

A systematic review on the factors associated with positive experiences in carers of someone with cancer

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Review

Abstract

The aim of this review was to identify the factors associated with positive experiences in non-professional carers of someone with a cancer diagnosis. A systematic search of the following electronic databases was undertaken: Cochrane Library, CINAHL, PsycINFO, SocINDEX and Medline. Literature was searched using terms relating to cancer, caring and positive experiences. Additional records were identified through a manual search of relevant reference lists. The search included studies published in English from 1990- June 2015. Two raters were involved in data extraction, quality appraisal, coding, synthesis, and analysis. Evolutionary concept analysis was used as a guiding framework in order to focus on attributes associated with positive experiences. Fifty two articles were included in this review. Analysis identified four overarching attributes: 'gender', 'personal resources', 'finding meaning' and 'social context'. Despite the challenges associated with caring this combination of internal and external factors enabled some carers to report positive experiences related to caring. This knowledge may be clinically helpful when designing supportive interventions. Strengths and limitations of these claims are discussed.

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Key words: positive experiences, carer, cancer, systematic review,

Introduction

Informal carers are people who undertake care work for kin or friends on an unpaid basis. The increasingly important role that carers play in society and the need to provide personalised support services is recognised within international health and social care policy (Departement of Health, 2014). Despite this recognition, literature that specifically focuses on the role of the carer within the cancer field remains sparse (Fletcher et al, 2012). There is even less literature associated with the positive outcomes of caring.

The physical, emotional, financial and social impact of caring for an individual with cancer can be considerable (Hudson, 2008). Certain external factors appear to be associated with carer burden and distress such as being single, unemployed or supporting someone in treatment (Chambers et al., 2012). Internal psychological responses, such as coping style, may help to minimize distress (Butow et al., 2014). Predictors of distress therefore involve an interrelationship between known caregiving stressors such as socio-demographic factors and characteristics of the carer.

Positive aspects of caregiving

The relationship between positive affect in adaptation and resilience has been documented (Fredrickson, 2001). Yet, researchers predominately examine anxiety and distress in carers of someone with cancer (Roberts et al., 2013). Compared to research on burden and other negative outcomes there is little research associated with positive psychological outcomes. For example, a meta-analysis of 78 studies in the field of family care indicated that 57 used some form of burden measure and 40 included depression as an outcome, whereas only 3 considered the positive experiences of carers (Sörensen et al, 2002). Theoretically driven models are required that pay greater attention to the multifaceted experience of caring rather than solely documenting predictors of distress. This will then facilitate understanding around the optimal way of supporting caregivers.

Individuals can experience well-being under difficult circumstances (Folkman and Greer, 2000) but little is known about how this may apply to those who care for someone with cancer. A review on the positive aspects of caring for cancer patients identified various outcomes such as an enhanced relationship with the care receiver, feeling rewarded and a

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3 sense of personal growth (Qiuping & Loke, 2013) However, while there is some
4 understanding on the positive outcomes of caring the authors suggest that further research
5 should be carried out to examine the *determining* factors to these positive outcomes. It is
6 particularly important to identify factors relating to positive experiences so they can be
7 maintained or increased through clinical interventions (Kang et al., 2013). Addressing the
8 psychosocial needs of cancer carers can improve patient outcomes, reduce strain and
9 decrease economic costs to the healthcare system (Waldron et al, 2013). In the first
10 instance, a systematic review is needed. The aim of this review was to establish what factors
11 are associated with positive caring experiences. The first step in this process was to select a
12 theoretical framework coherent with the purpose of the review.
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24 *Theoretical framework*

