concepts, as well as the participants' and the authors' assumptions.

6. Burden of choice

The increased expectation of patient control (by patients and by health professionals) puts a burden of choice on the patients. The literature suggests there has been a significant shift of responsibility from health professionals to patients.

4. Concept of control considered by the different treatment/stage groups: summary of differences

The codes related to the theme of control were most prevalent in the General (A) and Mind-body (B) groups. They were much rarer in the Body-based (C) and Long term survivors (E) groups, and the concept of Control was non-existent in the advanced cancer group (D).

5.2.2 Connectedness

CAM as a way of connecting

In the context of feeling isolated or depressed after a diagnosis of cancer, many participants experienced a sense of connecting as an important factor in their CAM treatment. There were different aspects of feeling connected through CAM use – particularly, 3 main areas.

a) Connecting with care provider/ a therapeutic relationship

Some studies (e.g. Markovic) found that a major weakness of biomedical treatments mentioned was the personal care aspect - hospital setting was viewed as depersonalised. And so people turned to CAM for more personal care. Sometimes the time taken to complete the CAM therapy was the factor which led to stronger relationships and better communication than with the often rushed biomedical system.

b) Connecting mind and body

A facet of connectedness which was regularly brought up by participants and authors (Angen, Moore, Astin) was the idea of connecting, or reconnecting, between mind and body, or body and spirit. This was also sometimes called 'healing a breach'. For example, Astin noted that "Movement therapies [were] used to reduce stress and connect with the mind and body". Moore and Spiegel suggested that CAM was helping cancer patients to re-connect with their bodies. A number of authors make links between wellbeing and Connecting relating to the physical and emotional connection between one's mind and body. Or healthy and sick body. And, sometimes, the concept of spiritual connectedness (to be returned to shortly).

c) Connecting with others in a social group

A recurring theme was that participants particularly valued their CAM treatment as a means of connecting with others, especially in a group therapy situation. For example, Walker found that people enjoyed the connected feeling of being in a group, and that mutual support was an important aspect of the aromatherapy treatment. For some, this social aspect, and particularly the chance to meet others in the same situation, was the primary benefit of the CAM treatment. It was a way of reducing feelings of isolation and depression.

Opposite concepts – Isolation and Disconnecting are opposites of the rest of the Connecting themes. But Isolation is constructed as undesirable, and Disconnecting is constructed (by the participant who uses it in this example) as desirable.

In general, there were themes about connecting or relating or communicating in many of the papers, but few explicit definitions. One paper with a connecting theme provided some theorising around the concept, Mulkins and Verhoef considered the themes of connecting and disconnecting. They suggest a continuum along the cancer journey – starting with a “feeling of disconnection and loneliness”, moving through the transformative experience of CAM for many participants, towards a connectedness. As they put it:

“This feeling of disconnection and loneliness resonated in many of the participants’ accounts and appeared to mark the beginning of the process of transforming the experience of living with cancer”

Many participants felt a sense of connecting or relating through the CAM therapy process. This occurred (according to participants' accounts) due to the therapeutic relationship between therapist and patient, or the relationship between fellow group members, and/or due to the process of the CAM itself, and/or due simply to the time taken to complete the CAM therapy which led to stronger relationships and better communication than with the often rushed biomedical system.

A number of authors make links between **wellbeing** and **Connecting** relating to the physical and emotional connection between one's mind and body. Or healthy and sick body. And perhaps the concept of spiritual connectedness (see below).

Another facet of connectedness was also regularly brought up by participants and authors. The idea of connecting, or reconnecting, between mind and body, or body and spirit. This was also sometimes called **healing a breach**.

Concept considered by the different treatment/stage groups

- a) **Connecting with therapeutic provider** was particularly strong in Group C body-based therapies and group D Palliative care/advanced cancer. Present in group A. Did not emerge in group B mind-body therapies, or group E long term survivors.
- b) **Connecting in a social group** was present in all groups, particularly strong in the Body based therapies group (C).
- c) **Connecting mind and body (and spirit)** was particularly strong in groups A and B (mind-body therapies). The theme did not emerge in groups C and D.

5.3.3 Polarisation

Summary

The most notable barrier to patients reporting a satisfactory experience was the perceived polarisation of CAM and conventional medicine. Many of the authors noted that

participants experienced CAM and biomedicine as opposing, polarised approaches. It was rare for the two to be experienced in an integrated system. Patients reported difficulties in using both CAM and biomedicine, in particular many found it hard to talk to their biomedical practitioners about their decisions to use or experiences of CAM, and this was viewed by patients as a problem. They consequently worried about the compatibility of treatments, and about incurring the disapproval of their biomedical practitioners. A common theme in many of the articles was of participants' experience of hostility from biomedicine towards CAM^[g1]. Moreover, as the participants were, in the majority of studies, those who had used CAM after a diagnosis of cancer, it is likely that the difficulties in openly talking about CAM options with biomedical practitioners is a significant deterrent for many patients in trying out CAM therapies^[g2].

The concept of Polarisation in the wider literature

The wider literature on CAM and cancer does mention the tensions between CAM and biomedicine but some aspects of this have come out particularly strongly in our synthesis – the effect on the patient experience of the lack of communication, interest in or approval of, the other system.

The concept of Polarisation in these studies

Many of the authors concluded that participants **experienced CAM and biomedicine as opposing, polarised approaches**. It was rare for the two to be experienced in an integrated system (notable exceptions are described in the Integration analysis). This experience was mainly but not exclusively one way – patients felt that it was difficult to talk to their conventional health care providers about their experiences of CAM. This caused anxiety, including worries about incompatibility of treatments or concerns over the impact of alternative treatments.

The experience of Polarisation is to do with the system or systems which participants are in, and is something that is rarely within the patient's control. Patients make choices to overcome or accommodate the experience of structural polarization.

While CAM and biomedicine are often conceptualised as occupying opposite ends of a spectrum in the literature, setting up a polarised view of these two modalities, participants, in contrast to this, want and need better integration between the two. Participants were less likely, it seems, than health professionals, to see the two domains as intrinsically hostile or polarised, and more inclined to view the two domains as, well, complementary. This finding in our study corresponds with the Boon et al levels of integration theory, in which they depicted participants (consumers, as they called them) tending to be happy about using both biomedicine and CAM, but the structures and processes of the two separate systems being increasingly distinct as you move away from the individual consumer level.

A common theme in many of the articles was of participants' experience of **hostility from**

biomedicine towards CAM. One effect of this was that participants often felt unable to discuss their CAM treatment, or concerns about CAM treatment, with their biomedical practitioners - caught between different clinicians.

Abandonment of biomedicine

The concept of abandonment came up particularly strongly in Montbriand, in a study of participants who abandoned biomedicine altogether, found that poor communication with biomedical professionals was a major cause of biomedical abandonment. It also emerged in other papers in milder (generally) forms, for example Bishop found that participants felt alienated from biomedical professionals, and found themselves opposing the doctor's advice in taking up CAM treatments.

Biomedical abandoners can be seen as an insight into the conflicts that occur between conventional medicine and CAM in cancer. It appears that often the needs and wishes of the patient are not fulfilled by appropriate communication with their conventional oncology team and their individual needs are overwhelmingly dominated by the context provided by CAM (supportive connecting spiritual therapeutic). They become overwhelmed with their failure to communicate with their conventional physicians and abandon (often ill-advisedly) conventional biomedicine.

In contrast, many cancer patients distance themselves from CAM and go for totally biomedical treatments, but as the study topic was experiences of using CAM they are not the main focus of this synthesis.

Appreciation of separate spheres

A few studies concluded that at least some participants wanted/valued this separation – they **appreciated the separate spheres** of experience/influence. A form of treatment away from the hospital, institutional, medicalised procedures. A separate space, either physically, or emotionally. Taylor et al found that patients were inhibited from attending the hypnotherapy centre because it was next to a hospice, they recommended a separate building off-site (link to CAM as treat theme).

David: The polarisation between biomedicine and CAM is clearly an important theme - my patients try to bridge that by asking me to check their CAM therapy for any potential conflict.

Concept of Polarisation considered by the different treatment/stage groups: summary of differences

The Polarisation theme is virtually non-existent in several of the groups. Themes to do with Polarisation came out strongly in our General group A and Mind-body therapy group B, and were virtually non-existent in body-based therapies, and in Palliative care/advanced cancer group D.

5.3.4 Integration November summary

Summary

The concept of integration came up explicitly as a concept in several of our studies, and implicitly in many others. The explicit mentions of integration were mainly in relation to Integrative Health care, by authors (Verhoef and Mulkins) who were looking in detail at this. Besides the papers studying experiences within this particular system, the theme of integration of biomedicine and CAM was important to participants in that they either had positive experiences of some level of integration of CAM and biomedical treatment (either in the same location, or provided by a united team, or at the minimum a perception that it was permissible to discuss one option with practitioners of the other system), or they wished for better integration between the two.

It is clear from our study that the (relatively rare) experience of integrated systems, or a perception of a unified health service offering both biomedicine and CAM options, was almost universally appreciated by cancer patients. Participants felt that having this chance to explore and find the right fit for them with practitioners and modalities helped to create an optimal environment for getting the most out of the available treatments. In contrast, the separation of CAM and conventional medicine perpetuates a split that does not help the individual on their healing journey.

The concept of integration came up explicitly as a concept in several of our studies, and implicitly in many others. The explicit mentions of integration were mainly in relation to a particular experiences of Integrative Health care - two related papers, Verhoef et al (05), and Mulkins et al (04), by a Canadian team – Verhoef, White, Boon, Mulkins - who have written a variety of papers on integrative health care.

Integrative health care

Mulkins and Verhoef (2004) say that “Integrative health care aims to restore physical, emotional, structural, energetic, and spiritual balance based on the body’s innate ability to heal. Integrative medicine shifts the paradigm from sickness to wellness, keeping the patient in the central focus of care, and multiplies the number of strategies available to the patient” (p230). They argue that “nonspecific effects and the effect of the patient-provider relationship are also of great importance to positive outcomes”. In their understanding of integrative medicine or integrative health care, they have a wider than usual conceptualization of what CAM is, seeing it not so much as medicine as a wider health care behaviour which benefits participants at a range of levels.

As with the opposite concept of Polarisation, Integration as understood in this synthesis is primarily about a surface organisation/practical issue. There appear, however, to be links between experience of structural integration (either provision on one site, or communication/information from biomedical providers about alternative options) and feelings of connectedness and wellbeing for participants.

What people want in terms of integration – at what level?

In most instances, there was a strong and often stated desire for better integration of CAM and biomedicine. People who experienced an integrated system of CAM and biomedicine usually found this to be very beneficial. For the patients who did experience CAM as polarised from biomedicine, there was a regular theme of wishing for better integration.

Comment from advisory group member: David: CAM in an integrated setting - The place of delivery of CAM is important - in or away from the biomedical institution. The communication issue is part of this. CAM offered in a the hospital setting gets over many of the negatives - it is an endorsement of safety and appropriateness.

Sometimes people wanted better information about CAM. Canales found a desire from participants for conventional practitioners to give information about CAM. In other instances, authors were describing a desire for better communication between CAM and biomedical professionals, or a desire for participants to be able to discuss the one form of treatment with the practitioners of the other (Partridge, Taylor).

