

Qualitative Analysis Guidelines for MYCaW

Purpose of the coding guidelines:

The purpose of these coding guidelines is to aid the researcher in the qualitative analysis of MYCaW data and to facilitate comparison of your data with other published data sets. Coding MYCaW consistently across different settings will help develop a common data set and improve our understanding of the impact of complementary and integrative cancer care on patient outcomes. Below you will find references to other studies that have reported MYCaW data.

Development of the coding guidelines:

The guidelines were developed by a multidisciplinary team and the development of the analysis framework is reported in detail in Polley et al (2007). Data was initially used from the UK to develop and test out the framework. (UK data sets from Breast Cancer Haven in London and Hereford (n=421, 2007-2008), and from Penny Brohn Cancer Care (PBCC) in Bristol (n=361, 2007-2008). At Breast Cancer Haven all patients have breast cancer whereas PBCC treats patients with any type of cancer, although approximately 50% of participants in these evaluations had breast cancer. Hence you will notice that the analysis may cater for breast cancer in more detail than some other cancers.

A review of the coding framework was undertaken in 2013-14 in collaboration with Dr Weeks from the Ottawa Integrative Cancer Clinic, Canada to add any new categories that may be recognised as MYCaW is used more widely. New data was added to the collective dataset from PBCC, UK (n=155, 2011-12) and from OICC, Canada (n=158, 2012-13). The OICC provides services to people with any type of cancer, most commonly breast (30%), colorectal (14%) and lung cancers (10%). Thus the frameworks are based on data from 1108 people. Each person can state up to 2 concerns, hence approximately 2000 individual concerns were coded. The review of the framework is detailed in the MYCaW validation paper listed below.

Using the analysis guidelines:

Qualitative data (words rather than numbers) are collected as answers to:

1. Stated 'concerns and problems' (initial form)
2. 'Other things affecting your health' (follow up form)
3. 'What has been most important for you?' (follow up form)

When analysing the 'concerns and problems' and 'other things affecting your health' from the follow up form, categories have been designed so that you can either do a fast analysis using the supercategories only, or you can breakdown each supercategory into sub categories for more detailed information. The approach you adopt will no doubt depend on what you want to use the information for and time available to you.

For the last question on the follow up form – 'What has been most important to you'-, there are just 10 categories, with no further breakdown.

It is intended for these categories to provide a relatively easy and accurate method for coding and summarising the qualitative data as well as enabling the comparison of data collected in different settings and time periods. If you want to analyse your data in such a way that will allow you to compare your MYCaW outcomes to other studies that report MYCaW data, then it is important to use the coding guidelines below.

There is no right answer when analysing and organising your qualitative data. Some people will give different meaning to patient concerns, dependent on their professional background for example. This is acceptable within the MYCaW framework. What is important is consistency in the application of the MYCaW guidelines within each data set. If you are trying to code a concern that does not fit well within any of the existing categories, please contact the authors of the guidelines for advice. See below for their contact information.

Citing the analysis guidelines:

The guidelines that have been produced can be used for free, and the authors ask that you cite the following references, as appropriate, when writing up your work:

Jolliffe R, Seers H, Caro E, Durrant J, Jackson S, Weeks L, Polley M. *Validation of the Measure Yourself Concerns and Wellbeing (MYCaW) patient reported outcome measure*. Submitted Psycho-Oncology, 2014.

Polley M, Seers H, Cooke H, Hoffman C, Paterson C. *How to summarise and report written qualitative data from patients: a method for use in cancer support care*. Supportive Care in Cancer, 2007; doi:10.1007/s00520-007-0283-2.

Seers H, Gale N, Paterson C, Cooke HJ, Tuffrey V, Polley MJ. *Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data*. Supportive care in cancer, 2009; 17(9):1159-1167.

The authors are interested in knowing who is using the MYCaW questionnaire and these guidelines and for what cohort. If you have feedback or would like clarification about using the qualitative analysis guidelines please contact either Dr Marie Polley (M.Polley01@westminster.ac.uk) or Dr Helen Seers (Helen.Seers@pennybrohn.org) who will be happy to help you.

Other publications that have used these guidelines:

Ben-Arye E, Steiner M, Karkabi K, Shalom T, Levy L, Popper-Giveon A, Schiff E (2012). *Barriers to integration of traditional and complementary medicine in supportive cancer care of Arab patients in Northern Israel*. Evidenced-Based Complementary and Alternative Medicine doi:10.1155/2012/401867.

Frenkel M, Cohen L, Peterson N, Palmer JL, Swint K, Bruera E (2010). *Integrative medicine consultation service in a comprehensive cancer center: findings and outcomes*. Integr Cancer Ther, 9(3):276-83.

