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Patients' experience with cancer recurrence: A meta-ethnography

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**Abstract**

Objective: Recurrence is a difficult stage in the cancer journey as it brings to the fore the life threatening nature of the illness. This meta-ethnography examines and synthesises the findings of qualitative research regarding patients' experience of cancer recurrence.

Methods: A systematic search of the qualitative studies published between 1994 and April 2014 was undertaken. Seventeen relevant papers were identified and a meta-ethnography conducted.

Results: Six third-order concepts were developed to capture patients' experiences:

*Experiencing emotional turmoil following diagnosis*, which described the emotional impact of diagnosis and the influence of previous experiences on how the news were received; *Experiencing otherness*, encompassing changed relationships; *Seeking support in the health care system*, describing the extent of information needs and the importance of the relationship with health care professionals; *Adjusting to a new prognosis and uncertain future*, highlighting the changes associated with uncertainty; *Finding strategies to deal with recurrence*, describing ways of maintaining emotional well-being and regaining a sense of control over cancer; and *Facing mortality*, describing the difficulties in facing death-related concerns and associated consequences.

Conclusions: This meta-ethnography clarifies the fundamental aspects of patients' experience of recurrence. It suggests that health care professionals can promote a positive experience of care and help lessen the psychosocial impact of recurrence by providing information in an approachable way, listening to patients and being sensitive to their

changing needs and concerns. It also points to the importance of supporting patients in adopting strategies to regain a sense of control and to address their potential mortality and its impact on loved ones.

## Background

In 2011, over 331 000 people were diagnosed with cancer in the UK [1]. Unless cancer is already advanced at the time of diagnosis, patients are usually offered surgery, chemotherapy or radiotherapy or a combination of these. If after a period of being disease free, cancer comes back, it is defined as a recurrence [2]. Despite improvement in initial cancer treatments, recurrence is still relatively common [e.g 3 4 5]. Though the risk varies across cancer types, and by stage, grade and other tumour characteristics, improvements in treatments mean many more people will live for longer with active and advanced disease [6].

Recurrence is a difficult stage in the cancer journey. It challenges patients' hopes that cancer can be cured, emphasises the life threatening nature of the illness [7-10] and highlights uncertainty about the future [11-13].

Qualitative research and qualitative syntheses have been increasingly recognised as filling an important gap in providing an understanding of patient experience to inform policy [14].

Meta-ethnography is one of the interpretative methods available to bring together evidence from qualitative research. Although it originated in the area of education [15], interest in meta-ethnography has been extended and further developed in the field of health care research [16]. It has been suggested that meta-ethnography is most suitable when looking at individuals' experiences [17]. The meta-ethnography presented in this paper followed the approach developed by Noblit and Hare [15] further developed by Toyne and [18 19] and was conducted to explore, evaluate and synthesise the existing knowledge base regarding patients' experiences of a recurrence of cancer.

## Methods

Noblit and Hare [20] identified seven stages (Figure 1), which constitute the iterative process of meta-ethnography [18].

### **Figure 1 1 Seven stages of Noblit and Hare's meta ethnography**

- 1. Getting started**
- 2. Deciding what is relevant to the initial interest**
- 3. Reading the studies**
- 4. Determining how the studies are related**
- 5. Translating the studies into one another**
- 6. Synthesising translations**
- 7. Expressing the synthesis**

Stage one involved an initial scoping review of research on the experience of cancer which identified the experience of cancer recurrence as appropriate for a meta-ethnography.

#### Systematic search and critical appraisal

Stage two comprised defining the scope and terms of the search strategy and critically appraising the studies identified.

Due to well-known difficulties of indexing qualitative studies, particular attention was paid to developing a comprehensive search strategy for studies which used a qualitative methodology. As the last two decades have seen major changes in cancer treatments and health care services, it was decided to restrict the search to this period. Three electronic databases – Medline, CINAHL and Psychinfo – were searched for studies published between January 1994 and April 2014, using the search terms listed in Table 2. The grey literature was not searched. The criteria for inclusion in the meta-ethnography were that the study: a)

explored the experience of patients with a cancer recurrence b) used qualitative methodology to gather and analyse results and c) were published in English.

[Insert Table 1]

While a number of tools are used in appraising qualitative studies, the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist is most commonly used in meta-ethnography [21]. All studies included in this review were appraised using the CASP tool and then coded using the coding scheme devised by Dixon-Woods: KP (key paper providing rich conceptual insights), SAT (satisfactory paper), FF (fatally flawed) and IRR (irrelevant: not meeting inclusion criteria) [22]. All papers were reviewed by one reviewer (Anonymous) and by one of two additional reviewers (Anonymous). Quality appraisal was conducted to gather information about the quality of the current evidence. It was decided not to exclude any papers based on quality as methodologically weak papers can still provide rich conceptual insights [23].