Concept of Integration considered by the different treatment/stage groups: summary of differences

In contrast to Polarisation, the Integration theme was distributed fairly evenly across the five groups.

5.3.5 Transformation

Summary

The notion of CAM as a transformative experience, and/or a means of personal or spiritual growth, was brought out explicitly in several of the studies, and implicitly in others. People talked about how CAM had changed their behaviour or perspective on the whole of life, not just on their illness or treatment. A couple of papers focused primarily on transformation, notably Mulkins and Verhoef looked at the “nature of transformation”: “Participants' stories revealed that transformation involved learning about themselves: becoming more aware of who they are and how they relate to the world”. The concept encompasses the notion that change is not just narrowly about the illness or treatment or response to these, but is about changes to whole outlook on life, and lifestyle and practices.

From our synthesis of the study findings, it seems that some participants undergo a transformative experience, through use of CAM, after a diagnosis of cancer – a process which is linked to, or follows from, the experience of gaining empowerment (or, in some cases, surrendering control).

A related concept - Spirituality

Spirituality was an emerging theme in many of the studies. Our understanding of spirituality in this context draws on recent theorisation of the concept's use in cancer research, and can be exemplified by Mackenzie in our studies, talking about a Mindfulness Based Stress Reduction (MBSR) programme:

“Despite the programme’s secular stance, the development of spirituality may be an inevitable outcome of the practice, as one becomes aware of the intricate interconnections among themselves, other individuals and eventually all aspects of nature through direct experience.”

On this definition, spirituality is very close to our definition of Transformation, it is clear that there are many links between these two concepts.

The concepts of Transformation and Spirituality in the wider literature

Spirituality

Koffman et al, “Conceptual confusion is common in relation to religion, faith and spirituality and there is little consensus about what these terms mean both in the USA and the UK literature... we understand religion as a system of faith and worship expressive of an underlying spirituality which is frequently interpreted in terms of particular rules, regulations and practices... Spirituality is a relatively newer construct...is recognized as representing a search for existential meaning within a life experience, usually with reference to a power other than the self, not necessarily called ‘God’, that enables transcendence and hope.. we acknowledge these definitions may not be understood in the same way by patient participants” Koffman et al (2008: 780-781)

Definitions of ‘spirituality’ in cancer and CAM related literature often include dimensions such as making meaning of life, faith, purpose, and connection with others and a higher power (Kroepfer, 2000; Mytko & Knight, 1999).

The concept of Transformation in these studies

The notion of CAM as a transformative experience, and/or a means of personal or spiritual growth, was brought out explicitly in several of the studies, and implicitly in others. People talked about how CAM had changed their behaviour or perspective on the whole of life, not just on their illness or treatment.

*“I am changed... my whole pace has slowed down... I am more present in my life”
(in Verhoef)*

“I am savouring life now, taking it all in... trying things I would have never dreamed of trying.”

Mulkins, in a related paper, outlined 4 “Transformative dimensions of integrative health

care”:

12. Having access to a range of therapies
13. Care that focuses on one's overall well being
14. Control over cancer management
15. Developing healing relationships with care providers.

Several papers (Astin, Bishop, Angen, Mulkins and Verhoef) pick up on concepts which appear to be to do with changes through use of CAM besides the immediate effects on the cancer/symptoms. Longer term, shifts in attitude or behaviour. For example, Astin reports a patient as saying:

*“There is **more to be healed than just the cancer**.... We're still working on that and I think that's where all these other things [CAM] come in.”*

Mulkins and Verhoef consider the “nature of transformation” from participants' stories: “Participants' stories revealed that transformation involved learning about themselves: becoming more aware of who they are and how they relate to the world”. The concept encompasses the notion that change is not just narrowly about the illness or treatment or response to these, but is about changes to whole outlook on life, and lifestyle and practices:

“I am changed and so the way I do things in my life is different My whole pace has slowed down, so how I organise my day is different, so then my relationships with the people around me are different. I am more present in my life. Overall, I guess I just really, I feel different. I think I even look different. This has been a very profound and wonderful experience for me”

Brennan and Stevens, in their study of a meditation course, talked about something very similar to Transformation though they don't use that word. They talk about “Motivation to change behaviour” - one of their main themes emerging from their study.

“I cannot believe how good it's made me feel in so many different ways, psychologically as well as physically” (p23).

Spirituality

Spirituality was an emerging theme in many of the studies. It was noted that the term is used in different ways by participants and authors, and by the project team. For example, Mulkins had a participant who talked about healing in a spiritual sense:

“Healing is more about the spirit and freedom that comes from the reality that is within me”

Several authors (Angen, Bishop, Gambles, Montbriand) included spirituality as a second order concept. One of Mackenzie's five second^d order concepts from the MBSR programme was Spirituality. They suggest that “Despite the programme's secular stance, the development

of spirituality may be an inevitable outcome of the practice, as one becomes aware of the intricate interconnections among themselves, other individuals and eventually all aspects of nature through direct experience.”

Astin found that the majority of their participants considered psychosocial and spiritual activities crucial in treatment and recovery”- the spiritual and social aspects appear to be linked here.

“Support groups [are part of complementary medicine] because your mind and spirit have a huge amount to do with healing for anything... knowing you're not alone”.

While spiritual healing as a form of CAM was not included in this meta-synthesis, many participants did view their alternative therapies and treatments as enhancing them spiritually, or making them feel spiritually more connected.

Concepts considered by the different treatment/stage groups:

Themes to do with **Transformation** were more common in groups A and B, and rare in the other three groups (this was also the case for themes about fighting cancer).

5.3.6 Wellbeing

Summary

Many people use CAM in a very pragmatic way – in the hope of possible benefits. Important outcomes (from the patient perspective) of using CAM treatments after a diagnosis of cancer include the local, perhaps short term benefits of pain relief, time to talk to a therapist, better social relationships. CAM as a way of enhancing current Quality of life. For example, Gambles found that CAM helped with improving quality of life for patients struggling to cope with effects of cancer and treatment.

Some participants viewed CAM as a treat or reward, rather than a treatment (Bishop et al, 08). For example, Dunwoody has a concept of Aromatherapy as a reward, which she defines as participants having time for themselves without the demands of others; hands on approach gave a feeling of worth, being cared for, after a tough time. Angen found that, for some, deep relaxation and meditations were antidotes to the anxiety of tests, treatments and awaiting results.

The concept of Wellbeing and Quality of life in these studies

Wellbeing was explicitly mentioned as a concept in a few papers (Bishop, Bilhult, quality of life in four as a 2nd order concept.

Correa-Velez, one of 4 sub themes for group with advanced cancer, talked about

“I started reiki and then I realised it was working.... And that makes you much more aware of what you are doing. It makes you realise that quality is the thing not quantity”

Evans suggested that men may enjoy **better quality of life** through accessing CAM. Gambles found that CAM helps with **improving quality of life** for patients struggling to cope with effects of cancer and treatment. Ribeiro noted that most women in their study felt conventional medicine was adequate to treat the disease but lacking in other areas such as **improving the quality of life**. Some other authors used different terms but were perhaps thinking along similar lines. For example, Bennett found that, for women with returning breast cancer, participants were able, through CAM, to conceptualise that life had not ended with a second diagnosis. Moore found people used CAM (guided imagery) to carve a niche of health out of illness.

Concepts considered by the different treatment/stage groups: summary of differences

The Wellbeing concept occurred in all the groups but was particularly strong in group C (body based therapies) and group D (Advanced cancer/palliative care) – in contrast to the weak occurrence of higher order outcomes

Chapter 6 Translation

Contents

1. What is translation?
2. Translation grids mapping the key concepts across the papers.
3. Refutational translation

6.1 What is translation?

Translation, in the meta-ethnography process, is the process of determining the relationships between concepts. A recap of some key definitions of the Translation activity in the meta-ethnography process:

4. Noblit and Hare (1988) defined Translation as the examination of key concepts relation to others within and across studies analogous to constant comparison (X is like Y except...). They distinguished between Reciprocal and Refutational translation. Most meta-ethnographies tend to focus more on Reciprocal translation.
5. Pound et al (2005) described Reciprocal translation as “determining how the findings relate to each other” (Pound et al 2005). The key concepts in a study are defined and relate to the key concepts in the other studies. To clarify how the findings relate to each other, Pound et al developed “maps” of the key findings for each of the groups by drawing the relationships between them.
6. Bondas and Hall (2007) describe Reciprocal translations as one study being presented in terms of another. “The accounts are then directly comparable as reciprocal translations and are analogous” (2007: 118).

6.2 Translation grids mapping the key concepts across the papers

In this chapter I consider the translation/mapping across studies of some of the key concepts described in chapter 5

While the analysis was partially conducted according to cancer stage/treatment group (see chapter 5), our studies did not fit neatly and uniquely into these categories. For this reason the translation was not conducted within groups of papers (as it was in the Pound et al study, for example) but the key findings were considered in five groups of concepts – which became six after studying the translation grids. Transformation and Wellbeing were separated as concepts at this point.

The key concepts which came out of this study, according to the data extraction, repeated readings of the studies, and discussions among the 5 members of the team doing this work, were:

- Connectedness and Communication
- Control/Empowerment
- Transformation
- Wellbeing
- Polarisation
- Integration.

To compare where and how these concepts were used and defined, both as 1st order concepts (participants' words) or 2nd order concepts (researchers' words, or defined concepts) a series of Translation Grids were devised [see later in this document, they are there in full] for the five key concept areas above.

Each of the five groups had a main concept (which had been identified in the earlier stages of analysis) and the grid helped define how the other concepts related to this. Empty cells show where a paper did not have relevant data for that concept at that level. Because of the short, practical nature of many of the papers (and also the quality of the research described) there was often a significant lack of description/elaboration/ theorising of second order concepts, so in these grids we include where possible first order concepts from the papers – relevant participant quotes which appear to be drawn on by the authors in their analysis.

As well as making the task of translation possible even for those papers which did not provide much in the way of second order analysis, this method also has the benefit of addressing one of the regular criticisms of meta-ethnography – that the process leads to an analysis which is too far removed from the original data.

Grid headings explained

Paper	1st order concept	2nd order concept	contrasted with...	Our definition
Paper author	Direct quotation from participant, which authors appear to be drawing on to form 2 nd order concept	Concept described (explicitly or implicitly) by authors in paper	Where an explicit contrast to the concept is provided, we show it here.	3 rd order concept – based on 2 nd order and, where appropriate, 1 st order concepts in papers

Translation grid 1. Connectedness and Communication (YOU CAN SEE THIS LATER IN DOC)

In the grid for the Connectedness concept we note the instances of when the core concept of Connectedness/Connecting was used (in those terms) in the first order or second order concepts. We also note 8 main sub-concepts which were used in at least two of papers either as a first or second-order quote:

3. Social Relating.
4. Therapeutic Relating
5. Communicating through touch
6. Normalisation
7. Connecting mind and body

8. Communicating with caregivers
9. Isolation
10. Disconnecting

We use these 8 sub-concepts, drawn from the 1st order and 2nd order concepts, as our definitions (in the final column of the grid) and in this way the translation of both the 1st order and the 2nd order terms into the terms from other studies can be seen.

Contrasts: The grid also has a column showing what the key concepts are contrasted with, where this is explicitly mentioned in the 1st order or 2nd order quotes.