25 Research into caring has been largely guided by Lazarus and Folkman's stress and coping
26 theory (Lazarus and Folkman, 1984). This theory emphasises the relationship between the
27 person and their environment suggesting that stress emerges when an individual appraises
28 their environment as being a threat to their well-being. The cancer literature has historically
29 conceptualised caregiving as stressful, meaning theoretical models of caring have followed
30 suit (Weitzner et al, 2000). These theorists and much of the wider literature on cancer care
31 therefore presuppose stress.
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40 In contrast, the field of positive psychology focuses on the strengths and characteristics that
41 may enable someone to thrive (Sheldon & King, 2001). Adopting a strengths based approach
42 shifts focus towards positive traits in the individual as opposed to emphasizing undesirable
43 mental characteristics (Fayed et al, 2011). This approach aims to facilitate understanding
44 around positive emotions and other positive aspects such as optimism, resilience and life
45 satisfaction.
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50 Within the wider caring literature there is debate as to whether positive well-being is on a
51 continuum with distress or if it's a conceptually separate dimension of the caring experience
52 (Carbonneau et al, 2010). This complexity is acknowledged by professionals who suggest
53 that the application of the positive psychology approach does not neglect the presence of
54 distress but it aims to overcome the negatives and enhance the positives (Casellas-Grau et
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3 al, 2014). Consequently, the value of this approach has been recognised in the cancer
4 context (Casellas-Grau et al., 2014; Gorin, 2010) providing further rationale to develop
5 understanding in this area.
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9 We acknowledge that 'positive experiences' is an umbrella term that may be conceptualised
10 differently across studies. For that reason, we take guidance from the literature and define
11 positive experiences as an optimal state of experience and functioning (Duckworth et al,
12 2005). This definition refers to positive characteristics and gains including positive affect,
13 optimism, mastery, hope and meaning (Aspinwall and Tedeschi, 2010).
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19 In order to systematically examine the range of possible factors associated with positive
20 caring experiences it was necessary to describe how and when it may arise, under what
21 conditions and what happens as a result. Rodgers' (Rodgers, 2000) method of evolutionary
22 concept analysis views concepts as being embedded within a process. Antecedents are the
23 events that must arise before the concept can be experienced. Consequences are
24 experienced as a result of the occurrence of the concept and various attributes have an
25 impact on this process (figure 1). This framework has been used previously by the authors to
26 systematically analyse complex literature and illuminate discrete elements of social
27 processes such as how, where and why a concept may occur (Snowden et al, 2014). It is not
28 the purpose of this review to conduct a full concept analysis. Rather, this structure has been
29 chosen to systematically guide this review and identify the attributes of positive experience
30 within a neutral framework.
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42 *Figure 1. Relevant sections of Rodger's Evolutionary Concept Analysis (Insert here)*
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44 **Method**

45 Search strategy

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47 This review was conducted in accordance with the Preferred Reporting Items in
48 Systematic Reviews and Meta Analyses (PRISMA). A systematic search of the following
49 electronic databases was undertaken: Cochrane Library, CINAHL, PsycINFO, SocINDEX,
50 and Medline. The search included studies published from 1990 – June 2015. This time
51 period was chosen as it is unlikely that any articles relating to positive experiences in
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3 cancer carers would be found before 1990. This relates to the fact that
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5 recommendations to support friends and family were not made in policy, in the UK until
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7 1995 (Department of Health, 1995). The reference lists of 11 recent articles were also
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9 searched to discover additional articles. Search terms were derived from prior
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11 systematic review on positive aspects of caring (Qiuping & Loke, 2013) and literature on
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13 positive psychology in cancer care. Thesaurus terms and free-text terms relating to
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15 positive experiences were then combined. Boolean operators 'OR' 'AND' were used to
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17 focus and broaden the search. The strategy was to conduct a broad search that captured
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19 the factors associated with positive experiences in carers of someone with cancer.

20 The search terms were:

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- 22 1. care*
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- 24 2. cancer OR oncology
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- 26 3. positive experiences OR positive psychology OR optimism OR mastery OR positive
- 27 affect OR benefit finding OR post-traumatic growth OR hope OR meaning OR self-
- 28 esteem OR self-efficacy OR appraisal OR confidence OR well-being OR coping OR
- 29 resilience OR happiness
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- 31 4. 1 AND 2 AND 3
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36 Inclusion and exclusion criteria

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38 Inclusion criteria were as follows: (i) carers of an individual over 18 years old with a cancer
39 diagnosis; (ii) any type or stage of cancer including bereaved carers; (iii) written in English;
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41 (iv) empirical research published from 1990 onwards; (e.g not discussion papers, and grey
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43 literature) (v) primary focus on positive aspects of caring. Research involving professional
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45 carers, for example, carers who are paid to provide care were excluded.
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48 *Figure 2 Flow diagram for identifying the literature (insert here)*
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Search and quality appraisal

Figure 2 summarises the process used to identify and select relevant articles. To minimize possible bias, both authors (JY and AS) were involved at all stages of data extraction, quality appraisal, coding, and analysis. Any discrepancies were systematically resolved by consensus. Qualitative papers and systematic reviews were appraised using the Critical Appraisal Skills Programme (CASP). CASP approaches appraisal in 3 ways: validity, clinical importance and relevance to research question. Quantitative papers were assessed using a standard quality assessment for evaluation of primary research (Kmet et al 2004). Five papers were excluded on the grounds of quality (Table 1). Remaining papers were imported into NVivo 10 to extract data for evidence analysis and synthesis.

Table 1 Reason for exclusion following quality appraisal (insert here)

Data analysis/synthesis

Each research article was read by both reviewers to identify its general focus. Once agreed suitable for inclusion, summary codes were assigned to label the central claims made within the results and discussion sections of every paper. Next, both authors compared meanings and interpretations across studies. This involved identifying whether the codes in different studies complimented or challenged one another and what implication this had for understanding positive experiences. This enabled the next stage of analysis. For the purpose of more general categorisation the codes were grouped into broader themes. For example, codes such as self-esteem, self-efficacy and confidence were all themed as 'personal resources' (Table 3). Any discrepancies were resolved through discussion. Using Rodgers (Rodgers, 2000) framework the themes were then categorised as 'attributes'. For example, personal resources are attributes of positive experiences. The antecedents and consequences were not explored in detail, as they were largely consistent. That is, the antecedent in each case was caring for someone with cancer and the 'consequence' was always a positive experience as that was the purpose of the search. A table was created (Table 2) to summarise this noting each paper's setting, methodology, variables of interest, main findings and attributes or consequences of positive experiences. Finally, the original papers were revisited to ensure these themes were consistent with the papers original findings.