Harrington JE, Baker BS, & Hoffman CJ (2012). *Effect of an integrated support programme on the concerns and wellbeing of women with breast cancer: A national service evaluation*. *Complementary Therapies in Clinical Practice*, 18(1):10-15.

Polley M, Jolliffe R, Jackson S, Boxell E, Seers H (2013) *Penny Brohn Cancer Care: Service evaluation of 'Living Well with the Impact of Cancer' courses*, Penny Brohn Cancer Care, University of Westminster. Available from www.pennybrohn.org.

Selman LE, Williams J, Simms V (2012). *A mixed-methods evaluation of complementary therapy services in palliative care: yoga and dance therapy*. *Eur J Cancer Care*; 21(1):87-97.

Vaghela C, Robinson N, Gore J, Peace B, & Lorenc A (2007). *Evaluating healing for cancer in a community setting from the perspective of clients and healers: A pilot study*. *Complementary Therapies in Clinical Practice*; 13(4):240- 249.

Concerns and Problems

This section categorises the concerns and problems that are reported by the individual, the first time they fill out the MYCaW form. Table 1 below provides an overview of the supercategories for the data (S1- S5) and the breakdown of what comprises each supercategory. Beyond Table 1 are the detailed definitions of specific categories you can choose from when coding your data.

Supercategory (S)	Breakdown of supercategory
S1 Psychological and emotional concerns	a. Adapting and coping
	b. Body image concerns
	c. Confidence issues
	d. Depression
	e. Emotional problems
	f. Family and relationships
	g. Fear and anxiety
	h. Psychological issues
	i. Regaining balance and normality
	j. Sleep problems
	k. Stress and tension
	l. Support
	m. The future
S2 Physical concerns	a. Hot flushes and night sweats
	b. Fertility
	c. Pains/aches
	d. Physical problems not related to cancer
	e. Poor energy levels
	f. Cancer recurrence
	g. Spreading of cancer
	h. Weight change
S3 Hospital cancer treatment concerns	a. Cancer treatment in general
	b. Side effects of chemotherapy
	c. Side effects of hormonal treatment
	d. Side effects of surgery
	e. Side effects of radiotherapy
S4 Concerns about wellbeing	a. Exercise
	b. General wellbeing
	c. Healing
	d. Information and guidance on complementary therapies
	e. Nutrition
	f. Relaxation
	g. Spiritual wellbeing - meaning and peace
	h. Spiritual wellbeing - faith
S5 Practical concerns	a. Finance
	b. Work

Table 1. Overview of categories of 'concerns and problems' stated on the first MYCAW form

S1 – Psychological and Emotional Concerns

This category includes data pertaining to psychological and emotional issues. Excludes physical concerns

a. Adapting and coping - include references to coping on any level with cancer and treatment as well as adapting to life as a result. Do include 'acceptance' citations. Include data in this category if the thrust of the sentence pertains to adapting to or coping with something.

b. Body image concerns – Anything with direct reference to body image and the physical self, appearance or 'looking' different/better i.e. acceptance of new body. This may be in relation to surgical treatment or the effect of treatment.

c. Confidence issues – include direct references to confidence or self-confidence. If the comment refers to confidence in the physical self then go to category S1b.

d. Depression – anything with direct reference to feeling depressed.

e. Emotional problems – include anything with a direct reference to emotion or mood. This category relates to the emotional aspects of the cancer process and treatment regime, and mood issues.

f. Family and relationships – include references to situations, problems or concerns with members of the family or relationships.

g. Fear and anxiety – include anything with direct reference to being fearful or anxious about cancer, e.g. the treatment of it, fear of the cancer returning, fear the cancer treatment will not work, or fear and anxiety around waiting for the results of scans/ blood tests.

h. Psychological issues- reference anything to do with the mental state or a change in mental state or if there is direct reference to psychological issues. If the main theme of the comment is to do with adapting or coping then go to category S1a. If the main comment refers to emotional issues then go to category S1e.

i. Regaining balance and normality – include references to establishing normality and balance in life.

j. Sleep problems – any reference to insomnia or poor sleep. If poor sleep is stated to be a result of treatment for cancer, go to the relevant section in S3.

k. Stress and tension – include any reference to being stressed, wanting to de-stress or experiencing tension.

l. Support – include anything with a direct reference to feeling unsupported, isolated or needing support of some kind. Reference to emotional support goes in section S1e.

m. The future – include direct references about the future or long-term implications or plans, i.e. being clear of cancer.