#### Data extraction and Synthesis

Stage 3 involved reading the articles selected for the synthesis and re-reading for further familiarisation. As part of this process, relevant information including background, methods and results were extracted.

Stage 4 focused on determining how the studies were related. As part of this process, first order constructs (quotes from the participants) and second order constructs (key concepts and themes and their interpretation by the paper's authors) were extracted by MW and one of MB or EW independently. Second-order constructs form data for meta-ethnography and the purpose of extracting first order constructs is only to provide illustrative quotes. As Toye et al [18] have pointed out quotes provided under a particular second-order constructs are selected

by authors and therefore may not illuminate all aspects of it. To aid this process, a table was created, with each second-order construct from each paper listed alongside the representative quotes from the participants [16]. Each row represented one second order construct from a particular paper.

Stage 5, reciprocal translation of the studies, involved looking at how studies were related to each other and required reading each row, comparing across studies, to consider how the constructs were related. The focus here was on the descriptions of the second order constructs rather on the terms used.

Stage 6, synthesising translations, involved generating third-order constructs. For example, the second order construct *diagnosis of recurrence* in the study by Mahon and Casperson [9] and *emotional reactions* in Griffiths et al. [24] each contributed to the third order-construct *experiencing emotional turmoil after diagnosis*. An illustration of the process is presented in Table 1. The aim here was not only to summarise the data but to create conceptually rich third-order constructs, encompassing the dynamic experience of participants. This synthesis took form of a reciprocal translation, which is possible when studies included describe similar findings [15].

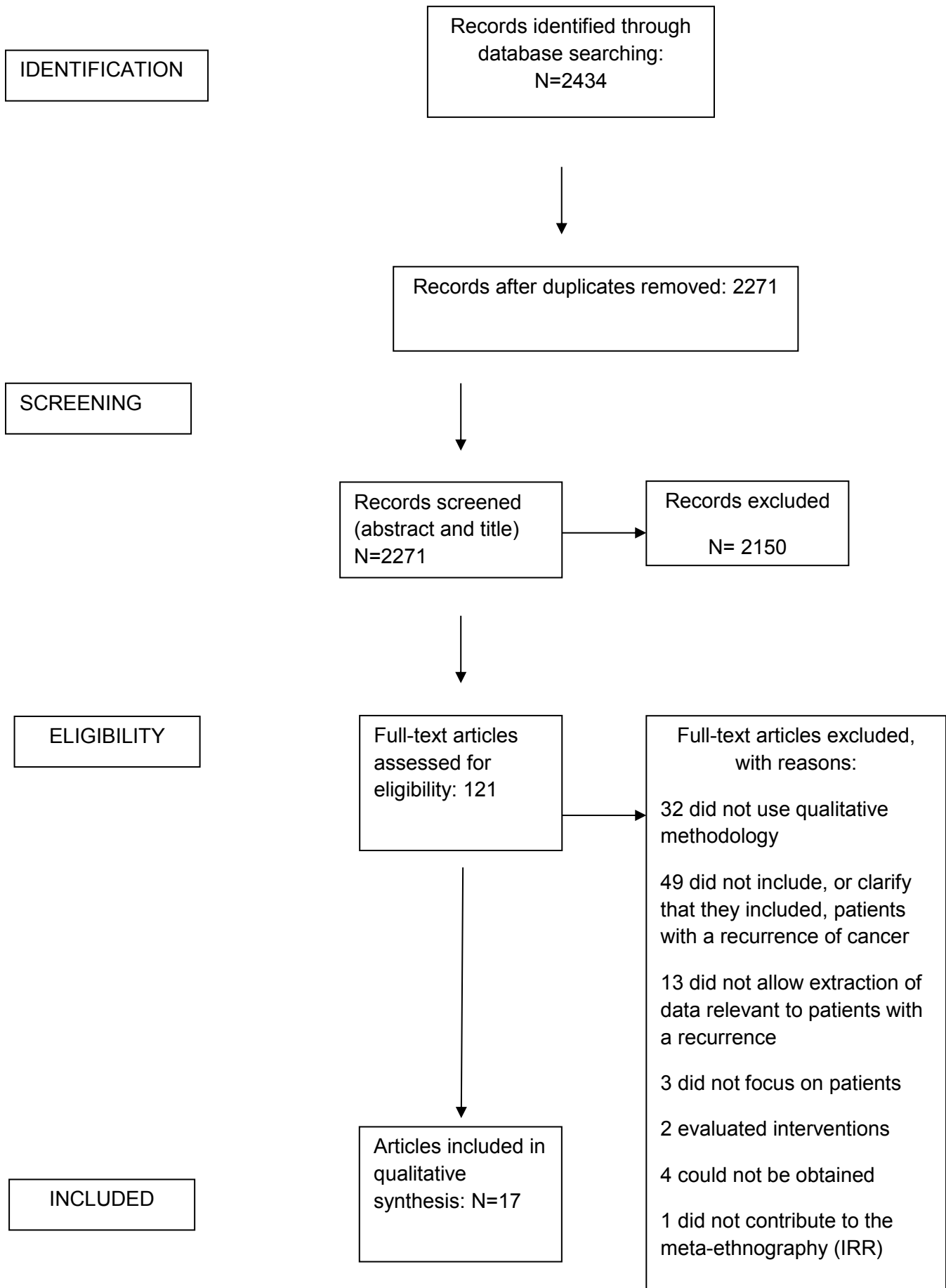
[Insert Table 1]