Results

Table 2 Overview of included studies (insert here)

Characteristics of the selected studies

Table 2 presents a summary of the 52 articles included in the review. The majority of the studies were conducted in the United States (n=16) followed by the UK (n=9) and then Australia (n=8). Most had a quantitative design (n=32) using questionnaires to measure variables related to positive constructs and then examine associations. Validated instruments assessed quality of life (n=18), social/support resources (n=14), stressors (n=19) or positive constructs such as well-being or benefit finding (n=17). They comprised of samples of carers of patients with a range of cancer types. Time from diagnosis ranged from two months (Kim et al, 2010) to 16 years (Turner et al, 2013). Four studies focused on bereaved carers (Burton et al., 2008; Kang et al., 2013; Kogler et al., 2015; Wong et al, 2009). The majority of the participants were partners or key family members of the person with cancer. Carers of paediatric cancer patients were excluded due to the distinct experiences these carers may face (Svavarsdottir, 2005).

Analysis

Table 3- Codes, themes and theoretical framework (insert here)

A summary of how the codes and themes were grouped into attributes and consequences is presented in Table 3. The primary antecedent to caring described in all the papers was a diagnosis of cancer. For that reason, antecedents were not analysed beyond a description of cancer type. However, it is acknowledged there may be time between the care recipient's diagnosis and then identifying with the term 'carer'.

The following section focuses solely on attributes and consequences of positive experiences. Further details of individual studies including cancer type are reported in Table 2.

Attributes

Attributes are characteristics of the concept. In this review the concept under scrutiny was positive experiences. The four overarching attributes associated with positive experiences

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3 were gender, personal resources, finding meaning and the social context in which they
4 occurred. Whilst they are clearly interlinked they are described individually below.
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7 *Gender*

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10 The relationship between gender and positive experiences was discussed in the literature
11 more than any other demographic factor (Duggleby et al, 2012; Fletcher et al., 2012;
12 Gaugler et al., 2005; Haley et al., 2003; Kang et al., 2013; Kim et al., 2007; Kim et al., 2015;
13 Thomas et al., 2002; Ussher et al., 2013; Valeberg & Grov, 2013; Zwahlen et al., 2010).
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15 Despite this, there was little consensus as to whether being male or female is associated
16 with a greater likelihood of having a positive experience whilst caring.
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21 A meta-analysis on gender effects in couples facing cancer found that female carers
22 reported higher rates of depression, anxiety, lower life satisfaction and quality of life than
23 men (Hagedoorn et al., 2008). This has been replicated in subsequent research (Moser et al,
24 2013) implying that being female may be associated with a greater risk of developing a
25 negative emotional state whilst caring. However, whether this suggests that males are
26 more likely to report a positive experience is not clear from the identified literature.
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31 It is proposed that gender is a socially constructed phenomenon (Gerson, 1985). This makes
32 comparison between males and females difficult, particularly across different cultures
33 where this social construction may differ. For example, Kim et al. (2007) after carrying out a
34 multivariate analysis on survey data from American carers, found that males were more
35 likely than females to appraise the care experience as boosting their self-esteem. In
36 contrast, Kang et al.(2013) conducted a nationwide survey in Korea and found that females
37 were more likely than males to perceive feelings of reward from the caring experience.
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39 Ussher et al. (2013) examined the difficult and rewarding aspects of care through semi-
40 structured interviews with 53 cancer carers in Australia. The carers differed in terms of the
41 cancer type and stage of the person they cared for. They also found that females were
42 more likely than males to experience feelings of reward and strength. Yet, they found that
43 females were more likely to report negative changes in the relationship with the person
44 with cancer; neglect of self and social isolation. Males were more likely to experience
45 increased closeness with the person with cancer but also the burden of additional
46 responsibilities. The role of gender is therefore complex and irreducible from this literature.
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3 Further analysis requires an interpretation that provides insight into how meaning and
4 behaviour may be associated with the role of gender. In the literature studied here it
5 differed depending on context, culture and even the theoretical approach taken by the
6 particular researcher.
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10 11 12 *Personal resources*