S2 - Physical Concerns

This category includes data pertaining to physical concerns that are not specified as being a direct result of cancer or its treatment. Excludes concerns relating to cancer treatment.

a. Hot flushes and night sweats – Flushes and sweats may be a concern for women with cancer, but may be associated with normal menopause, not necessarily an effect of cancer treatment. *References to flushes and sweats without any supporting information about cancer treatment are included here. If the reference to hot flushes and night sweats is linked to a specific treatment for cancer, go to the relevant section in S3.*

b. Fertility – Fertility issues can exist prior to cancer diagnosis and treatment. *Concerns relating to fertility issues, and not being able to have a family go here. If the reference to fertility is linked to a specific treatment for cancer, go to the relevant section in S3.*

c. Pain/aches - *must refer directly to pain or ache anywhere in the body, or to general muscular aches and pains and pain management. Specific concerns about arm pain go in S3d. If the pain/ ache is a direct result of a specific cancer treatment, go to the relevant section in S3.*

d. Physical problems not related to cancer – Some concerns stated by patients are not necessarily about their cancer but refer to health problems that existed before they were diagnosed with cancer, for example diabetes, back problems or epilepsy. *If a concern relates to a physical problem that is not specifically related to cancer or its treatments include it in this category.*

e. Poor energy levels – *different to poor sleep as one can sleep well and still have no energy. Include concerns with direct reference to energy levels, fatigue or tiredness. If poor energy levels are the direct result of a specific cancer treatment, go to the relevant section in S3.*

f. Recurrence – *references relating to a recurrence of cancer. Include worry about cancer recurrence. If the concern relates to 'fear' of recurrence then it goes in S1g to recognise the psychological importance.*

g. Spread of cancer - *references relating to the further spread or metastasis of cancer. Include references pertaining to worry or uncertainty around the spread of cancer. If the word 'fear' is used, use S1g.*

h. Weight change - *include any references to wanting to gain or lose weight, or experiencing difficulties with weight gain/ loss. If the concern relates to body image due to weight change go to S1b to reflect the psychological component. If weight change is a direct result of treatment for cancer go to the relevant section in S3.*

S3 - Hospital Cancer Treatment Concerns

This category includes data pertaining to concerns that are a direct result of having hospital based treatment for cancer. Excludes concerns relating to other health conditions or wider physical problems.

a. Cancer treatment in general – This section captures patients' concerns over having cancer treatment, when the reference might be unspecific or may include several of the treatments in their conventional treatment plan.

Generally includes:

- *Wanting help understanding the prescribed hospital treatment*
- *Generally worried about having treatment and the effect that it will cause*
- *Concern relates to more than one type of biomedical treatment*
- *If concern specifically relates to cancer treatment but type of treatment is not specified*

b. Side effects of chemotherapy - Include any of the following concerns if they are specified as being a result of chemotherapy treatment. You may just see a concern described as 'side effects of chemotherapy', but without stating a specific side-effect. Below are a list of common side effects you might see from chemotherapy, but it is not exhaustive, so you may have others that would fit in this category.

- Fatigue
- Nausea/ Vomiting
- Loss of appetite (if change in weight is specifically mentioned go to S2h)
- Hair loss
- Problems with memory and concentration
- Trouble sleeping
- Fertility issues
- Sore or bleeding gums
- Diarrhoea or constipation
- Digestive problems
- Numbness/ tingling in hands or feet

c. Side effects of hormonal treatment – often specific to breast and prostate cancer, incorporates any concerns that directly refer to being a result of taking hormonal treatment e.g. poor sleep if directly linked to hormonal treatment. *Any mention of sleep problems without reference to hormonal treatment then go to category S1j. Any mention of hot flushes or night sweats without mention of hormonal treatment then go to category S2a.*

d. Side effects of surgery - include concerns here if they are specified as being a direct result of surgery for cancer. Some common side effects of cancer surgery include:

- Lymphoedema
- Scarring
- Stoma
- Arm problems
- Mobility issues
- Incontinence
- Erectile dysfunction

- Infection
- Loss of appetite
- Pain
- Tiredness

e. Side effects of radiotherapy - include concerns that are specified as being a result of radiotherapy. Common side effects of radiotherapy include:

- Fertility issues
- Sore skin
- Mouth sores
- Hair loss
- Tiredness
- Nausea
- Loss of appetite
- Difficulty swallowing
- Stiffness in muscles and joints

S4 - Concerns about Wellbeing

This category includes data pertaining to wider issues around living well and regaining/maintaining health.

a. Exercise -references around starting to exercise, returning to exercise, doing more exercise. Can also include any negative comments about not being able to do exercise at the moment or not knowing what exercise to do that is safe for the patients' circumstances.