## Results of the search

The search yielded 2271 articles after duplicates were removed. One reviewer (Anonymous) screened each abstract and two additional reviewers (Anonymous) screened a subset (10%) to establish if the paper was 1) a qualitative paper and 2) addressed the topic of interest. This initial screen resulted in 2150 articles being rejected. The remaining 121 were subjected to full text review and 103 were excluded for a number of reasons. Figure 2 summarises the screening process.



Figure 2. PRISMA flowchart



A total of 17 articles were included, based on 15 data sets. Studies were published between 1997 and 2014 and were conducted in UK, Europe (Sweden) and North America (Canada and USA). They included patients with a range of cancer types, with breast and ovarian cancer most common. The main method of data collection was individual interview but a variety of analytical approaches were used, including Phenomenology, Grounded Theory and Content Analysis. Chunlestkul et al. [25-27] conducted one study, which resulted in two publications [25-27] and Ekwall et al [7,27] conducted one study which resulted in two initial publications and, following further interviews with a sub-group of the initial sample three and five years later, they published a third paper [28]. Table 3 provides a description of all the studies included in the meta-ethnography.

[Insert Table 3]

Critical appraisal:

Papers differed in the extent to which they met the quality criteria. All papers clearly stated aims and the rationale for choosing a qualitative methodology. However, some described their chosen methodology in greater detail and displayed a more critical approach to their findings. Few explicitly considered the way the researchers' assumptions may have shaped the findings and in some papers, the analytical approach used was not made explicit. Studies also differed in the extent to which they provided rich conceptual insights. Seven were coded as a key paper, and 10 as of satisfactory quality. No papers were rated as fatally flawed.

## Results

The synthesis identified wide-ranging ways in which a cancer recurrence impacted on participants. The third-order constructs developed to capture these were: *Experiencing emotional turmoil following diagnosis*, *Experiencing otherness*, *Seeking support in the health care system*, *Adjusting to a new prognosis and uncertain future*, *Finding strategies to deal with recurrence*; and *Facing mortality*.

### 1. Experiencing emotional turmoil following diagnosis

Diagnosis of recurrence was a distressing emotional experience for the majority of patients, generating a range of responses including shock, fear, anger, devastation or hopelessness [7 9 10 23 31]. In two studies of patients with a recurrence of oral cancer and ovarian cancer, participants described feelings of shame and guilt for developing cancer again [7 23].

With two exceptions [10 32], the studies found that awareness of the possibility of recurrence did not lessen the emotional impact [9 10 31 32]. As one participant said: "I knew all along it could come back but let me tell you, nothing could ever prepare you for it" [9 p.183 ]. While

experiencing symptoms facilitated detection of the recurrence for some [7 8 10 28 29], others initially attributed the symptoms to non-cancer causes [9 28 30]. For those who did not experience any symptoms and were diagnosed on the basis of a change in a tumour marker, the experience was particularly shocking [7 30].

## 2. Experiencing otherness

Recurrence of cancer had wide-ranging social impacts and challenged existing relationships between patients and those close to them. These challenges related to expressing feelings as well as managing changing bodies. Growing closer and sharing the burden of cancer was also part of the experience for some patients.