Opposite concepts – Isolation and Disconnecting are opposites of the rest of the Connecting themes. But Isolation is constructed as undesirable, and Disconnecting is constructed (by the participant who uses it in this example) as desirable.

Translation grid 2. Control

In the grid for Control we note the instances of where the core concept of Control was used (in those terms) in the first order or second order concepts. We also note 5 main sub-concepts which were used in at least two of the papers either as a first order or second order quote:

- Empowerment
- Agency
- Control over treatment/illness progression/symptoms
- Self control
- Surrendering control

Contrasts: The grid also has a column showing what the key concepts are contrasted with, where this is explicitly mentioned in the 1st order or 2nd order quotes.

Opposite concepts – Surrendering control is a clear (apparent) opposite to the rest of the Control theme. But rather interestingly, in the three papers this concept appears in it is pick up on as a positive, empowering behaviour., and related to Empowerment.

Translation grid 3. Transformation/Wellbeing/Spirituality/Holism

In this grid we note the instances of where these four concepts have been (in those terms) in the first order or second order concepts. I include a 5th concept in the 3rd order concept list - Quality of life. This was often a 1st order term, and it seems to suggest a general improvement in wellbeing without having more transformative connotations. So, Wellbeing at a fairly pragmatic level, whereas Wellbeing is often used with hints of a transformative element.

Spirituality: If you look at the 2nd order definitions of Spirituality in these papers and in the wider literature, I think it covers very similar ground to Transformation. We might say that they are the same concept, according to the definitions we have. Going to look at this a bit more.

Contrasts: Often the contrast is not clear. Several times there is explicit contrast with Cure. Spiritual Healing or Overall Wellbeing rather than physical cure. Which fits with the literature on this too.

Translation grid 4. Polarisation

We distinguished the following categories.

- Polarisation of service provider. Contrasted with Integration. Structural polarisation.
- Polarisation of systems. Separate spheres. Conceptual polarisation.
- Polarisation wrt communication. Processual polarisation?
- Abandonment.
- Treatment incompatibility
- Positive concept of separate spheres

Problematic polarisation contrasted with patients acceptance or appreciation of CAM and biomedicine as catering to different needs.

Contrasts: Integration, shown in separate grid.

Translation grid 5. Integration

In the grid for Integration we distinguish the following categories/3rd order concepts

11. **Integrative Health Care (IHC)** = integrative system of biomedical and CAM healthcare in same setting. (Structure?)
12. **Holism** = experience of CAM as integrated/holistic concept. (but generally not integrated with biomed). (Concept?)
13. **Integration with regard to communication** (Process?)

Boon et al outlined a model for understanding integration at different levels. Drawing on this, IHC can be seen as Integration at a Structural level, Holism encompasses the concept of Integration as a concept, and Integration wrt communication (biomedical and CAM professionals communicating between each other and to the patient about the alternative system) can be understood as a Process of integration.

We also outline three contrasting, or opposing, concepts to Integration, as they appeared in these papers:

Opposing concepts:

14. Fragmentation (opposed to Holism). Concept.
15. Polarisation (opposed to Integration). Structure.
16. Communication difficulties (opposed to Integration with regard to communication). Process.

6.3 Refutational translation

As noted in the beginning of chap 6, the studies we are looking at are quite consistent in many ways. Many of the papers have similar themes emerging, and also similar ways of interpreting by the authors. Corroborating each other rather than refuting. This emergence of a fairly consistent overall “story” about use of CAM during the cancer journey, will be considered in the next chapter.

Studies with concepts which in some way refute the majority of the study concepts

Where there is a different theme it is usually from the marginal papers which look at significantly different patient groups or stages of disease or treatment. Three papers in the study which are particularly distinctive are Montbriand, Moss, and Hok.

Montbriand's study is of a specific set of people, “biomedical abandoners”, seven Canadian participants who all refused conventional treatment for cancer. The different themes which emerge in this context can be attributed to the different context – these participants are the only ones in the meta-study who are using the therapies/treatments/regimes as Alternative rather than Complementary Medicine.

The second paper, Moss, is a study of a controversial treatment (cytoluminescent therapy) which did have considerable impact in health and pain levels for participants. The participants in this study were seriously ill with late stage or terminal cancer, and the treatment course was more intrusive than many CAM therapies. The differences in the concepts which emerged in this paper can therefore be attributed to the uniqueness (in our meta-study) of the treatment context, as well as due to the seriousness of the stage of cancer for participants in that study.

Hok’s paper is a narrative analysis of one patient, who died of liver cancer, via their spouse who describes the experience of integrating biomedicine and alternative medicine.(more here)

All of the following concepts do at some level refute the general understanding of that concept within the meta-study:

16. Control: surrendering control → empowerment.
17. Disconnecting as a Good, rather than general assumption Connecting is good.
18. Separate spheres experienced as a benefit not as a negative polarisation.

Translation Grid 1: concept of Connectedness and Communication in each of the 26 papers

Our definitions/3rd order concepts. Sub-themes of **Connecting**:

17. Social Relating.
18. Therapeutic Relating
19. Communicating through touch
20. Normalisation
21. Connecting mind and body
22. Communicating with caregivers
23. Isolation
24. Disconnecting

Paper	1st order concept	2 nd order concept	contrasted with...	Our definition 3 rd order concept
Angen et al (2003)	<i>"The group sessions... they were the greatest thing that could ever happen, because I had never talked to any other cancer patients before. It was just tremendous"</i>	Mind body therapies helped participants relax and recover a connection to their physical selves	Isolation, depression	Connecting mind and body Social relating
Astin et al (2006)		Movement therapies used to reduce stress and connect with the mind and body.		Connecting mind and body
Bennett et al (2006)	<i>"I was some kind of leper", and that the CAM treatment "normalised the condition".</i>	Concept of Social Isolation.	People feel isolated by/with a diagnosis of cancer	Isolation. (they link concept to Control) Normalisation.
Billhult and Dahlberg 2001	<i>"It's a person you know – the staff are in a hurry all the time"</i> Well, I disconnect everything, it feels as it follows almost up to the head	The course encouraged the development of a positive relationship with hospital staff . concept of meaningful relief from/leaving suffering	In contrast to lack of time with biomed professionals.	Therapeutic relating Disconnecting as a benefit
Billhult et al 2007	<i>What I feel is that I really get confirmed when someone touches me</i>			Communicating through touch
Bishop and Yardley (2004)				

Paper	1st order concept	2 nd order concept	contrasted with...	Our definition 3 rd order concept
Brennan and Stevens (1998)				
Canales and Gellar (2003)	<p>Relationships were “<i>more important than this busyness of life</i>”</p> <p><i>I do take vitamins and I do read Prevention magazine, so I am aware of some of these things, but I am hesitant, because I have so many different things that I'm dealing with to try these things on my own. So I feel like I need somebody who is versed in the whole body.</i></p>			<p>Social relating</p> <p>Connecting between mind and body. Holism</p>
Correa-velez et al (2005)				
Dunwoody et al (2002)	<p><i>“She’s [the aromatherapist] a part of the therapy, ‘cause she’ll listen to you”</i></p> <p><i>“It’s lovely, it’s really lovely, someone working with your body, it is just sheer pleasure”</i></p>	<p>Participants talked about the Counselling role of the aromatherapist</p> <p>Communication through touch - someone cared enough to work with their bodies especially following breast surgery or colostomy; comfort and reassurance</p>	<p>In contrast to lack of time with biomed professionals.</p> <p>In contrast to feeling scarred by surgery.</p>	<p>Therapeutic relating</p> <p>Communicating through touch</p>
Evans et al (2007)		<p>Participants reported good communication with CAM practitioners</p> <p>CAM may provide a vehicle for men to communicate need for comfort, emotional and psychological support.</p>		<p>Therapeutic relating</p> <p>Communicating with caregivers</p>
Gambles et al (2002)	<p><i>I like the people – they put you at ease. They listen and this helps you to relax and I feel good when I have had my reflexology.</i></p> <p><i>The staff make you feel like people and not just a</i></p>	<p>Relationships were highlighted as important aspects of the experience of reflexology</p>		<p>Social relating</p> <p>Therapeutic relating</p>

Paper	1st order concept	2 nd order concept	contrasted with...	Our definition 3 rd order concept
	<p>number. They are kind and courteous. (patient 25)</p> <p>(I benefited from) being able to discuss illness with caring and friendly staff.. . (patient 43)</p>			
Hok (2007)		<p>CAM can become a space where practitioners, even biomedical ones, can form a meaningful relationship with patients.</p> <p>2nd order concept of Making connections between symptoms of a diseased body and the life of ill people and their families.</p>		<p>Therapeutic relating</p> <p>Connecting</p>
Humpel and Jones (2006)				
Mackenzie et al (2007)	<i>“Profound understanding because we all share a similar experience.”</i>	Shared Experience of CAM as being one of the 5 major concepts emerging.		Social relating
Markovic et al (2006)	<i>That (Reiki) centred my mind and body. It got me together some way or other</i>			Connecting mind and body
Montbriand (1998)		Social group association was instrumental in choice of CAM.		Social relating
Moore and Spiegel (2000)		CAM helping cancer patients to re-connect with their bodies		Connecting mind and body
Moss (2003)				
Mulkins and Verhoef (2004)	<p><i>“Sometimes I think my biggest healing comes from my connection with the therapists, and the benefit I get from the technique itself is not so important”.</i></p> <p><i>“The major turning point</i></p>	<p>Connection with their therapists was the primary benefit of the treatment:</p> <p>Development of Therapeutic relationships between patient and provider.</p> <p>Preserving the</p>		<p>Therapeutic relating.</p> <p>Connecting</p> <p>Connecting mind</p>

Paper	1st order concept	2 nd order concept	contrasted with...	Our definition 3 rd order concept
	<p><i>for me was.... we had a ritual in the group that we did to kind of make amends with our bodies and cancer. It was what was so life altering... I feel more confident and a lot more calm.</i></p> <p><i>Everyone was nice enough but I really felt like I wasn't truly connecting with anyone; I felt isolated. I was looking to other options besides my chemo</i></p>	<p>balance. (their 2nd order concept)</p> <p>Authors have concept of Disconnecting</p>	<p>Contrasted with Isolation</p>	<p>and body</p> <p>Connecting (1st order concept)</p> <p>Isolation</p>
Partridge et al (2005)		The acupuncturist spent more time with participants than biomedical professionals did, leading to a good relationship		Therapeutic relating
Ribeiro et al (2006)		Importance of the social group both as a predictor of someone's openness to cam and as a benefit of CAM.	In contrast to poor communication in participants' biomedical experience	Social relating
Taylor and Ingleton (2003)				
Verhoef and Mulkins (2005)	<i>"The power of working with others who have been where I have been was incredible"</i>	Noted social group benefits and called them "feeling connected"		Social relating Connecting
Walker et al (2007)	<p><i>"Women enjoyed the group aspect of the therapy. "cancer tends to cut you off... you weren't alone"</i></p> <p><i>'Nice to know that people are leaving drips everywhere' 'your problems are not unique'.</i></p> <p><i>I'd not known anyone with breast cancer and talking to other people and finding out all the little niggles that you had, they weren't unique to you, especially if</i></p>	<p>Found a similar feeling connected theme of being in a group.</p> <p>Mutual support an important aspect of aromatherapy</p>	<p>Social relating/connecting in contrast to feeling alone, having no one to talk to in the same position.</p>	<p>Social relating AND connecting. (Major themes in this paper)</p> <p>Isolation</p>