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14 Certain beliefs and characteristics help an individual to positively adapt to the caring role
15 (Fletcher et al., 2012). These include self-esteem, self-efficacy, confidence, control,
16 optimism and mastery. While there are distinct features to each of these characteristics,
17 collectively they appear to have a protective function over the carer. For example, two
18 studies using a questionnaire design and statistical methods (Butow et al., 2014; Cassidy,
19 2013) found an association between factors such as self-esteem, optimism and positive
20 experiences. Gaugler et al (2005) found that mastery, which is the feeling of proficiency and
21 ability, acted as a strong buffer against stress. Similarly, Gustavsson-Lilius et al (2012) found
22 that optimism acted as a buffer against depression and anxiety. Consequently, personal
23 characteristics are a major element in conceptual models of cancer caregiving as they
24 appear to mediate the impact of stress (Cassidy et al, 2015; Fletcher et al., 2012) . For the
25 carer identification of these characteristics is important as they may be susceptible to
26 clinical intervention (Gustavsson-Lilius et al., 2012).
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38 It is recommended that more understanding is required around *how* these characteristics
39 may cause positive well-being or if they change over time. This is particularly relevant to the
40 cancer carer who may face different challenges in line with the patients cancer trajectory. A
41 suggestion is that these personal resources are used when individuals develop their coping
42 strategies (Fitzell & Pakenham, 2010; Saita et al, 2015). However, given the complex nature
43 of caring, coping strategies are likely to be related to specific caring demands (Fitzell &
44 Pakenham, 2010; Stamataki et al., 2014). Investigation into the direct and interacting
45 relationship between these variables and positive experiences would be valuable.
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Finding Meaning

The search for and discovery of meaning is a key component in the psychological adjustment to stress (Hasson-Ohayon et al., 2015). At the centre of this process is appraisal. Appraisal is the subjective evaluation of a situation. Three qualitative studies (Mehrotra & Sukumar, 2007; Ussher et al., 2013; Wong et al., 2009) found that having attributes such as optimism and mastery enabled the carer to appraise the caring role in a meaningful way. Subsequently, research highlights the mediating role of appraisal in promoting positive outcomes such as effective coping, adjustment, strength and higher life satisfaction (Fletcher et al., 2012; Haley et al., 2003; Kim et al., 2007; Kim et al, 2011; Lambert et al, 2015; Mehrotra & Sukumar, 2007; Pitceathly & Maguire, 2003; Tang et al, 2008; Ussher et al., 2013). For example, Fitzell & Pakenham 2010 using regression techniques, found better adjustment outcomes when the carer appraised the caring experience as offering them a personal challenge, than as being threatening and limiting opportunities for personal growth.

The theory suggests that an individual gains positive value by appraising their situation as having provided benefit (Folkman & Greer, 2000). This is a well-established finding, particularly in the cancer patient population (Jenkins and Pargament, 1988). However, more insight is needed within the carer population. Kim et al. (2015) investigated the role of gender, motivation and quality of life. They found that self-determined motives for caring played a larger role among males than females. That is, having a greater sense of autonomy was related to improved quality of life, including finding meaning. This highlights the interrelated nature of these themes and the need to investigate positive experiences from the individual, social and cultural context it occurs.

Social context

Positive experiences in the context of the carers' everyday life were examined. As described in many studies, social support plays a key role in promoting positive aspects of caring (Butow et al., 2014; Cassidy, 2013; Cavers et al., 2012; Connell et al., 2013; Fitzell & Pakenham, 2010; Fujinami & Otis-green, 2012; Gaugler et al., 2005; Haley et al., 2003; Kescu et al., 2009; Matthews et al, 2004; Mehrotra & Sukumar, 2007; Northouse et al, 2010; Ownsworth et al, 2010; Teixeira & Pereira, 2013; Weiss, 2004). Specifically, it is suggested

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3 that frequency and satisfaction with support was found to act as a buffer against the
4 negative impact of caring (Choi et al., 2015; Teixeira & Pereira, 2013; Weiss, 2004). Wider
5 research proposes that positive relationships with others is a defining element of well-being
6 (Ryff & Singer, 2000). The majority of research focuses on social support in general although
7 variation in the preference and effectiveness of support from friends, family, health care
8 professionals and peer support groups have been noted (Cassidy et al., 2015; Mosher et al,
9 2015). The importance of relatedness for well-being is highlighted here. Yet, a substantial
10 gap in the cancer literature is a theoretical understanding of what the support does.

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There has been a shift in the literature away from study of the individual carer towards
exploration of the relationship between the carer and the person they care for (Fletcher et
al., 2012). The function of the carer/patient dyad has been explored (Chen et al, 2004; Kim
et al., 2011; Qiuping & Loke, 2013; Murray et al., 2010; Turner et al., 2013; Valeberg & Grov,
2013; Wadhwa et al., 2013; Weiss, 2004; Weitzner et al, 1999; Zwahlen et al., 2010). In
particular, the quality of the relationship between the carer and care-receiver appears to be
central to the expression of positive experiences (Li & Loke, 2014). Factors such as
frequency and intensity of interaction, relationship satisfaction, motivation to care, quality
of communication, supportiveness and collaborative coping were also cited as influential
variables (Chen et al., 2004; Elliott et al., 2015; Gustavsson-Lilius et al., 2012; Kim et al,
2008; Pitceathly & Maguire, 2003; Tsilika et al, 2014; Valeberg & Grov, 2013; Zwahlen et al.,
2010;). Hence, contextual factors that precede the caring role are an important component
in the expression of positive aspects of caring.