### *2.1 Experiencing difficulties in sharing the uncomfortable with others*

Sharing emotional as well as physical suffering with family members was found to be challenging [7 28 29]. Negotiating disclosure of the diagnosis as well as receiving support in making decisions regarding treatment were also described as difficult by some patients [29 31 32]. Inability to express feelings and concerns about triggering negative reactions in people could result in patients withdrawing from work or leisure activities and some studies highlighted that this made the experience for patients a lonely one [10 32 33]. The fear that they were becoming a burden and contributing to the family's suffering also hindered patients in sharing their distress [10 26 32].

Sharing feelings and preparations related to mortality and death was also challenging for some patients [26 32]. Chunlestsukul and colleagues [26] and Vilhauer [32], in describing the experiences of women with metastatic breast cancer, highlighted their sense of being silenced from discussing their mortality as it made people feel uncomfortable and generated

superstitious fears about bringing on death. Other patients felt that by discussing death, they could be perceived as having lost their “fighting spirit” [25 32].

While they rarely mentioned to clinicians their difficulties in discussing mortality [25], patients valued the opportunity to discuss their death-related concerns with counsellors and support groups [26]. At the same time, maintaining normality and not always being treated as an ill person was also welcomed by some participants [29 32]. The balance between being able to talk about their experience and trying to live a normal life was difficult to achieve, however, as families could sometimes be overprotective [29 32].

## *2.2 Managing their social lives with a changing body*

Feelings of otherness were also generated by bodily changes as a result of treatment. A loss of physical ability and ongoing symptoms caused a number of patients to reduce their daily activity and had an impact on their quality of life [7 24 29 30 33]. Accepting these physical limitations was often difficult, as it meant increased dependence on other people and losing previous roles, though support from family could facilitate adjustment to these changes [29]. An altered body image caused distress and affected individuals’ well-being and their relationships with others. Side effects and changes to bodies following breast cancer treatment were perceived as disfiguring and difficult to accept [7 10 32]. Some felt that their altered bodies were a visible sign of dying and as such, triggered uncomfortable reactions from others [10 28 32 33]. For patients with oral cancer, the consequences of further treatment could affect their ability to communicate, which made them feel isolated [34]. Becoming frustrated with pain could also negatively impact on family dynamics [29]. These changes lead some people to withdraw from social activities [32], while some needed time to adjust to bodily changes before returning to previous social lives [34]. Those in intimate

relationships experienced changes to sexual life [7 11] while those wanting to form relationships perceived it as a barrier [32].

A diagnosis of recurrence also seemed to create a number of changes to the daily rhythms of participants' lives, which had to be negotiated within the context of their social relationships. Patients decisions on whether or not to undertake activities were often influenced by fluctuating periods of deterioration and recovery, which families sometimes struggled to adjust to [33]. The need for support also depended on the illness cycle, which other people sometimes found difficult to understand [32]. Relentless treatment regimens meant the loss of capable bodies and demanded constant adjustment. This often resulted in careful monitoring of their bodies and sensitivity to changes [33].

### *2.3 Connecting and growing with people*

For some, a recurrence of cancer resulted in positive changes to relationships. Being able to share death-related concerns was appreciated and facilitated growth and feelings of closeness with families and other cancer patients [25 26]. An awareness of the fragility of life and facing one's mortality could also contribute to a greater appreciation of family and friends [7 27 35]. Social and practical support from family as well as other cancer patients lessened the distress, gave them strength to carry on [8 34] and helped in accepting and living with the limitations of the illness [8 29 34 35].

### 3. Seeking support in the health care system

Interaction with health care professionals when re-entering the system following the news of recurrence was an important part of patients' experience. *Seeking and negotiating medical information* and *Wanting to be known and valued by clinicians* were important components of that interaction.

### *3.1 Seeking and negotiating medical information*

Information provision and communication were integral to patients' experience of recurrence. Dealing with information about prognosis was a complex process carefully negotiated between patients and clinicians. Both patients and clinicians searched for clues on how to talk about prognosis [36]. This was well described by Step and Ray as the "prognosis dance", as illustrated by the following participant: "*She wanted to tell me as little as possible to get me through to the next step and I pushed a bit*" [36 p.54]. The amount of information wanted and needed by patients varied. Some wanted greater recurrence-specific information, including prognosis, treatment options, reasons for recurrence and risks of further recurrences [7 31 36 37] and carefully sought the required information [36], while others found this level of information overwhelming [8 29]. Information provision could lessen anxiety and facilitate understanding of the situation. Although the clinical team was seen as the main source of information, some also wanted, but did not always get, access to other cancer patients with a recurrence to share information and experience [8 31]. Some participants also described the need to be more proactive in order to obtain the information they wanted regarding treatment and prognosis [30]. Terminology related to cancer recurrence was also found to be confusing for patients, especially when compared with information provided at the initial diagnosis. This often left them to interpret things on their own [36]. In contrast, two studies described how information at the initial diagnosis facilitated their understanding of the situation at times of recurrence [8 9].