b. General wellbeing– include references to improving general health, improving immune system, or generally taking more time for self. Also include references to wanting to improve aspects of health to prevent development of cancer.

c. Healing – include anything that references healing unless it begins with the word emotional – that goes in section S1e.

d. Information and guidance for complementary therapies – include references about information on alternative treatments, finding the right information, choosing between all the information available.

e. Nutrition – to include any concerns pertaining to nutritional or diet problems or advice required, particularly for supplement taking. Include things such as help with digestive system.

f. Relaxation – anything with direct reference to relaxing.

g. Spiritual wellbeing: meaning and peace - include spiritual concerns relating to finding meaning or peace in one's life. Also include improving the connection between the mind, the body and/ or the spirit as a means of becoming more in touch with one's self or adopting a more holistic approach to life.

h. Spiritual wellbeing - faith - *include spiritual concerns specifically relating to faith/ religion. Include references to finding comfort/ strength in faith or religious beliefs, feeling connected to God. Also anything pertaining to a struggles with/ loss of faith as a result of cancer.*

S5 – Practical Concerns

This category includes data pertaining to non health related concerns.

- a. Finance-** *include anything related to concerns about a financial situation.*

- b. Work-** *include any references to concerns regarding work/ employment such as being unemployed, difficulty finding or maintaining a suitable job, work environment or set up, taking early retirement.*

Other Things Affecting Your Health (on follow up form)

This section categorises the answers to question 2 on the follow-up MYCaW form. The supercategories (OT1-OT6), can be used to identify the overall themes of the data. The table provides an overview and is then followed by detailed instructions for breaking the supercategories down.

The comments generally fall into positive or negative categories hence '(positive)' or '(negative)' in the brackets after the subcategory name (below). If you are unable to tell if it is a positive or negative comment then just use the supercategory number i.e. for the work section if it is difficult to know for some people if early retirement was good or not, code it as OT5. Other comments such as 'have changed working hours to suit lifestyle more' was a positive comment hence was coded OT5a.

Table 2. Overview of categories from the data regarding 'what else is going on in your life', stated on the follow-up MYCAW form.

Supercategory (OT)	Breakdown of supercategory
OT1 Awareness of wellbeing	a. Taking exercise
	b. Improved nutrition
	c. Improved awareness of own wellbeing
	d. Difficulties in maintaining change
OT2 Receiving complementary therapies	a. Benefit of therapies at the centre
	b. Benefit of therapies outside of the centre
OT3 Major life events	a. Positive change of environment
	b. Negative change of environment
	c. Bereavement
OT4 Social support	a. Increased social support
	b. Family problems
	c. General lack of support
OT5 Work situation	a. Improved work set-up or financial situation
	b. Work or financial problems
OT6 Health issues	a. Cancer related and positive
	b. Cancer related and negative
	c. Non cancer related
OT7 Other	

OT1 Awareness of Wellbeing:

This category includes data pertaining to positive changes being by patients to their lifestyle, or about changes that a person feels that they should be making but are unsuccessful.

a. Taking exercise (positive)

Any reference to starting or increasing the amount, intensity or duration of any type of exercise regimen, e.g. started pilates, increased aerobics to twice a week now, walking for longer when I take the dog out.

b. Improved nutrition (positive)

Include any references about being more aware of healthy eating or improving diet.

c. Improved awareness of own wellbeing (positive)

Include data that pertains to improving lifestyle through being more relaxed, getting less stressed, changing priorities, letting go of negative habits etc.

d. Difficulties in maintaining change (negative)

This category recognises that not all people can make or sustain the changes to improve their lifestyle that are recommended and for some, this is a stressful situation to be in. Include any reference to a lifestyle change that contains a negative comment such as 'trying unsuccessfully'.

OT2 Receiving Complementary Therapies

This is a simple category to recognise the benefits of the complementary therapies that people are receiving either within or outside of the centre they are attending.

a. Feeling benefit of therapies at the centre (positive)

Include any reference to benefits from individual or group therapies received at the centre, or benefit from advice issued by a therapist. Points may be very specific or general such as 'am feeling better and the centre is instrumental in this'.

b. Having complementary therapies outside of the centre (positive)

This category recognises that people will receive complementary therapies outside the centre, and should capture any benefits from specific therapies, or advice offered by therapists.

OT3 Major Life Events

This category refers to major events that occur that do not fit into the other categories.

a. Positive change of environment

A dream holiday or long awaited change of environment, or moving house which is viewed with excitement and positivity.

b. Negative change of environment

Any references to selling or moving house which is stressful or a change in the environment which is also viewed negatively.

c. Bereavement (negative)

The loss of a close member of family or a close friend.