Paper	1st order concept	2 nd order concept	contrasted with...	Our definition 3 rd order concept
	<p><i>someone could come up with something worse than you then you feel better. All the way through until I'd had the acupuncture I'd not really discussed it with anyone. So to talk to other people that have been through exactly the samey I did find very good.</i></p>			
Wong-Kim and Merighi (2007)	<p><i>'I don't understand the interaction and you are not supposed to mix western complementary medicine'</i></p>	<p>Problem for patients created by the lack of communication between biomed and CAM specialists.</p>	<p>Lack of communication</p>	<p>Polarisation due to not connecting?</p>

Translation Grid 2: concept of Control in each of the 26 papers

Our definitions/3rd order concepts. Sub-themes of **Control**:

- Empowerment
- Agency
- Control over treatment/illness progression/symptoms
- Self control
- Surrendering control

(wellbeing concept is mentioned on occasion though it's not part of Control theme but pops up occasionally and I don't want to lose the connection)

Paper	Control as 1st order concept	Control as 2 nd order concept	Control contrasted with...	Explicit theory/definition in paper?
Angen et al (2003)	n	n		
Astin et al (2006)	n	n		
Bennett et al (2006)		<p>Bennett had the 2nd order theme of Being active agents as a very important aspect of CAM treatment.</p> <p>Gaining a sense of control, feeling empowered</p> <p>Participants belief that intervention helped them not only function better but to take control.</p> <p>Control of own treatment, being active agents, very important. (</p>	<p>Emergence of cancer - An event out of their control.</p> <p>Control over own treatment in contrast to handing over control to others.</p>	<p>Agency</p> <p>Control over treatment</p>
Billhult and Dahlberg 2001	<p>I feel like I have gotten some strength and balance.</p> <p><i>Is there a difference before and after the massage?</i></p> <p>Yes I think so...</p> <p><i>When you say strength, what do you mean legs or the body?</i></p> <p>Well first the legs and then the body and the overall well-being</p>	<p>Agency: Taking active part in their health process.</p> <p>Patients feeling empowered</p>		<p>Agency</p> <p>Empowerment (2nd order)</p> <p>Well-being (1st order)</p>

Paper	Control as 1st order concept	Control as 2 nd order concept	Control contrasted with...	Explicit theory/definition in paper?
Billhult et al 2007				
Bishop and Yardley (2004)		Complementary medicine as a domain in which patients can take on agency (while leaving health professionals with agency for biomedicine). (Bishop)	In contrast to control of health care by biomedical staff	Agency. They have elaborated on this, need to summarise it.
Brennan and Stevens (1998)	<p><i>"I control it with my mind now"</i> said one. And another said: <i>"I got a lot of pain following the second operation. I did not think I could stand it. Took the strongest pain killers.. get you off to sleep but then you'd wake up in pain and that was your night. I decided to take control of myself after I'd attended a few meditation classes. I got on top and I did not need the pain killers again".</i></p> <p>In another quote from Brennan, a woman said <i>"Meditation gives you control, takes it back from them (doctors and nurses) ad I give it to me. I think that that's so important and probably the great change in my life as a result of this event"</i>.</p>	Brennan noted that "being proud of themselves fro achieving their own control without having to resort to strong medications was expressed by all (p23):	<p>in contrast to the pain she experienced before the experience of meditation.</p> <p>Also control in contrast to health professionals having the control</p>	Self control
Canales and Gellar (2003)	<i>"I definitely have changed. I definitely take more control of my own body than... you know, I don't leave the control to the doctor in that, you know, like if he said I really think you should go to a</i>	Canales 2 nd order theme Relying more on themselves . I think this is similar to the agency theme.	control in contrast to leaving control to the doctor:	Self control

Paper	Control as 1st order concept	Control as 2 nd order concept	Control contrasted with...	Explicit theory/definition in paper?
	<i>specialist, I'll tell him right out I don't need to. And I don't want to".</i>			
Correa-velez et al (2005)				
Dunwoody et al (2002)		2 nd order concept of Patient Empowerment		Empowerment defined as "treatment being catered to their individual needs; being given information, explanation and choice; what would you like to do today?"
Evans et al (2007)	<i>I've rarely had continuity of care. This consultant once again hadn't read my notes and he wouldn't let me see the scans, the whole thing was very dismissive . . . he was very unsupportive, his mobile phone went off in the middle of the session and he answered it, I was very angry and I wrote and asked for my previous consultant – I took it into my own hands which was a good thing for me to do, it was good for me to take charge of the situation'.</i>	taking charge or taking control/ need for control	In contrast to consultant not being focused on situation, in contrast to polarisation maybe?	Empowerment?
Gambles et al (2002)				
Hok (2007)				
Humpel and Jones (2006)		CAM giving greater sense of control over lives/treatment.		Control over treatment
Mackenzie et al (2007)	<i>"Meditation and yoga are ways to take control of our lives in a positive way. What the meditation does is give me time to look within. By looking within, that gives me control".</i>	2 nd of 5 emerging themes was about self control. They also mention surrendering control:		Self control refers to patients developing the ability to control their own behaviours.... Surrendering control

Paper	Control as 1st order concept	Control as 2 nd order concept	Control contrasted with...	Explicit theory/definition in paper?
	<i>“When I do the yoga and meditation I’m in better control of myself... not that it works all the time... if I don’t do it I really notice it. Things go haywire.”</i>	“Participants developed a sense of knowing where there was potential for influencing outcomes, and when to simply let go and relinquish efforts at controlling the uncontrollable.”		
Markovic et al (2006)	<i>“Reiki - gets me together some way or other. I felt like I was more in control because I felt like I had completely thrown myself into the hands of the medical world.”</i>	talks about feeling in control	In contrast to leaving control to medical profession	Empowerment?
Montbriand (1998)		Taking control Also giving away control.		Taking control. Surrendering control
Moore and Speigel (2000)		Guided imagery can give patients a sense of control over progression of disease. (Moore)	Contrasted with “spoiled identity” due to cancer	Control over illness progression They related need for control to spoiled identity.
Moss (2003)				
Mulkins and Verhoef (2004)	<i>“My approach to controlling everything was not going to work.... Take a step back from it all. And now that has been my new approach. I am taking it day by day. Who knows what will happen. I can’t dwell on that”.</i> <i>It is a matter of being ready to embrace all of this chaos.</i>	Surrendering control		Surrendering control. Empowerment.
Partridge et al (2005)				
Ribeiro et al (2006)				
Taylor and Ingleton (2003)	<i>I think it really helped me relax all the way through and</i>	Feeling in control, confidence building, and visualisation – strongly		Empowerment? They explicitly related control to fighting talk

Paper	Control as 1st order concept	Control as 2 nd order concept	Control contrasted with...	Explicit theory/definition in paper?
	<i>visualizing that I was actually helping my body to get rid of the cancer and make myself better."</i>	interwoven in participants' accounts. Following patients' agenda rather than therapist's in determining therapies.		
Verhoef and Mulkins (2005)	<i>"IHC allows you more control over your health. Because there are no barriers... you are making decisions about how you want to live your life</i>	don't make a second order concept out of Control though – they talk in terms of Transformation instead		Empowerment?
Walker et al (2007)				
Wong-Kim and Merighi (2007)		Importance of using CAM to control pain for women with breast cancer.		Control over symptoms

Translation Grid 3: concept of Transformation/Wellbeing/Spirituality/Holism in each of the 26 papers

I haven't yet settled on an overarching concept for this set but they seem very interrelated in the papers.

See how respondents and authors use terms and how we define/interpret them:

- 25. Transformation
- 26. Wellbeing
- 27. Spirituality
- 28. Holism
- 29. Quality of life. Often a 1st order term. General wb improvement without more transformative connotations. Maybe.

Paper	as 1st order concept	as 2 nd order concept	contrasted with...	Our definition
Angen et al (2003)	<p><i>“Up to that point I only had the physical...curing, but I didn't have the healing.”</i></p> <p><i>“There is more to be healed than just the cancer.... We're still working on that and I think that's where all these other things [CAM] come in.”</i></p> <p><i>“The retreat didn't solve my issues, but it It enabled me to believe that I could go on, that there was hope that I could go on living, that I could enjoy it, and that I could deal with whatever was around the corner”</i></p>	<p>Spiritual impact as 2nd order concept</p> <p>sense of increased social and spiritual connectedness from participation in mind-body therapy.</p> <p>one participant made a distinction between physical cure and healing.</p> <p>Holistic approach as one of the key 2nd order concepts.</p> <p>Looking beyond the cancer experience/hope</p>	<p>deep relaxation and meditations were antidotes to the anxiety of tests, treatments and awaiting results.</p> <p>(Spiritual) healing in contrast to physical cure.</p>	<p>Wellbeing in contrast to treatment anxieties</p> <p>Spirituality linked to Connecting</p> <p>Holism</p> <p>Transformation ?</p>
Astin et al (2006)	<p><i>“Support groups [are part of complementary medicine] because your mind and spirit have a huge amount to do with healing</i></p>	<p>majority of their participants considered psychosocial and spiritual activities crucial in treatment</p>		<p>Relates Spirituality and Connecting</p>

Paper	as 1st order concept	as 2 nd order concept	contrasted with...	Our definition
	<i>for anything... knowing you're not alone".</i>	and recovery"		
Bennett et al (2006)		Concept of Self-Identity: the perception of 'self' changed before there were any surgical or medical procedures that may change the physical 'self', and that this change was apparent at the first diagnosis of breast cancer Women with returning breast cancer, participants were able, through CAM, to conceptualise that life had not ended with a second diagnosis.		Transformation (changed self identity)? Wellbeing?
Billhult and Dahlberg 2001	<i>When you say strength, what do you mean legs or the body?</i> Well first the legs and then the body and the overall well-being	feeling good		Wellbeing
Billhult et al 2007	<i>It is a feeling of well-being; it is a feeling that you feel good . . . [How does it feel?] It feels good; I think it just feels good to be massaged</i>	feeling good as a concept in itself. Also Wellbeing "experiencing a sense of well-being despite a troublesome situation"	WB in contrast to "feeling of uneasiness in chemo treatment."	Wellbeing Conceptualised on pragmatic terms. No sense of spir healing or transformation here.
Bishop and Yardley (2004)	<i>I also have healing, spiritual healing which uplifts you. I don't say it cures you, but it makes you feel better anyway, and I think that you've got to have, well, you've just got to go on hope – you-, you-, you can't give in, you've got to fight it. Don't you, don't you all agree?</i>	Feeling good Value of spiritual healing in terms of personal well-being	Contrast to physical cure	Spiritual healing (1 st order concept) Wellbeing (2 nd order concept explicitly translating spir healing into wb)
Brennan and Stevens (1998)	<i>"I cannot believe how good it's made me feel in so many different ways, psychologically as well as physically" (p23).</i>	"Motivation to change behaviour" - one of their main themes emerging from their study.		Transformation ?