### *3.2 Wanting to be known and valued by clinicians*

The nature of the relationship was also found to be an important factor contributing to either positive or negative experiences of health care at the time of recurrence. Having information provided in an approachable and sensitive way, being listened to and being offered help were facilitators of positive experiences of care [29 35 37]. Being seen as a partner to a health care professional and sharing responsibility of care with them was also seen as important [37]. Continuity of care was valued as it facilitated not only the diagnosis but also more effective and trusting relationships [8]. Conversely, feelings of being rushed, insensitive communication, use of jargon, lack of communication between staff and broken promises were inhibitors of positive experiences of care [27 35 37]. For example, Howell and colleagues found that patients with a recurrence of ovarian cancer often perceived that clinicians' attitudes had changed and felt that they had given up on them [30].

#### 4. Adjusting to an uncertain future and a new prognosis

Following the diagnosis, worry about further disease progression was common [32 34 35] and participants often balanced awareness of the possibility of death with hope for more time. Progression of disease usually signified fewer treatment options and transition from cure to controlling active disease or symptoms [8 30 35 36]. As a participant with ovarian cancer recurrence noted: *"I didn't feel that I had any options, because she presented two things to me and they were dependant on the state on my health"* [8]. Those who were able to have surgery perceived it as a better option than systemic therapy [9 34 35], regardless of the lack of guarantees for cure [35]. Although longing for a break, patients continued with treatment in the hope of prolonging their lives [29 33]. The uncertainty around prognosis and changing treatment regimens could also be overwhelming for patients [37] and prevented them from having long-term plans, which they found difficult.



Some studies highlighted that the diagnosis of a recurrence signified for patients the need to become familiar with a new disease and its implications [8 9 10]. Previous experiences of cancer could have an impact on how current experience was understood [9]. The diagnosis of a recurrence often brought a realisation that a cure may no longer be possible and that death was now a real possibility. This was often in contrast to how they viewed their prognosis after initial diagnosis, which was more positive [8 10]. Equally, having experience of a previous recurrence reinforced for some the belief that remission was once more possible [9].

## 5. Finding strategies to deal with recurrence

### *5.1 Attempting to regain control over cancer*

In the context of uncertainty, attempting to take control over cancer was important for patients. Taking responsibility for one's own health by eating well or exercising was perceived as facilitating recovery following treatment and maximising the chances of survival [7]. Adopting a fighting spirit and positive attitude were also seen as ways to aid recovery and halt disease progression [7 29 35]. Seeking second opinion and asking for a specific treatment or alternative therapies was an important part of this process. [28 30 37]. In one study of patients with metastatic cancers who were experiencing pain, patients did not always adhere to their medication as prescribed, as they felt they knew when medication was needed and chose to stop or reduce activities to control pain [31].

### *5.2 Taking steps to preserve emotional well-being*

Taking steps to preserve emotional well-being in the context of the threat of death was an important way of dealing with the impact of cancer recurrence and studies described a variety of ways on which patients attempted to do so, including activities which restored emotional

balance [25] and leaving a legacy in the form of life projects [26]. Giving up activities which were found to evoke stress, such as employment, was taken as a conscious decision by some, and aided the preservation of emotional resources [32 33]. Conversely, for some, being able to maintain pre-cancer routines could help create feelings of normality [35]. Focusing on the present, taking one day at a time and accepting losses also helped participants to deal with challenges and regain wellness [10]. Building relationships with people and connections with nature was found useful for some patients [33]

## 6. Facing mortality

### *6.1 Having to face one's mortality*

Hearing news of recurrence brought to the forefront thoughts of their mortality. Facing death and making preparations was acknowledged as emotionally challenging and required time to work through [25 26]. Participants faced the paradox of wanting to know the implications of the diagnosis, while also preferring information to be given gradually in order to allow them to prepare to face their mortality [36]. Undertaking practical preparations and relinquishing roles was part of this process [26] with some realisation that this process is never complete [25]. Patients grieved the loss of their envisaged future and the prospect of their early death [9 10 32]. Experiencing symptoms triggered thoughts of death, while periods of recovery heightened their desire for prolonged life [25].