OT4 Social Support

This category contains any references to a change in the amount of social support a person is receiving, this can be from friends, family or within social groups they have joined.

a. Increased social support (positive)

Increased support from family / friends, a greater sense of community.

b. Family problems (negative)

Relationship problems with partner, illness of partner, sibling or child or any family situation that is creating difficulty and stress. Death of a close relative or close friend should be put into OT3c.

c. General lack of support (negative)

Any reference to lack of support in a person's life that is not family related.

OT5 Work Situation

This section is directly related to changes in work or financial situations.

a. Improved Work Set Up or Financial Situation (positive)

Re-organisation of work hours to create more time for self or less stress, working from home to reduce travelling etc. Also include any comments related to positive changes in financial situation.

b. Work or Financial Problems (negative)

Change or resignation from job as unable to cope with the demands of the job. Effect of the job on health such as stress or tiredness, or concern about returning to work.

OT6 Health Issues

This category relates to any health issues that are continuing and are either positive or negative:

a. Cancer related (positive)

Any positives relating to cancer treatment such as finishing chemotherapy, receiving a mastectomy or changing brand of Tamoxifen and reducing side effects, having reconstruction or feeling the benefit of changing oncologist.

b. Cancer related (negative)

Any comments relating to pain, aches, lymphoedema or discomfort from hospital treatment for cancer. Also include anxiety, fear, worry at length of recovery time etc. Also include diagnosis of more cancer or spread. Include any negative comments about medical staff e.g. being unprofessional or overly pessimistic.

c. Non-cancer related (negative)

These are health problems that are unrelated to the cancer that may have existed pre-cancer treatment e.g. infertility, back problems, thyroid problems, diabetes.

OT7 Others

This captures the data that doesn't always appear to be directly related to the question asked and so does not fit into the categories above, such as - difficulties getting appointments at the centre, comments about religion.

Important Aspects

The final follow up question asks what is the most important aspect of the centre that you visited. Comments can be positive or negative but in our experience are generally positive and will fall into categories 1-9. Category 10 is for negative feedback and category 11 is for comments that don't fit 1-10. As there were only 10 categories, supercategories have not been derived for this section.

1. Support and understanding received

Include any data that refers to feeling supported or receiving support through the centre, on any level (emotional, spiritual, psychological, physical). Also include any data that mentions feeling understood by the therapists at the centre or gaining a greater understanding. Also include references to being able to express emotions at the centre that are difficult to talk about anywhere else. Include in here any comments regarding support from the therapists or staff. For comments about support from other patients, go to category 6.

2. Individual and group therapies

This section covers data that refers to the individual and group therapies offered at each centre. Group sessions that are run at the centre may include educational seminars and talks as well as group based therapy. Also include comments about the therapists. These comments may or may not state which therapy was received.

3. Access to therapies

Include data referring to being able to access the complementary therapies, either relating to times of service or not having to pay for it, also being able to indulge in them or having the opportunity to try out some therapies. Also references to the service being available should be included in this section.

4. Confidence in the therapists

This section covered the comments about the experience, trust and professionalism of the therapist(s).

5. Care and kindness

Include any comments that pertain to the care or the kindness that was experienced by the visitor/patient to the centre - either by a therapist specifically or the staff at the centre. Do not include anything that talks about experience or professionalism of the staff - that is for 'Confidence in the therapists' section 4, above.

6. Being with other visitors

Include any comments about meeting others, companionship, support from or meeting others in a similar situation / with the same issues / similar diagnosis.

7. Relaxation and time for self/ self-development

Include data that refers to having time to relax, time for self, time to listen to one's body, time out or any other expression that encompasses this concept. Self-development refers to a positive change as a result of receiving therapies and guidance e.g. finding acceptance.

8. The environment / atmosphere

This category is for the comments about the environment and atmosphere at the centre. Anything along the lines of the peace, tranquillity, calmness, solace is accepted. Include comments about reception staff if it pertains to the atmosphere.

9. Appreciation of the centre and its resources

This section covers many aspects of the centre such as resources e.g. the library, food, or the staff. If staff are mentioned then only include them in this section if it isn't relevant to the individual therapies section 3, first. Also include general positive comments about the centre such as the whole place/ ethos, all the therapies or the organisation as a whole.

10. Negative feedback

To include any data that has a negative basis to it, which may include references to distance travelled, therapists or other visitors/patients, decor.

11. Non-specific

Please include any data that is too un-specific to fit in to any of the other categories.