Consequences

These identified attributes are important to understand because they all had a role in
facilitating positive experiences. The final theme relates to the consequences of these
positive experiences. The theme 'Discovery of growth' is an articulation of how carers may
experience feelings of satisfaction, privilege, adjustment, growth and strength (Cavers et al.,
2012; Cormio et al., 2014; Ellis et al, 2013; Fitzell & Pakenham, 2010; Fletcher et al., 2012;
Levesque & Maybery, 2014; Nicholls et al , 2014; Qiuping & Loke, 2013; Tamayo, 2010;
Turner et al., 2013; Ussher et al., 2013; Weiss, 2004; Wong et al., 2009; Zwahlen et al.,
2010). Carers were able to articulate meaningful and rewarding accounts of the caring
experience. This was expressed as either a reflection on how they had changed, such as

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3 discovering strength, or how the relationship with the person they cared for had improved.
4 For example, Cormio et al. (2014) found that levels of personal strength were significantly
5 higher in the carer compared to the person they care for. Accounts of benefit finding in
6 cancer caring can be interpreted as the carers' way of managing distress through
7 constructing meaningful interpretations (Wong et al., 2009). Three studies (Choi et al., 2015;
8 Elliott et al, 2015; Kim et al., 2007) examined the factors that might influence these positive
9 outcomes. Gender, the patient carer dynamic and social supports were all influential. With
10 the caveat discussed above in relation to the complex role of gender there is support here
11 for Qiuping & Loke (2013) finding that certain attributes act interdependently to reinforce
12 positive experiences in carers.
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23 Discussion

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26 Attributes of positive experiences have been identified. Personal resources such as
27 confidence and self-esteem facilitated positive aspects of caring, as did the capacity to
28 construct meaning from the experience. These attributes and abilities were expressed
29 within the social context of the caring relationship with social support being cited as an
30 important factor. However, greater understanding into how the support generates well-
31 being is required. For that reason, the quality of the relationship between the carer and
32 care-receiver is a valuable unit of analysis. Complementing this, research that examines how
33 experiences and relationships are shaped by motivations to provide care is insightful.
34 Treating the dyad as the unit will certainly provide a fuller picture than attempting to
35 understand positive experiences in isolation. The ability to develop a positive experience
36 from caring was associated with personal growth. Consequently, there is potential to gain
37 from the caring experience. This is somewhat neglected within the literature.
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49 It is unlikely that any of the factors identified here either act in isolation or can be
50 considered one-dimensional. For example, in relation to gender, it is unclear whether
51 women as a group were more distressed than men, or whether they were more
52 comfortable identifying and reporting the distress. Gaugler et al (2005) suggest the latter.
53 Social constructivists propose that traditionally caring was positioned as a feminine practice
54 (Ussher et al., 2013) causing men to experience a threat to their identity. It has been
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3 suggested that men enact a gender-specific style of caregiving, characterised by features
4 such as strength, machoism, rationality and courage (Maughan et al. 2002). For some this
5 may lead to feelings of well-being. For others, this enactment of masculinity can lead to
6 feelings of helplessness and bewilderment. However, these findings may not be
7 generalizable. They paint a narrow picture bordering on stereotypical. Furthermore, less is
8 known about male cancer carers (Gilbert et al, 2014) which prevents us from concluding
9 whether being male or female is a greater predictor of a positive caring experience.
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17 The focus of this review was on positive caring experiences. Yet, the intertwined
18 relationship between positive and negative aspects of caring was evident. This was
19 particularly relevant for the bereaved participants in this review. Further, there were a
20 number of quantitative studies that despite having an overall focus on positive aspects of
21 caring included a measure of distress. Mainly, the purpose of this was to test relationships
22 and interaction effects between positive concepts and stressors to form conclusions on
23 when positive experiences may be more likely and under what conditions. Further analysis
24 is needed to examine if these positive experiences help to allay the negatives. In particular,
25 to what extent they are modified by the identified attributes in this review and other factors
26 relevant to the cancer carer such as stage and severity of the disease. This will hopefully
27 develop understanding around whether positive well-being is on a continuum with distress
28 or conceptually distinct.
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40 Limitations to these claims are acknowledged. We deliberately made our key concept
41 'positive experience' a broad search term as this is a relatively new research area. The
42 search was coherent with the current body of literature but it is recognised that this general
43 term may pose conceptual problems relating to theoretical consistency. Further limitations
44 are also related to this conceptual issue. For example, the majority of the included studies
45 were cross-sectional in method and relied on self-reported questionnaires. Causality could
46 not be established so it is not clear whether attributes such as self-esteem enable and
47 maintain positive experiences or whether the positive experience generates self-esteem.
48 The search strategy may have failed to identify all articles in this field. Despite the effort to
49 conduct a broad search other terms may have been used in the literature. There is selection
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3 bias as we did not include studies published in other languages than English, unpublished
4 studies and dissertations. The review mainly consisted of papers from America and the UK
5 meaning the generalizability of our findings to other cultures may be limited. Only 14
6 studies in this review focused on carers' experiences of a specific cancer type. Based on
7 mortality rates between the different cancers, there is likely to be differences in the caring
8 experience. Four studies focused on bereaved carers, presenting a different perspective to
9 the majority of the other participants included in this review. The bereaved participants in
10 these studies were recalling a retrospective account of their caring experience. This will be a
11 summary account formed over time, with the ability to reflect on the experience as a whole.
12 Consequently, an enquiry into the determinants of positive experiences, specific to different
13 sub groups of carers would allow greater generalizability of these findings. Finally, there was
14 a lack of consistency in the papers with regards to reporting characteristics of the patient
15 (care recipient). Factors such as cancer severity and functioning levels may have a direct
16 impact on carer experience (Burridge et al , 2009) which is a further issue in terms of the
17 generalizability of these findings.
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31 Nevertheless, the chosen theoretical framework proved to be valuable as it offered an
32 inclusive method of capturing relevant positive attributes despite the heterogeneity of the
33 literature. In taking this approach this review is the first attempt to bring clarity to the small
34 number of findings relating to factors that specifically focus on positive experiences in carers
35 of people with cancer. We hope that the findings of this review will guide further research.
36 Qualitative research is needed to explore carer's accounts of *how* they find meaning, with
37 particular focus on appraisal. Equally, longitudinal research in this field is rare. The role of
38 attributes such as optimism and their function across the cancer trajectory requires further
39 enquiry. Longitudinal research will help to uncover critical periods where processes such as
40 positive appraisal may fluctuate (Fletcher et al., 2012). Finally, we recommend that any
41 future research focuses on the relational aspect of the caring experience so as to capture
42 the context within which any particular attribute or intervention is expressed.
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Conclusion