### *6.2 Changing perspectives on life as a result of facing mortality*

Diagnosis of recurrence provided an opportunity to evaluate previous life choices and, for a number of participants, led to a change in priorities [9 27 31], where previous concerns lost their importance [27]. Heightened appreciation of life and their remaining time was common among participants [9 10 25 26 32 33]. Engaging with their mortality enhanced self-

awareness of both personal strengths as well as weaknesses [10]. Facing one's mortality and finalising preparations for death, allowed some to live in the present [26].

## **Conclusions**

Stage 7, expressing the synthesis, is the last of Noblit and Hare's stages and concerns the dissemination of the findings to maximise their impact. We have interpreted this from the perspective of applied health research as identifying the implications for health care practice.

This meta-ethnography has demonstrated the complexity of the issues patients face when diagnosed with a recurrence. It fills an important gap in the literature by bringing together a wide range of qualitative studies of the experiences of patients at this difficult stage. It builds on an earlier narrative review of the psycho-social impact of recurrent cancer, which included both qualitative and quantitative studies up to 2007. In addition, the interpretative nature of the current qualitative synthesis, has allowed us to develop a new conceptual understanding of the experiences of patients with a recurrence [18].

The diagnosis of cancer recurrence evoked a range of emotions including fear, anger, shame and guilt. Quantitative studies have questioned whether the initial cancer diagnosis or the diagnosis of a recurrence is more distressing and have assessed levels of anxiety and depression at each stage [38] whereas the evidence presented in this synthesis adds to our understanding of the complexity of the emotions experienced by patients. We found no evidence that recurrence is either more or less demanding emotionally than initial diagnosis and suggest a more useful focus may be on describing the nature of their distress, rather than on measuring its intensity.

Studies also highlighted that regardless of their vigilance and knowledge that cancer can return, patients still found the news of recurrence unexpected and deeply distressing. In

addition, several studies in our review found that patients initially attributed symptoms of recurrence to non-cancer causes [9 28 30]. A recent review of patients views of follow up suggested that patients see the aim of follow up appointments as providing reassurance, and that they lacked information on the effectiveness of follow up tests [39]. We would agree with the authors of this review that it is important for patients to be provided with easy to understand information regarding the aims of follow up, and to be prepared for the possibility of recurrence and what signs to look out for. It is a difficult balance for health professionals to achieve between offering hope and preparing for the worst – patient preferences are likely to vary in this regard and skilful communication is required.

The perception of recurrence as shattering hopes for cure and bringing a real threat of mortality, has also been found in reviews of the experiences of patients with recurrent breast cancer [12 13]. In our review, these concerns seem to be magnified for those not eligible for surgery, with patients viewing surgery as the only possible route to a cure. Health care professionals could play an important role in helping patients to adjust to a changing situation by balancing hope with acceptance that a cure may not be possible.

In the context of the changing meaning of a diagnosis, information about the illness and its prognosis was important to patients, with most studies finding that patients wanted more information specific to recurrence. They valued information from both their clinical team and other cancer patients at the same stage of illness, but sometimes this was lacking. Previous qualitative studies have demonstrated that compared with mixed-stage groups, stage-specific support groups can be more helpful for patients [40]. It could be useful for health care professionals to provide them with opportunities to meet other cancer patients at stage of recurrence or signpost them to charities, which could complement support from health care

professionals. Equally, providing information in a sensitive manner was also important as it facilitated positive experiences of care. Thorne and colleagues [41] point out that communication can facilitate or hinder human connection and it is important that health care professionals are sensitive to patients at this vulnerable stage.

In order to deal with uncertainty, patients tried to regain control by taking care of themselves, using complementary therapies or seeking second opinions. Previous studies have also recognised these as facilitating hope and a sense of empowerment [42 43]. Leaving a legacy, giving up stressful activities and focusing in the present also helped patients to restore their emotional well-being. It is important that health care professionals provide support to patients to help them access self-management strategies such as these, as appropriate to their own individual circumstances.

Recurrence clearly had an impact not only on individuals but also on families and the patients' wider social context. Patients valued having an opportunity to talk about their concerns, but this was often limited with both family and the clinical team. Closer collaboration between secondary care and palliative care may be needed to facilitate these conversations. This is expressed in the vision of NCSI for Active and Advanced Disease which focuses specifically on the early introduction of palliative care services to facilitate discussions in a timely manner [44]. Equally, support is needed to assist family members to help patients face the possibility of death.