Paper	as 1st order concept	as 2 nd order concept	contrasted with...	Our definition
Canales and Gellar (2003)	<i>Well you definitely appreciate life more and you definitely don't take it for granted : : : like just going for a walk on the beach, you just take in every little moment, you know, you do, you appreciate it more, not like before, where you didn't realize what life was really about, and now you do.</i>	Feeling good. Concept of Philosophy of Life the desire to attend to the present and live each day to the fullest.	Contrast to cure	Wellbeing Transformation
Correa-velez et al (2005)	<i>"I started reiki and then I realised it was working.... And that makes you much more aware of what you are doing. It makes you realise that quality is the thing not quantity"</i>	Boosting energy CAM for enhancing Quality of Life, relieving general well-being. CAM to reduce psych and spiritual distress.	WB in contrast to spiritual distress.	Wellbeing Quality of Life
Dunwoody et al (2002)				
Evans et al (2007)		men may enjoy better quality of life through accessing CAM 2 nd order concept: Desire for a more holistic approach. "Many participants hoped for psychological, emotional or spiritual support, and they valued the more individualized 'whole-person' approach with an emphasis on selfhealing that typifies many CAM therapies."		Quality of Life Holism. Concept elaborated on.
Gambles et al (2002)		CAM helps with improving quality of life for patients struggling to cope with effects of cancer and		Quality of Life

Paper	as 1st order concept	as 2 nd order concept	contrasted with...	Our definition
		treatment. importance of touch and spiritual nourishment		Spirituality
Hok (2007)				
Humpel and Jones (2006)				
Mackenzie et al (2007)	<i>“I’ve become a lot more spiritual”.</i> <i>Doing meditation brought me more into the spiritual.</i>	2 nd order concept of Spirituality development of spirituality may be an inevitable outcome of the practice, as one becomes aware of the intricate interconnections among themselves, other individuals and eventually all aspects of nature through direct experience.		Spirituality Mackenzie elaborates, connects with Interconnecting
Markovic et al (2006)		Concept of Spiritual healing		
Montbriand (1998)		participants stressed the Importance of personal mysticism and spirituality as a cushion against fears.		
Moore and Spiegel (2000)		people used CAM (guided imagery) to carve a niche of health out of illness.		Wellbeing? Quality of Life?
Moss (2003)	My quality of life is better than it was before I started treatment.”			Quality of life
Mulkins and Verhoef (2004)	<i>“healing is more about the spirit and freedom that comes from the reality that is within me”</i> <i>It is a matter of being ready to embrace all of this chaos. This kind of self-involvement won’t happen unless you are 100% into it. It has been my own personal journey, and looking back, I don’t</i>	2 nd order concept <i>Secure in well-being</i> Transformative dimensions of integrative health care”: Care that focuses		Spirituality Wellbeing. Transformation Wellbeing, Holism

Paper	as 1st order concept	as 2 nd order concept	contrasted with...	Our definition
	<i>think it would have happened any sooner. You truly need to be ready to take it on. Once you are I guess maybe things just start to happen.</i>	on one's overall well being		This paper elaborates on concepts of transformation and wb.
Partridge et al (2005)				
Ribeiro et al (2006)	<i>'had an experience that led them to a more positive outlook on life and made them stronger as individuals' (resilience).</i>	Boosting energy women in their study felt conventional medicine was adequate to treat the disease but lacking in other areas such as improving the quality of life		Wellbeing Quality of Life Transformation ?
Taylor and Ingleton (2003)				
Verhoef and Mulkins (2005)	<i>"I am changed... my whole pace has slowed down... I am more present in my life"</i> <i>"I am savouring life now, taking it all in... trying things I would have never dreamed of trying."</i>	Personal transformation as one of their 6 main benefits of an IHC programme.		Transformation
Walker et al (2007)	<i>I thought "Oh this is good", it's just giving quality of life, basically</i>	Sense of increased overall well being		Wellbeing. (2 nd order concept). QoL (1 st order concept).
Wong-Kim and Merighi (2007)				

Translation Grid 4: concept of Polarisation in each of the 26 papers

- Polarisation of service provider. Contrasted with Integration. Structural polarisation.
- Polarisation of systems. Separate spheres. Conceptual polarisation.
- Polarisation with regard to communication. Processual polarisation?
- Abandonment.
- Treatment incompatibility.
- Positive concept of separate spheres.

Problematic polarisation contrasted with a positive experience of polarisation - patients acceptance or appreciation of CAM and biomedicine as catering to different needs.

Paper	Polarisation as 1st order concept	Polarisation as 2 nd order concept	Contrasted with...	How categorise this?
Angen et al (2003)				
Astin et al (2006)		Participants had concerns about herbs vitamins and supplements interfering with conventional treatment. Or promoting cancer.		Treatment incompatibility
Bennett et al (2006)				
Billhult and Dahlberg 2001	Massage participants experienced a “retreat from uneasy, unwanted, negative feelings about chemotherapy”			Positive use of separate spheres.
Billhult et al 2007				
Bishop and Yardley (2004)		Participants felt alienated from biomedical professionals, and found themselves opposing the doctor's advice in taking up CAM treatments.		Structural Polarisation
Brennan and Stevens (1998)	<i>“I don’t want them to say it’s a lot of rubbish and me have to say I don’t agree. That would ruin a lot of things.”</i>	None of the participants had told their oncologist that they were practising meditation.		Polarisation wrt communication
Canales and Gellar (2003)	<i>See, my primary care doesn’t accept anything that my naturopath doctor, who is an official MD does. But the naturopath is very</i>			Polarisation wrt communication

Paper	Polarisation as 1st order concept	Polarisation as 2 nd order concept	Contrasted with...	How categorise this?
	<i>tolerant of the conventional doctor. Which I think there are good points to each.</i>			
Correa-velez et al (2005)				
Dunwoody et al (2002)				
Evans et al (2007)		Men acknowledged the difficulty of measuring effectiveness of CAM when used in parallel with biomedicine.		Treatment incompatibility
Gambles et al (2002)				
Hok (2007)				
Humpel and Jones (2006)		Participants had worries about CAM interfering with conventional treatment. Wariness about mentioning CAM to biomedical professionals. Doctors often opposed CAM and were unwilling to discuss it.		Treatment incompatibility Polarisation wrt communication
Mackenzie et al (2007)				
Markovic et al (2006)	<i>“That's when you go to the complementary therapy - it's when they leave you alone in between. Because, you know, otherwise you're left alone”. You can see an acupuncturist every day but if you went to see a Western doctor every day, people would think you were crazy.</i>	Markovic found that a major weakness of biomedical treatments mentioned was the personal care aspect - hospital setting was viewed as depersonalised. And so people turned to CAM for more personal care.		Structural polarisation.
Montbriand (1998)		Poor communication with biomedical professionals was a major cause of biomedical abandonment.		Abandonment. Polarisation wrt communication
Moore and Spiegel (2000)				
Moss (2003)		Participants felt abandoned by their CAM (cytoluminescent therapy) practitioner.		Abandonment
Mulkins and				

Paper	Polarisation as 1st order concept	Polarisation as 2 nd order concept	Contrasted with...	How categorise this?
Verhoef (2004)				
Partridge et al (2005)				
Ribeiro et al (2006)				
Taylor and Ingleton (2003)	<p><i>I think that maybe the GPs need . . . more awareness about the availability of this kind of service because they're the person who has contact . . . and I think it's very important for them to offer this kind of facility and alternative to the conventional chemical medicines, erm – because I think if it's worked in conjunction with that, erm – it can only be . . . helpful to the patient.</i></p>	<p>Patients were inhibited from attending the hypnotherapy centre because it was next to a hospice, they recommended a separate building off-site.</p> <p>main criticism was lack of information about the existence of the service in appropriate clinics, closely followed by the need for health professionals to explain the programme beforehand.</p> <p>Problems with lack of communic/info from biomed ab cam.</p>		<p>Structural polarisation.</p> <p>Processual/information polarisation</p> <p>Polarisation wrt communication</p>
Verhoef and Mulkins (2005)				
Walker et al (2007)				
Wong-Kim and Merighi (2007)		<p>CAM tried after conventional medicine so as not to “counteract anything”</p> <p>participants reported problems with lack of communication between biomed and CAM professionals</p>		<p>Treatment Incompatibility</p> <p>Polarisation wrt communication.</p>

Paper	as 1st order concept	as 2 nd order concept	Contrasted with	Our definition/3 rd order concept
Billhult et al 2007				
Bishop and Yardley (2004)				
Brennan and Stevens (1998)				
Canales and Gellar (2003)	<p><i>“It was nice to be in a conventional setting and get a lot of support for what you feel is valuable”</i></p> <p>I do take vitamins and I do read <i>Prevention</i> magazine, so I am aware of some of these things, but I am hesitant, because I have so many different things that I’m dealing with to try these things on my own. So I feel like I need somebody who is versed in the <i>whole body</i>.</p>	Some participants preferred the massage and chiropractic sessions to be in a biomedical setting:	Polarisation between biomed and CAM	Desire for integration/holism.
Correa-velez et al (2005)				
Dunwoody et al (2002)	<i>“Faith in having it at cancer unit. Happier here...somewhere else people will be looking at me.”</i>	Liked having CAM at integrated (hospital) setting		IHC
Evans et al (2007)				
Gambles et al (2002)	Quotes about which bits of experience patients liked: caring environment, talking to therapist.	Patients evaluated the whole experience - the ambience of the centre, the staff, the therapist, as well as the experience of the treatment itself.	Fragmentation?	Holism
Hok (2007)	Narrative quotes to this effect.	<p>participant used discussions about CAM use with biomedical professionals as a means of reconciliation between CAM and biomedicine.</p> <p>biomedical professional involved in the case came to agree with him about this - reconciling CAM</p>	Polarisation between biomed and CAM	Integration wrt communication

Paper	as 1st order concept	as 2 nd order concept	Contrasted with	Our definition/3 rd order concept
		and biomedical approaches		Holism
Humpel and Jones (2006)				
Mackenzie et al (2007)	<i>“This was an institutionally supported programme. It was respectable and authorised. That was important to me”</i>	People liked the integration of the MBSR programme.	Polarisation between biomed and CAM	IHC
Markovic et al (2006)				
Montbriand (1998)				
Moore and Spiegel (2000)				
Moss (2003)				
Mulkins and Verhoef (2004)	<i>My doctor here, she was funny, graceful, and loving and so she empowered me. We make decisions here as equals. She said, “Okay, so what do you want to do?” It was like I was the doctor</i>	While receiving integrative care, individuals were expected to engage with the program and services at their own pace. Participants felt that having this chance to explore and find the right fit for them with practitioners and modalities helped to create an optimal environment for transformation to occur	Polarisation between biomed and CAM. Communication difficulties	IHC. Definition give
Partridge et al (2005)	Can’t spot a 1 st order quote for this. <i>“I think I would if it came from Dr M ... It would have to be from somebody that I respected”</i>	Acupuncture made the treatment complete by focusing on more than the purely medical aspects of treatment. Patients relied on physician and were more likely to try a CAM therapy if physician recommended	Polarisation	Holism Integration wrt communication.
Ribeiro et al (2006)				
Taylor and Ingleton (2003)	<i>I think that maybe the GPs need . . . more awareness about the availability of this kind of service because</i>	Some patients experienced difficulties with referral, which may reflect communication deficits and/or	Contrasts with Polarisation between biomed and CAM	Integration wrt communication. CAM as a holistic experience?