There is a moral and political imperative to recognise the significant contribution that carers make to society. In order to support carers we need to understand the multifaceted nature of caring, including the positive elements. The literature on caring for someone with cancer has traditionally focused on vulnerability factors. Subsequently, interventions have been designed to reduce burden rather than focus on the nature and quality of relationships and positive outcomes. This review expands understanding around the expression of positive experiences when caring for someone with cancer. This is not to discount the level of burden the carer may face but to offer insight into the suggestion that individuals may experience both positive and negative experiences simultaneously.

Traits that precede diagnosis, coping mechanisms and support processes are part of the carer's response to their role. Gaining insight into these attributes is clinically helpful when designing interventions to support carers. The relational element of the caring experience is important. Positive experiences were largely associated with the social context in which the caring took place. This suggests that research into the positive aspects of caring should continue to focus on the patient and carer as a unit rather than as separate individuals.

Conflict of interest

The authors have no funding or conflicts of interest to disclose

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Table 1 Reason for exclusion following quality appraisal

Reason for exclusion	Number of articles
Lacked methodological rigour – no information of inclusion/exclusion criteria or quality appraisal	4
Data analysis not sufficiently rigorous	1

For Peer Review

Table 2- Overview of included studies and categorisation of themes

Authors, year	Country	Type of cancer	Measures	Method	Findings	Attributes	Consequences
Burton <i>et al</i> (2008)	USA	Lung	Demographics Caregiver stressors Appraisals Social resources Well-being	Questionnaire	Social resources buffer against negative well-being.	Social context	
Fujinami <i>et al</i> (2012)	USA	Lung	Demographics QoL Distress level Functional level Preparedness for caring Burden	Case study	Social support, communication, coping and control impact QoL ¹	Personal resources Social context	

¹ QoL- Quality of Life

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Kim <i>et al</i> (2007)	USA	Breast (21%), Prostate (21%), Colorectal (15%) Lung (10%) Kidney (7%) Ovarian (7%) Non-Hodgkin's lymphoma (5%) Other < 5%	Gender Relationship to care recipient Appraisal QoL	Questionnaire	Males more likely to appraise experience as positive than females	Gender Finding meaning	
Kim <i>et al</i> (2008)	USA	Breast (25%), Prostate (24%) Colorectal (11%) Non-Hodgkin's lymphoma (11%) Lung (9%) other <5%	Benefit finding Life satisfaction Depressive symptoms	Questionnaire	Attachment related to motivation to provide care	Social context	

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Kim <i>et al</i> (2011)	USA	Prostate (25.5%) Breast (24.7%) Colorectal (13.9%) Kidney (7.8%) Lung (6.4%) Ovarian (7.2%) Other < (5%)	Spiritual well-being QoL	Questionnaire	Spiritual well-being (SWB) associated with mental health and each person's SWB related to partners SWB	Finding meaning Social context	
Kim <i>et al</i> (2010)	USA	Cohort 1 were newly diagnosed with colon or rectal Cancer. Cohort 2/3 bladder, breast, colorectal, kidney, lung, non-Hodgkin's lymphoma, ovarian, prostate, skin melanoma, and uterine	Demographics Needs assessment QoL	Questionnaire	Interventions designed to help caregivers find meaning and foster supportive familial relationship improve QoL scores	Finding meaning	