A strength of this meta-ethnography is that, in contrast to previous reviews [12 13], it has included studies of a number of different types of cancer. It has thus been possible to identify the challenges across a range of cancer types as well as those relevant to specific patient groups. A limitation, however, is the diversity of time frames used in the studies that were included. A few studies conducted interviews shortly following diagnosis of a recurrence (up

to two months), some in an intermediate period (5-10 months), while some were based on largely retrospective data gathered up to 6 years following news of the recurrence. The time between initial diagnosis and the recurrence of cancer also varied widely which may also have affected their experience of the recurrence their cancer [11].

The majority of studies in our review focused on breast and ovarian cancer, and further studies are needed to explore any specific issues regarding the impact of cancer recurrence in other cancer groups, especially bowel cancer given its high incidence and recurrence rates.

This meta-ethnography has identified, reviewed and synthesised the qualitative studies of patients' experience of a recurrence of cancer published in the last 20 years. Six third order constructs were developed to capture features common to the experience of recurrence across a range of cancer types. These constructs have provided the framework for discussing the diversity and complexity of patients' experiences and for considering the implications for health care professionals.

Conflict of interest: None

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Table 1: Search terms

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1. (maximum variation or snowball).mp.
  2. (thematic\$ adj3 analys\$).mp.
  3. (participant\* adj3 observ\*).mp.
  4. (nonparticipant\* adj3 observ\*).mp.
  5. (non participant\* adj3 observ\$).mp.
  6. (structured categor\* or unstructured categor\*).mp.
  7. action research.mp.
  8. (audiorecord\* or taperecord\* or videorecord\* or videotap\*).mp.
  9. ((audio or tape or video\*) adj5 record\*).mp.
  10. ((audio\* or video\* or tape\*) adj5 interview\*).mp.
  11. (content analy\* or field note\* or fieldnote\* or field record\* or field stud\*).mp.
  12. (qualitative\* or ethno\* or emic\* or etic or emic or phenomenolog\*).mp.
  13. (hermeneutic\* or heidegger\* or husserl\* or colaizzi\* or giorgi\* or glaser or strauss).mp.
  14. (van kaam\* or van manen or constant compar\*).mp.
  15. (focus group\* or grounded theory or narrative\* or lived experience\* or life experience\*).mp.
  16. (theoretical sampl\* or purposive sampl\* or ricoeur or spiegelber\* or merleau ponty).mp.
  17. IPA.mp.
  18. interview\*.mp.
  19. biographical.mp.
  20. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
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21. adjustment.mp.
  22. perception.mp.
  23. "information need\*".mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, tc, id, tm]
  24. "supportive need\*".mp.
  25. "supportive care\*".mp.
  26. experience\*.mp.
  27. psycho-social.mp.
  28. psychosocial.mp.
  29. psycholog\*.mp.
  30. social.mp.
  31. adaptation.mp.
  32. information\*.mp.
  33. 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
  34. (cancer\* or carcinoma\* or malignan\* or tumour or tumor or neoplasm\*).mp.
  35. (secondar\* or recur\* or relapse\* or metasta\* or advanced).mp.
  36. 34 and 35
  37. 20 and 33 and 36
  38. limit 37 to English language
  39. limit 38 to humans
  40. remove duplicates from 39
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Table 2: An example of the first and second-order extraction:

Third order construct	Paper	Second-order constructs	Description of the second-order construct	First order construct (quote from the participants)
Fears of recurrence becoming a reality	Mahon and Casperson [9]	Diagnosis of recurrence	Participants experienced a variety of symptoms and attributed them initially mainly to non-cancer causes. They described the emotional reactions of being overwhelmed and shocked even though being prepared for recurrence.	<i>I knew all along that it could come back but let me tell you, nothing could prepare you for it. Even though I knew it was happening. I got real lightheaded when doctor told me.</i>
Fears of recurrence becoming a reality	Griffiths et al. [27]	Emotional reactions	Participants described the emotional impact of diagnosis including shock, devastation, emotional vulnerability and hopelessness. Also experienced intense feelings of shame, often related to feeling a burden on loved ones.	<i>I just felt numb. I was speechless.</i>

Table 3: Studies descriptions

Study and Dixon- Woods et al. (2004) Coding (K=Key paper, SAT- satisfactory, FF- fatally flawed IRR -Irrelevant)	Country setting	Sample N (age, gender and cancer site: primary)	Time since the initial diagnosis	Length of time with diagnosis of recurrence	Methods of data collection	Methods of data analysis	Aim
Chunklestskul et al. [26] K	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenological approach (not defined)	To explore the lived experiences of women with metastatic breast cancer in preparation for their death
Chunklestskul,et al. [25] K	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenological approach (not defined)	To examine enabling and impeding factors in death preparations