Paper	as 1st order concept	as 2 nd order concept	Contrasted with	Our definition/3 rd order concept
	<p><i>they're the person who has contact . . . and I think it's very important for them to offer this kind of facility and alternative to the conventional chemical medicines, erm – because I think if it's worked in conjunction with that, erm – it can only be . . . helpful to the patient.</i></p> <p><i>They obviously try to assess exactly what your personal needs are and try to work to them.</i></p>	<p>mistrust of hypnotherapy.</p> <p>Patients tended to view the intervention as a treatment package, not separating cognitive and behavioural elements.</p>		<p>Study is in UK IHC setting.</p> <p>Holism</p>
Verhoef and Mulkins (2005)	<p><i>“Integrative Health Care allows you more control over your health. Because there are no barriers... you are making decisions about how you want to live your life and hopefully you will respond to that.”</i></p>	<p>Integrative Health care. Patients liked the integration for the lack of barriers:</p>	Fragmentation?	<p>IHC.</p> <p>Related to Mulkins paper</p>
Walker et al (2007)				
Wong-Kim and Merighi (2007)				

Chapter 7 Synthesis

Contents

- 7.1 What is Synthesis?
- 7.2 Findings in this study – the building blocks
- 7.3 A story of the experience of CAM after a diagnosis of cancer
- 7.4 A lines of argument synthesis
- 7.5 A diagram of the synthesis

7.1 What is Synthesis?

“**Synthesis** is achieved by maintaining the central metaphors and/or concepts of each account and comparing them to other key metaphors or concepts in that account (Noblit and Hare, 1988). The process is, metaphorically, a sewing together of analysis and synthesis (Kewrney, 1998a). The language that is used in the synthesis might contain new metaphors that have more adequate economy, cogency, range, appearance, and credibility than those of either study” (Bondas and Hare, 2007: 118).

However, it is vital to remember that the methodology is a cyclical, iterative process. Processes of translation/synthesis/analysis/theory building going on simultaneously and cyclically.

Lines of argument synthesis: Tying the studies together by noting just how one study informs and goes beyond another (Bondas and Hall 07 citing Noblit and Hare 88). Presumably, in an ideal world that works by studies being informed by other relevant recent research, which is also in the meta-study. Which is rare in our study and also in other meta-studies. They do often refer to other papers but aren't based on them very often.

Synthesising translations: reading the concepts and interpretations and establishing the relationships between these four studies.

“In Schutz's terms, the building blocks for the synthesis were the second-order interpretations of the original studies, from which we constructed several (third-order) interpretations” (p212)

p213 has a table, 1st, 2nd and 3rd order concepts. Q useful. I think I could do this with control etc.

Outcome: “It is these third-order interpretations that justify the claim that meta ethnography achieves more than a traditional literature review, but in relation to a more focussed question. They represent a conceptual development that constitutes a fresh contribution to the literature. In particular, six key concepts have been identified and linked together in a line of argument that accounts for patients' medicine-taking behaviour and communication with health professionals in a different setting” (Britten et al, 2002: 214).

Noblit and Hare: *The worth of studies is determined in the process of achieving a synthesis*. I think we could agree that for our studies. Some provided more conceptual development than others. (and importantly, I think, were they the ones we expected when we first read them and did a quality appraisal?)

Pound et al long rep. Explore links between the issues identified by use of a “map”. See what terms use, reclassify in terms of other papers' terms.

Gavin in long rep. Compared findings of each paper with that in key (index) paper. Is that what I need to do more of? Can try more explicitly. Perhaps in the subgroups, or for the papers which talk about control, etc.

Smith, Pope, Botha (2005) describe the relation of concept translation and synthesis:

“It (meta-ethnography) entails the systematic identification of shared concepts and themes in published work, which are mapped across studies included in the synthesis. The synthesis translates the findings of individual studies to provide understanding of how they inter-relate (a process similar to the constant comparative techniques used in primary qualitative research).

7.2 Findings in this study – the building blocks

We decided to look at the key themes from 3 frames of reference. We looked at the 7 main concept areas, and considering them in relation to each other, but also in relation to the main treatment/illness stage groups. We synthesised the various building blocks of the analysis (the themes, levels, groups) into a whole – a line of argument synthesis - in three main ways.

1. A story (verbal) of the experience of using CAM after a cancer diagnosis.
2. A description (verbal) of how all the themes fit together and the mediating influences of the other themes, the treatment groups/stage of treatment, the levels of influence.
3. A diagram, or map, to demonstrate the links and influences.

7.3. A story of the experience of using CAM after a cancer diagnosis.

The diagnosis of cancer has the potential to lead to distressing symptoms and treatment side effects, isolation, loss of control and biographical, emotional and physical disruption and distress (need a ref for this). People who use complementary therapies at this time may experience an effect, usually beneficial, in all of these spheres, but this experience is influenced by the degree to which complementary therapies are integrated at a structural level. Most people desire a degree of integration either in the form of integrative cancer services or in terms of their biomedical practitioner being open to and knowledgeable about such therapies (more can be said about this). Without this, when there is a degree of polarisation between biomedicine and complementary therapies, the desired connecting up and reduction in isolation is limited. Nevertheless, most people who use complementary

therapies at this time experience an increased connection between themselves and practitioners, care-givers and other people with cancer, as well as a reconnection and integration of mind and body (and spirit?). This connection is closely associated with communication, both verbal and touch, and is often related to a sense of a more balanced sense of control. The process of gaining a new sense of control appears to be central to many people's experiences of complementary therapies and encompasses a feeling of empowerment that leads to people gaining, taking or surrendering control over their illness, their treatment and/or their life more generally¹. A relief from, or control over, symptoms of cancer and/or biomedical treatment may be experienced as a short term benefit that increases quality of life or feelings of wellbeing. In addition some patients may experience longer term changes that indicate a more fundamental shift in perspective, relationship to control, or spirituality – a process that some authors have described as transformation.

These experiences vary according to the type of therapy and the stage of the 'cancer journey'

7.4 A lines of argument synthesis: how all the themes fit together

7 key concepts have been identified and linked together in a line of argument that accounts for cancer patients' experiences of using CAM. The aim of this synthesis is to develop a Line of Argument by considering each theme and its interpretations, and drawing together the key aspects of the experience of CAM after a diagnosis of cancer into a unified whole.

1. The sense of loss of control/disruption at the point of diagnosis

While our study focused on experiences after a diagnosis of cancer, our line of argument implicitly starts at a stage before this, at the point of diagnosis of cancer. The diagnosis stage for chronic or life-threatening illnesses, such as cancer, is a point of major disruption². Gateley et al (2008) suggest that "being diagnosed with a chronic illness involves disruption of the normal life course, changes to self perception, adaptation to the social world, the redefinition of people's competence as social actors" (Gateley et al, 2008; 146). Besides the shock of the diagnosis, patients often also struggle with medical paternalism – a feeling that decisions are being made for them and that they have few options in the process.

Mulkins and Verhoef put it:

"This feeling of disconnection and loneliness resonated in many of the participants' accounts and appeared to mark the beginning of the process of transforming the experience of living with cancer"

¹ GL suggests this sentence is central

² Bury, M. (1982), Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4: 167-82.

In this state, many people feel a sense of being out of control, a loss of identity, a disruption to the familiar life narrative. Our study focuses on what happens after this point, for people with a diagnosis of cancer who use complementary therapies³.

2. CAM as a way taking back control over life at a time of disruption

From the studies in this meta-synthesis, it is clear that many patients use CAM in a variety of ways, but, generally, as ways of feeling more in control of the situation they are in – either in terms of taking/having control over their treatment, the progression of the illness, or of having some control over symptoms of the illness or the biomedical treatment, such as nausea or pain.

It seems that a particular benefit of CAM is the way it enables patients to take control of, or negotiate within, a small area of their own health and treatment, having some choice in what's happening. A “niche of choice”, as one participant put it. This is important as, in the majority of cases, participants did not want to take charge of their biomedical treatment, but they did want an area of their life and treatment which they could take charge of.

3. CAM as a way of connecting

In the context of feeling isolated or depressed after a diagnosis of cancer, many participants experienced a sense of connecting as an important factor in their CAM treatment. There were different aspects of feeling connected through CAM use – particularly, 3 main areas.

a) Connecting with care provider/ a therapeutic relationship

Some studies (e.g. Markovic) found that a major weakness of biomedical treatments mentioned was the personal care aspect - hospital setting was viewed as depersonalised. And so people turned to CAM for more personal care.

“That's when you go to the complementary therapy - it's when they leave you alone in between. Because, you know, otherwise you're left alone.”

Sometimes the time taken to complete the CAM therapy was the factor which which led to stronger relationships and better communication than with the often rushed biomedical system.

“You can see an acupuncturist every day but if you went to see a Western doctor every day, people would think you were crazy.”

b) Connecting mind and body

A facet of connectedness which was regularly brought up by participants and authors was the idea of connecting, or reconnecting, between mind and body, or body and spirit. This

³ The vast majority of participants in the studies were using CAM therapies as complementary to, not as an alternative to, traditional biomedicine.

was also sometimes called healing a breach.

For example, Astin noted that “Movement therapies [were] used to reduce stress and connect with the mind and body”. Moore and Spiegel suggested that CAM was helping cancer patients to re-connect with their bodies

A number of authors make links between wellbeing and Connecting relating to the physical and emotional connection between one's mind and body. Or healthy and sick body. And, sometimes, the concept of spiritual connectedness (to be returned to shortly).

c) Connecting with others in a social group

A recurring theme was that participants particularly valued their CAM treatment as a means of connecting with others, especially in a group therapy situation. For example, Walker found that people enjoyed the connected feeling of being in a group, and that mutual support was an important aspect of the aromatherapy treatment. For some, this social aspect, and particularly the chance to meet others in the same situation, was the primary benefit of the CAM treatment. It was a way of reducing feelings of isolation and depression.

4. Empowerment

A major theme among the researchers writing up these studies was the ways in which CAM could empower cancer patients in a variety of ways at this stage of their life. The concept of Empowerment was used less often by the participants, who tended to talk about the more pragmatic benefits of CAM treatment – the social side, the sense of taking control, the relief from pain or nausea.

5. Surrendering control

Our meta-study has several examples of participants actively surrendering control, through CAM, and this was conceptualized by the authors as an empowering activity (Mackenzie, Moore, Montbriand). This highlights the ways that the dominant metaphors of taking control etc can be in fact disempowering to participants, limiting the acceptable ways of thinking and talking about their experiences. In some cases at least, CAM provided a means of letting go, of relaxing, or disconnecting” (as one patient put it). Seeing a therapist then involves some handing over of control since it implies a level of trust in the unknown person and therapy and so the patient. The study demonstrated that there is a range of ways in which, as a result of CAM, patients regain a sense of control or empowerment over different areas of their lives, and that letting go or surrendering control is a powerful experience for some at this time.

6. Increased wellbeing: Pragmatic benefits of CAM

Many people use CAM in a very pragmatic way – in the hope of possible benefits. Important outcomes (from the patient perspective) of using CAM treatments after a diagnosis of cancer include the local, perhaps short term benefits of pain relief, time to talk to a therapist, better social relationships. CAM as a way of enhancing current Quality of life. For example, Gambles found that CAM helped with improving quality of life for patients struggling to cope with effects of cancer and treatment.