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26	Butow <i>et al</i> (2014)	Australia	Ovarian	QoL Psychological distress Optimism Social support Unmet needs	Questionnaire	Optimism, social support, physical well- being predicted well-being	Personal resources Social context	
27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	Gustavsson- Lilius <i>et al</i> (2012)	Finland	Breast Gynaecological Prostate Lung Gastrointestinal	Optimism Sense of coherence Depression Anxiety	Questionnaire	Optimistic patients and their partners reported fewer symptoms of depression	Personal resources	

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Cassidy <i>et al</i> (2013)	UK	Not reported	Demographics Burden and perceived burden Optimism Pessimism Resilience Stress Self-efficacy Benefit finding Perceived social support General Health	Cohort sequential survey	Resilience, optimism, self-efficacy and social support related to benefit finding	Personal resources Social context	Discovery of growth
Connell <i>et al</i> (2013)	Australia	Palliative care-cancer types not reported.	Demographics QoL	Questionnaire	Psychological domain shown be an important factor in determining QoL	Personal resources Social context	

Weiss <i>et al</i> (2004)	USA	Breast	Post-traumatic growth Social support Quality of relationship Exposure to a model of positive changes Stressfulness of the event	Questionnaire	Social and perceived support- key factor. Transmission of growth between partners.	Social context	Discovery of growth
Wong <i>et al</i> (2009)	Australia	Respiratory Breast Pancreatic Renal Brain, Colorectal Haematological Gynaecological Mesothelioma Prostate	Positive aspects resulting from the experience of providing care.	Interviews	Discovery of strength, deepening of the relationship and personal growth	Finding meaning Social context	Discovery of growth

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Mehrotra <i>et al</i> (2007)	India	Not reported	Sources of strength and self-reported occurrences of positive moments	Interviews	Religious beliefs, appraisal of the role, prior experience of caring, staff, interpersonal traits and support network.	Finding meaning Personal resources Social context	
Cavers <i>et al</i> (2012)	UK	Brain	Multidimensional experience of caring for someone with glioma	Interviews	Different components of wellbeing are difficult to separate. Social support key to adapting.	Social context	Discovery of growth
Turner <i>et al</i> (2013)	UK	Breast (39%) Prostate (29%)	Demographics Health status	Questionnaire	Concordance between patients and	Social context	Discovery of growth

		Colorectal (31%)	Anxiety and depression Unmet supportive needs Positive outcomes		partners higher for positive outcomes. Two-thirds reported greater appreciation of life and 40% said become a 'stronger' person		
Northouse <i>et al</i> (2010)	USA	Not reported	Type and content of interventions and effect of these interventions on burden, coping, self-efficacy and QoL	Meta-analysis	Interventions reduced burden, improved ability to cope, increased self-efficacy and aspects of QoL	Social context	
Fletcher <i>et al</i> (2012)	USA	Various	N/A	Literature review	Expanded model has 3 elements- stress process, contextual factors and the	Finding meaning Personal	Discovery of growth

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					cancer trajectory	resources	
						Social context	
Zwahlen <i>et al</i> (2010)	Switzerland	Lymphoma (22%) Skin (17%) Intestinal (14%) Breast (10%) Lung (9%) Leukaemia (7%) Other (36%)	Post-traumatic growth Positive psychological effects	Questionnaire	Positive psychological experiences might be shared by partners in similar ways.	Gender Social context	Discovery of growth
Murray <i>et al</i> (2010)	UK	Lung	Do carers experience the patterns of social, psychological and spiritual well-being of patients	Interviews	Carers experiences mirrored the patient	Social context	

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25	Qiuping <i>et al</i> (2013)	China	Various	Positive aspects of caring for cancer patients	Systematic review	Enhanced relationship, feeling of reward, personal growth, perception of personal satisfaction.	Personal resources	Discovery of growth
26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	Kuscu <i>et al</i> (2009)	Turkey	Colon (19%) Lung (15%) Breast (10%) Lymphoma (10%) Other (48%)	Attachment Depression Anxiety Perceived social support	Questionnaire	Social support was a protective factor.	Social context	