Coward and Wilkie [28] SAT	USA	N=20, 10 women and 10 men, 26-73 years, breast, lung, bladder, prostate, kidney and thyroid	1-13 years	1 month- 8 years	Semi-structured interviews	Not specified	To explore gender differences in experience of metastatic bone pain
Dooks et al. [34] SAT	Canada	N=9, 1 woman and 8 men, 60-75 years oral	-----	6-12 months	In depth interviews	Interpretative descriptive approach by Sally Thorne (1997)	To describe patients' experience of reintegrating into community following surgery
Ekwall et al. [7] SAT	Sweden	N=12 women, 50-74 years ovarian	1-5.7 years (Mean=2.8)	5-10 months	Interviews	Phenomenological method (Giorgi and Giorgi, 2003)	To explore experiences of women diagnosed with recurrent ovarian cancer and its impact on daily lives

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Ekwall et al. [37] K	Sweden	N=12 women 50-74 years (Median=57.5) ovarian	1-5.7 years	5-10 months	Interviews	Qualitative content analysis: Grundheim and Lundman (2004)	To explore what women with recurrent ovarian cancer perceive as important in their communication with the health care team
Ekwall et al. [33] K	Sweden	N=4 women, 46-69 years, ovarian	6-10 years	3 years and 5 years	Open- ended interviews on two occasions (3 and 5 years after recurrence)	Phenomenological approach (Giorgi, 2009)	To explore the phenomenon of living with recurring ovarian cancer
Elit et al. [8] SAT	Canada	N= 26 women, 44-77 years ovarian,	6-36 months	2 months	Semi-structured interviews;	Unspecified Content analysis;	To explore treatment decision making process and experiences of women with recurrent ovarian cancer

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Griffiths et al. [27] K	UK	N=9, 6 women and 3 men, 63-85 years, oral	-----	1-8 weeks	Semi-structured interviews	Grounded theory approach	1) To investigate the psychosocial responses of patients with oral cancer recurrence; 2) To highlight the key psychological issues
Howell, Fitch and Deane [30] SAT	Canada	N=12 out of 18 women had recurrence; ovarian	-----	-----	Semi-structured telephone interviews	Not specified; coding scheme developed and used by all authors	To explore the experience of women with ovarian cancer
Maher and De Vries [29] SAT	UK: London	N=8, 5 women and 3 men, 48-74 years, myeloma	-----	-----	Unstructured interviews	Theoretical framework of Hermeneutic phenomenology; thematic content based on method of Colaizzi (1978)	To explore how the experience of living with relapsed myeloma had affected the quality of life of patients

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Mahon and Casperson [9] SAT	USA	N=20, 26-72 years (Mean=54); type not specified	8-94 months, (Mean=37 months)	30 days	Unstructured and semi-structured interviews	Not specified; Software used	To describe the meaning of a recurrence of cancer to the patient and possible differences between initial diagnosis and recurrence
McCahill and Hamel- Bissell [35] SAT	USA	N=12; 5 women and 7 men, 45-75 years, colorectal	-----	-----	In depth semi- structured interviews	Phenomenological approach; Three step analysis using Colaizzi method (1978)	To explore the lived experience of patients who experienced surgery for CRC liver metastasis
Misra et al. [31] SAT	Canada	N=15, 12 women and 3 men); thyroid	1-21 years (Median= 5)	11-79 months (Median=24)	Semi-structured interviews	Unspecified thematic analysis combined with grounded theory	To explore the individual patient experiences relating to diagnosis and surgical treatment of loco-regional recurrence of thyroid cancer

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Rose, Spencer and Rausch [45] IRR	USA	N=17, ovarian	-----	-----	Interviews	Phenomenological method by Colaizzi (1978)	To explore how patients with ovarian cancer recurrence experience humour
Sarenmaln et al. [10] K	Sweden	N= 20 women, 55-81 years; breast	Median= 68 weeks	2 weeks- 24 months	In depth interviews	Grounded theory: Glaser and Strauss 1967 and Glaser (1978)	To explore the main concerns of women with breast cancer recurrence and how they deal with breast cancer recurrence
Step and Ray [36] K	USA	N=30 women, 42-84 years, breast, lung, gynaecological and head and neck	7.3 years	-----	Interviews	Thematic analysis (not specified)	To explore patients' experience of communication at time of initial diagnosis and recurrence

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Vilhauer [32]	USA	N=14 women;	-----	Mean =25.8	Telephone	Content analysis	To investigate the
SAT		Mean age: 51.6		months	interviews		experiences of women with
		years , breast					metastatic breast cancer

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