Some participants viewed CAM as a treat or reward, rather than a treatment (Bishop et al, 08). For example, Dunwoody has a concept of Aromatherapy as a reward, which she defines as participants having time for themselves without the demands of others; hands on approach gave a feeling of worth, being cared for, after a tough time. Angen found that, for some, deep relaxation and meditations were antidotes to the anxiety of tests, treatments and awaiting results.

6. Transformation

The notion of CAM as a transformative experience, and/or a means of personal or spiritual growth, was brought out explicitly in several of the studies, and implicitly in others. People talked about how CAM had changed their behaviour or perspective on the whole of life, not just on their illness or treatment.

A couple of papers focused primarily on transformation, notably Mulkins and Verhoef looked at the “nature of transformation”: “Participants' stories revealed that transformation involved learning about themselves: becoming more aware of who they are and how they relate to the world”. The concept encompasses the notion that change is not just narrowly about the illness or treatment or response to these, but is about changes to whole outlook on life, and lifestyle and practices. Mulkins and Verhoef illustrated this with a first order quote:

“I am changed and so the way I do things in my life is different My whole pace has slowed down, so how I organise my day is different, so then my relationships with the people around me are different. I am more present in my life. Overall, I guess I just really, I feel different. I think I even look different. This has been a very profound and wonderful experience for me”

From our synthesis of the study findings, it seems that some participants undergo a transformative experience, through use of CAM, after a diagnosis of cancer – a process which is linked to, or follows from, the experience of gaining empowerment (or, in some cases, surrendering control).

It is important to note though that for many participants, when asked about the experiences of CAM, talk about the benefits more in terms of quality of life and immediate benefits, than in terms of transformation. This is likely to be partly a way of talking, participants typically use everyday language rather than abstract concepts to talk about their experiences. It is also likely that, for many participants, the benefits are at this level of improving quality of life, in the short term, and that this is valuable in its own right.

7. Spirituality

Spirituality was an emerging theme in many of the studies. Our understanding of spirituality in this context draws on recent theorisation of the concept's use in cancer research⁴, and can be exemplified by Mackenzie in our studies, talking about a Mindfulness

⁴ Koffman et al, “Conceptual confusion is common in relation to religion, faith and spirituality and there is

Based Stress Reduction (MBSR) programme:

“Despite the programme’s secular stance, the development of spirituality may be an inevitable outcome of the practice, as one becomes aware of the intricate interconnections among themselves, other individuals and eventually all aspects of nature through direct experience.”

On this definition, spirituality is very close to our definition of Transformation, certainly it is clear that there are many links between these two concepts. Participants regularly mentioned spiritual aspects of their CAM experience, for example, Astin found that the majority of their participants considered psychosocial and spiritual activities crucial in treatment and recovery”- the spiritual and social aspects appear to be linked here.

“Support groups [are part of complementary medicine] because your mind and spirit have a huge amount to do with healing for anything... knowing you’re not alone”.

8. *Expectations that patients take responsibility for their treatment*

The experience of CAM as a means of having some control over their life, health or treatment was portrayed, by both participants and authors, as a good thing, and reflects a wider discourse of actively fighting cancer⁵ and also a shift of responsibility from health professionals to patients⁶. The increased expectation of patient control (by patients and by health professionals) puts a burden of choice on the patients; the use of CAM treatments is part of this. While it is often welcomed by both patients and health professionals, there is a downside when treatments seem not to have the expected or desired effect – this puts a burden of choice on the patients, both at the stage of choosing treatments options, and accounting for a sense of failure or guilt.

9. *Sense of failure or guilt*

There appear to be two particular ways in which use of CAM can foster a sense of failure. In some cases, which apply to most forms of CAM, if the cancer recurs or spreads, the participant can feel that the CAM has “failed” (perhaps related to an often unstated hope that it would effect a cure).

The other type of sense of failure highlighted in these studies is the sense of personal failure or inadequacy if a person feels incapable of doing or using a CAM therapy, this

little consensus about what these terms mean both in the USA and the UK literature... we understand religion as a system of faith and worship expressive of an underlying spirituality which is frequently interpreted in terms of particular rules, regulations and practices... Spirituality is a relatively newer construct...is recognized as representing a search for existential meaning within a life experience, usually with reference to a power other than the self, not necessarily called ‘God’, that enables transcendence and hope.. we acknowledge these definitions may not be understood in the same way by patient participants”
Koffman et al (2008: 780-781)

⁵ Wilkinson and Kitzinger “(2000) Thinking positive.

⁶ Sinding and Gray (2005) link the survivor discourse to assignment of responsibility for cancer to patients.

was particularly so concerning the mind-body therapies, patients would blame themselves for not being able to visualise or be positive or stick to a regime. Guilt and sense of failure are therefore the negative outcomes of an approach based on taking control or thinking positive.

Barriers and facilitators, problems and benefits

While the overall “story” of the experience of CAM use after a diagnosis of cancer was notably consistent, despite the studies having been conducted in a variety of countries, taking in a wide range of CAM treatments, and by researchers with varying methods and agendas, our meta-study located a number of key barriers and facilitators which contribute towards patients having a positive outcome.

10. Polarisation

The most notable barrier to patients reporting a satisfactory experience was the perceived polarisation of CAM and conventional medicine. Many of the authors noted that participants experienced CAM and biomedicine as opposing, polarised approaches. It was rare for the two to be experienced in an integrated system. Patients reported difficulties in using both CAM and biomedicine, in particular many found it hard to talk to their biomedical practitioners about their decisions to use or experiences of CAM, and this was viewed by patients as a problem. They consequently worried about the compatibility of treatments, and about incurring the disapproval of their biomedical practitioners. A common theme in many of the articles was of participants' experience of hostility from biomedicine towards CAM. Moreover, as the participants were, in the majority of studies, those who had used CAM after a diagnosis of cancer, it is likely that the difficulties in openly talking about CAM options with biomedical practitioners is a significant deterrent for many patients in trying out CAM therapies.

While reporting that they had difficulties with the structural polarisation of the two, participants did not generally view CAM and biomedicine as incompatible. They typically viewed the two as intrinsically in separate spheres, but not problematically polarised, as they were two different types of thing - incommensurable paradigms. So, while CAM and biomedicine are often conceptualised in the literature as occupying opposite ends of a spectrum, setting up a polarised view of these two modalities, participants, in contrast to this, want and need better integration between the two. Participants were less likely, it seems, than health professionals, to see the two domains as intrinsically hostile or polarised, and more inclined to view the two domains as complementary – fulfilling different needs. This finding in our study corresponds with the Boon et al (ref) levels of integration theory, in which they depicted participants (consumers, as they called them) tending to be happy about using both biomedicine and CAM, but the structures and processes of the two separate systems being increasingly distinct as you move away from the individual consumer level.

11. Integration

The concept of integration came up explicitly as a concept in several of our studies, and implicitly in many others. The explicit mentions of integration were mainly in relation to

Integrative Health care, by authors (Verhoef and Mulkins) who were looking in detail at this. Besides the papers studying experiences within this particular system, the theme of integration of biomedicine and CAM was important to participants in that they either had positive experiences of some level of integration of CAM and biomedical treatment (either in the same location, or provided by a united team, or at the minimum a perception that it was permissible to discuss one option with practitioners of the other system), or they wished for better integration between the two.

Participants felt that having this chance to explore and find the right fit for them with practitioners and modalities helped to create an optimal environment for getting the most out of the available treatments. Mulkins and Verhoef quote a patient appreciating being able to discuss CAM treatments with her medical doctor:

“My doctor here, she was funny, graceful and loving and so she empowered me. We make decisions here as equals” (p236)

It is clear from our study that the experience of integrated systems, or a perception of a unified health service offering both biomedicine and CAM options, was almost universally appreciated by cancer patients. Integrated systems (such as the Canadian system of Integrated Health Care) appears to be a context which facilitates a positive experience for participants. In contrast, the separation of CAM and conventional medicine perpetuates a split that does not help the individual on their healing pathway.

12. Individual and group differences

Within the consistent overall “story” of the experience of using CAM after a diagnosis of cancer, there are variations due to stage of illness, type of treatment and also due to individual preferences.

Could include things on background, context, group, treatment type, illness stage. But this is a synthesis after all....

7.5 A diagram, or map, to demonstrate the links and influences.

Lines of argument synthesis

6 key concepts have been identified and linked together in a line of argument that accounts for cancer patients' experiences of using CAM. The aim of this synthesis is to develop a Line of Argument by considering each theme and its interpretations, and drawing together the key aspects of the experience of CAM after a diagnosis of cancer into a unified whole. These can be seen in Figure 2, a map of the synthesis.

Methodology Chapter 8

Reflections on the meta-ethnography method

Last updated 7 Jan

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- 8.1 Methodological limitations
- 8.2 Quality appraisal
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- 8.4 Definitions and conceptualisations
- 8.5 Concepts underdefined in the papers
- 8.6 Significant Omissions
- 8.7 Reflections on the project from the Patient Adviser

8.1 Methodological limitations

There were regularly-occurring weaknesses in many of the papers. In particular, there was often little description of the theoretical or methodological approach, and analysis sections tended to be short, with themes stated but not particularly demonstrated by relevant first order quotations. These limitations are partly due to the requirements of many of the journals for short papers, so there is little space to present qualitative data adequately, leaving the readers having to assume the authors have made a reasonable interpretation from the data. This causes problems when trying to draw out the detail about concepts and the links between them in a meta-ethnography.

However, some of the methodological limitations are not to do with short papers, but based on, it seems, authors' lack of experience in qualitative research. Many of the sample sizes are inappropriately small. For example, three papers state that they use Grounded Theory, and that they achieved Saturation with 11 or fewer interviews. Most papers use variations on Thematic analysis – often officially using Grounded Theory and phenomenological approaches, but frequently not adhering to the underlying principles of these approaches. Atkins et al similarly noted that

“Our assessment also highlighted that most papers failed to describe a recognised approach to analysis, although many appeared to use a thematic approach. We acknowledge that, while rigorous application of methods make for rigorous qualitative research, the two are not entirely interdependent [10], and that poor reporting of methods does not equate with poorly conducted research. We therefore decided that studies that did not include a clear description of the analysis methods might still make a valuable contribution to the synthesis.” (Atkins et al, 2008, pp8-9)

Generally, the first order quotes, and the interpretations, including the second order concepts, are too divorced from the context of the data. The reader does not know what the respondents

are responding to in their quotes, what has come before, and how the utterance it is reacted to by the interviewer or other focus group members. This is a problem with nearly all the papers.

8.2 Quality appraisal

Following the experiences of previous meta-ethnography researchers (Noblit and Hare, 1988; Campbell et al, 2002) we did not exclude papers on the basis of their appraised quality. The intention was that lower quality papers, with less well developed concepts, and less theorising, would fall to the bottom of the synthesis, while the concepts and theories in stronger papers would automatically figure more prominently in the synthesis. However, this did not appear to work as well in this study as it had in previous. The majority of papers in this study were short, with little theoretical awareness, truncated quotations and little means of the reader knowing the basis for the concepts presented. This caused problems in developing third order concepts – the research team drew where necessary on related literature to build on the underdeveloped concepts in the articles in the study. A meta-ethnography is necessarily limited by the limitations of the original articles.

In some cases, authors of papers in the meta-synthesis had also published related, more theoretical papers which elaborate on the concepts underdefined in the “Experience of CAM” papers. This suggests that there is a methodological concern with the method of including in the synthesis only at the papers based on primary research, thereby specifically omitting the related theoretical articles. The approach of publishing related data-based and theoretical articles can be traced to requirements of journal article length, and is especially the case in medical/health/nursing journals, less so in sociology journals. This contributed to the synthesis being dominated by papers with little theoretical depth. and so ending up with under-theorised research.

Maybe the reality is there are many weak papers and a few good ones in most areas of health research, Bondas and Hall (2007) suggest this:

“Difficulties in the analysis are usually due to problems in the primary studies, such as varied reporting styles, misrepresentations of data and analytic procedures presented as findings, misuse of quotes and theory, or lack of clarity” (Bondas and Hall, 2007: 117).

The conclusions of the project team about the value of the quality appraisal are consistent with Noblit and Hare’s (1988) position, and the conclusions of Pound et al, also Gateley et al (2008) – that the stronger papers, in quality and methodology terms, become the basis of the analysis, while the “weaker” papers (perhaps shorter, less reflexive, reports by less experienced researchers) can contribute to the body of analysis, but are not used as the basis for the main analysis. (Nicky mentioned a quote to put in here from a previous paper).

8.3 Decisions to exclude papers on related topics

As part of the process of narrowing down the set of articles to be focused on in the meta-ethnography, there was systematic exclusion of papers which were primarily looking at

decisions about using CAM, focusing instead on the papers about experiences of using CAM. However, many of the papers were in fact dealing with both issues, to a greater or lesser extent, raising questions about whether this was an unhelpful distinction. In talking about the experience, participants did regularly refer to decisions to use CAM – it seems for the participants the two are intertwined. A similar issue was found with papers about communication. We systematically excluded papers on Communication about CAM (left these for a future study) but in participants' terms the two are highly related. Some of the better quality papers excluded on these criteria would probably have added more to a synthesis about patients' experiences of CAM than many of the papers retained in the study.

For future meta-syntheses on this and similar topics, it might be worth considering expanding the topic area and using some form of quality appraisal.

Certainly, one conclusion is that a meta-ethnography can benefit from taking note of related research in the area, in particular theoretical articles and especially those by authors included in the meta-ethnography. There are precedents in meta-ethnography for this approach:

“Some of the concepts that had not been included in the chosen papers had in fact been published elsewhere. For example, the concept of selective dosage (not telling doctors of altered doses) did not appear in the actual paper that was included for the worked example but was described in another paper about the same study. In a comprehensive synthesis, both papers would have been included if they had each contributed something different” (Britten et al, 2002: 213).

Similarly, Thorne et al note that metasynthesis can usefully include imported concepts to frame data:

“Metasynthesis methods include, for example, constant comparison, taxonomic analysis, the reciprocal translation of in vivo concepts, and the use of imported concepts to frame data (Sandelowski & Barroso, 2003d).” (in Thorne et al, p1358)

8.4 Definitions and conceptualisations

Looking at the Translation grids in this study, we find a rather loose mapping of concepts both within and between papers. For example, the concepts of Wellbeing, Spirituality and Transformation are used by different authors to describe very similar concepts (in cases where explicit definitions of concepts are provided). But also, there are many instances of patients using a certain concept and this being picked up by the researchers, as far as can be seen from a close perusal of the paper*, as a slightly- or totally - different concept.

For example, Brennan and Stevens have the concept of doing battle but the first order quotes they illustrate it with are talking mostly about control and transformation, and not about fighting. This exemplifies what is happening a lot in our study. There is a lot of overlap of first order and second order concepts, so in one paper participants may talk about Control and the authors call this Doing Battle or Staying Positive. And in another paper the participants may talk about fighting cancer and this be categorised by the authors as Taking Control.

In the group of papers in this meta-ethnography, the phrases Taking control/keeping

positive/etc are used interchangeably within some papers, and also are used systematically differently across papers. So, besides translation of key concepts between papers, there is also translation of key concepts between 1st order and 2nd order concepts, I'm not sure whether this is an inevitable aspect of qualitative (interpretive) research, or is particularly happening in these papers.

What does this say about concept use and development in this subject area? And it has wider implications for the practice of social science research in general.

Noblit, in Thorne et al (2004), says that “*metaethnography became a way to talk about our understandings and the differences in our understandings. The synthesis that resulted was simply another interpretation of interpretations that, we hoped, would engage us in more dialogue and enable critique*”. (Thorne et al, 2004:

8.5 Concepts underdefined in the papers

A few concepts were rarely or never explicitly theorised in the papers in this study, and we drew on other relevant literature to define these concepts.

- **Spirituality**, Mackenzie had a definition, we also used a similar definition in the Koffman Religion and cancer paper.
- **Cancer Survivor**. Kaiser. And other paper. Use of and resistance of term, link to ways of talking about cancer in general. Rarely used in paper content but used twice in paper titles.
- **Integration**. Drew on Boon theory paper on integrative medicine.

8.6 Significant Omissions

Many of the papers use implicit (or occasionally explicit) assumptions about the concepts they are using. Some of the common ones picked up on here:

36. Control, and self control. Teasing out meanings of control but term often used as if self-evident (Wilkinson and Kitzinger, 2000), also literature on formulaic figures of speech without objects “taking control of *what?*” (Holt and Drew).
37. Lay knowledge and status of this, compared to “scientific” or “medical” knowledge. Why do people think lay feelings about a treatment is relevant? (refer to recent anon paper on this). What do people mean to do when they are using lay knowledge or intuitive feelings as a resource?
38. Assumption that control is good.
39. Assumption that battling/fighting cancer is good and morally right thing to do. (Kaiser paper on this and survivorship)
40. Anger and other emotions

8.7 Reflections on the project from the Patient Adviser

The Study For The Use Of *CAM* In Cancer Patients - My Experience,
By Sue Jackson-Pike

It is said that 'things come in threes'.

Well it certainly seemed to be that way for me in the three years between 2004 and 2007. I lost three very special things:- I lost my husband of 26 years to his much younger secretary!! I lost my much loved 25 year old Son, Terry, who died of an intestinal haemorrhage, and then I lost my right boob to breast cancer!

Then came 3 home moves and 3 jobs! However, all was not bad because they brought me to the place where I am today. Happily re-married, living in beautiful Devon and although I shall never get over losing Terry, I still have my other Son, Adam.

It was in the middle of my treatment for Cancer that I was asked by my Oncologist, Professor David Radstone if I wanted to take part in a research study about the effects of complimentary and alternative medicine on Cancer patients. Being of a curious nature I said I definitely would.

A few weeks later, in January 2008 I met the *CAM* cancer synthesis project advisory group members consisting of: Professor Nicky Britten (Chair), Ms Maggie Evans - Research Associate, Susan Margetts - (Minuting secretary), Dr Charlotte Paterson - Senior Research Fellow, Professor David Radstone - Oncologist, Dr Janet Smithson - Research Fellow, and Professor George Lewith - Professor of Health Research.

My part in this study was to read various papers and give my opinions. 'Easy', I thought. Well, how wrong can you be! I became immersed in the papers and found myself writing pages and pages of notes and thoughts, which, in the end, I would shorten it into what I thought were the key points.

What I didn't account for, however, was how interested and relevant I found the information about *CAM* in relation to my own situation. I read many articles about how patients were helped by having symptoms relieved, or by

relaxation. For instance one man had cranial osteopathy and said that relieved pain more than painkillers; and a native American Indian woman who decided not to have conventional medicine and go instead to her tribe's Medicine Man. She attributed her recovery to the various herbs he prescribed her, her time in the healing sweat lodge and her prayers to Mother Earth.

But what really interested me was how some Cancer patients had been given poor prognosis's but were still alive 7, 8 and more years later and they attributed CAM to this. There must be something in this, I thought. Especially since I have a friend, who also had breast Cancer about 8 years ago, and although I hadn't taken much notice at the time, I remembered that she also has regular sessions with a homeopath since her Cancer, and has constantly remained very well.

Having now had Cancer, I can't help but worry should it come back so I therefore decided to contact a homeopath, not just for this reason but also for help with a couple of things (coming off prescription tablets for pain and trying to get as many chemicals as possible out of my body). When I booked the consultation and was told the price I almost didn't go ahead because, for me, it was very expensive. But then I thought if it does work, and I didn't go, and the cancer came back, I would be furious with myself. So I went and found the consultation fascinating.

After taking a very long and detailed history of me and my family he said a couple of things which I found very interesting. Although I rarely get ill (I hardly ever get infections or colds) when I do get an illness I seem to get one which involves a fast overgrowth of cells. This has happened several times in differing parts of my body and I am keen to explore the reason why and how I can prevent this happening in the future. There are also hormonal deficiencies which I have never really addressed which I shall now be doing so. However, at the moment (we are doing things one step at a time) I am in the process of stopping a certain painkiller and my body is being supported in this with a homeopathic remedy.

I must say I am eagerly awaiting my next appointment and am keen to explore further the fascinating, and very possibly, necessary, topic of Complementary and Alternative Medicines. I feel very fortunate to have been asked to take

part in this study and very grateful because it has prompted me to be more proactive in self care.

Methodology chapter 9 Practical outcomes and implications

Conclusions

The experience of cancer – diagnosis, treatment choices and experiences, outcomes - is a journey, a long term experience, including cancer survivorship. Most research articles tend to be snapshots of participants at a particular stage of the journey. A strength of the meta-ethnography review is that it can draw on people at all stages in this overview study, providing a fuller picture of the experience of having cancer and using CAM.

Relevance to service users

The study demonstrates that for the majority of patients, using complementary treatments after a diagnosis of cancer is a very positive experience. Participants particularly liked having time to develop a relationship with a therapy or treatment provider. Social aspects of treatments – meeting other people in a similar situation - were seen as a particular benefit. A common problem with using or considering alternative treatments was concern about whether conventional health carers would approve.

Relevance to Practitioners

The research highlights a need for increased opportunities for cancer patients to discuss alternative treatment options and experience integrated health care. Most patients used alternative treatments after a cancer diagnosis as complementary, not alternative, and often to deal with non-medical aspects of the disease – taking control, relieving symptoms, social interaction. Perceived polarisation between biomedicine and alternative treatments was limiting patients' choices and causing anxiety. The benefits of time to develop a relationship with the alternative therapist, and to feel listened to, were particular motivations for seeking and using alternative treatments.

Limitations

Quality of many papers. Length constraints, also many authors were new to analyzing and writing about qualitative research, many articles not very theoretically developed (Atkins). Moreover, many of the sample sizes are tiny, especially for 3 papers which say they use Grounded Theory and achieved Saturation with 11 or fewer interviews. Considerations of quality appraisal have been covered in several articles on meta-ethnography, most authors have concluded that it is better to not limit papers by quality. However...

Directions for further research

What do people mean, in these contexts, when they talk about Control?

Status and use of lay knowledge. How do people position lay knowledge about CAM and illness against body of “expert” scientific or medical knowledge. Need to probe on these issues. Getting comparable but fairly bland responses in these studies, need to know what people are actually meaning underneath some of the stock phrases.

Anger and negative emotions in dealing with cancer. There was a lack of discussion about anger and other emotions in these studies.

Perhaps look again at the wider picture of the cancer journey and how people deal with it

(ref Wilkinson on this).

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