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Fitzell et al (2010)	Australia	Colorectal	Demographics Social support Appraisal Coping	Questionnaire and interviews	Adjustment related to higher social support, less reliance on avoidance and substance use. Stress appraisal strongest predictor of all adjustment outcomes	Finding meaning Social context	Discovery of growth
Kang et al (2013)	Korea	Various	Demographics Rewards and burdens of caring	Cross-sectional survey	Older age, gender, religion associated with reward.	Gender Finding meaning Personal resources	Discovery of growth
Ellis et al (2013)	UK	Lung	Factors that mediate distress	Semi-structured interviews	Participants use emotional and problem	Personal resources	Discovery of growth

					focused coping strategies		
Gaugler <i>et al</i> (2005)	USA	Lung (25%) Skin (15%) Colorectal (14%) Head and neck (12%) Bone (12%) Breast 6% Prostate (5%) Gynaecological (4%) Pancreatic (3%)	Demographics Care demands Emotional support Primary subjective stressors	Interviews and questionnaire	Sociodemographic context of care, cancer care demands and psychosocial resources could exacerbate or buffer carers from stress	Gender Personal resources Social context	
Ussher <i>et al</i> (2013)	Australia	Breast (25%) Brain (14%), Respiratory (14%) Colorectal (12%)	Experience of care, support, emotional reactions to caring and difficult and rewarding aspects of caring	Interviews	Caring as choice or privilege, appreciation of the relationship, personal strength and	Gender Finding meaning	Discovery of growth

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		Prostate (12%) Gynaecological (6%) Multiple sexual (6%), Haematological (2%) Other (9%)			growth.		
Thomas <i>et al</i> (2002)	UK	Lymphoma (58%) Breast (55%) Colorectal (33%) Lung (26%)	Psychosocial needs inventory General Health	Questionnaire and interviews	Care work demands, the need for help, emotion management, need to be strong and positive were expressed by the carers	Finding meaning	
Haley <i>et al</i> (2003)	USA	Lung	Demographics Primary caregiving stressors	Structured interviews and self-report measures	Appraisal, finding meaning, social resources related to	Gender Finding	Discovery of growth

			General health Negative social interactions Appraisal Social resources Depression Life satisfaction		higher life satisfaction Social context	
Weitzner <i>et al</i> (1999)	USA	Lung (34%) Breast (34%) Prostate (32%)	Depression Anxiety Burden ECOG performance Perceived social support Social desirability QoL Perceived health functioning	Questionnaire	Increased overall mental health is associated with better QoL.	Social context

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Waldron <i>et al</i> (2013)	USA	Prostate (33%) Breast (17%) Multiple (17%) Did not report (33%)	QoL	Systematic Review	Interventions that target communication and education improve QoL	Social context	
Wadhwa <i>et al</i> (2013)	Canada	Gastrointestinal (37%) Genitourinary (18%) Breast (17%) Lung (16%) Gynaecologic (11%)	Demographics QoL Health and functioning	Questionnaire	Carer QoL correlates with patient physical wellbeing	Social context	
Valeberg <i>et al</i> (2013)	Norway	Breast (46%) Prostate (18%) Colorectal (13%) Gynaecologic (5%) Other (18%)	Demographics Anxiety and depression QoL	Descriptive cross-sectional - demographic information and questionnaire	Gender and age impact on anxiety, QoL and mental health	Gender Social context	

Teixeira <i>et al</i> (2013)	Portugal	Digestive (60%) Reproductive (21%) Respiratory (7%) Other (12%)	Demographics Depression, anxiety and stress Satisfaction with social support Burden	Questionnaire	Satisfaction with social support- important mediator. Differential effect between perceived and actual support	Social context	
Tamayo <i>et al</i> (2010)	USA	Leukaemia	QoL Well-being	Descriptive cross-sectional questionnaire	Expressing feelings is central to well-being	Personal resources Social context	Discovery of growth

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Chen <i>et al</i> (2004)	China	Breast (34%) Head and neck (41%) Oesophageal (25%)	QoL	Cross-sectional study using standardized questionnaires	Social and functional aspects of patients' QoL play a significant role in determining the QoL of their caregivers.	Social context	
Owensworth <i>et al</i> (2010)	Australia	Brain (42%) Other (58%)	Psychological well-being Functional impairment Satisfaction with social support	Questionnaire	Caregivers supporting individuals with greater functional impairment had better psychological well-being if they were highly satisfied with their social support.	Social context	
Levesque <i>et al</i> (2014)	Australia	Breast (26%)	Benefit finding Outcome and	Questionnaire	Greater benefit finding was	Finding meaning	Discovery of growth

		Bowel (17%) Prostate (10%) Ovarian (10%) Lung (7%) Multiple myeloma (4%) Pancreatic (4%) Lymphoma (4%) Other (15%)	duration of illness Emotional reactions to cancer Grief Assessment of difficulties Assessment of satisfactions Involvement in care		positively associated with stronger emotional experiences and satisfaction with the caregiving role.		
Mathews <i>et al</i> (2004)	USA	Various	Demographics QoL Health stance Emotional strain	Questionnaires	Less isolation, overload, and feelings of being trapped predicted better overall QoL.	Finding meaning Social context	

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Nicholls <i>et al</i> (2014)	UK	Melanoma (6%) Breast (6%) Colorectal (6%) Lung (6%) Other (76%)	Assessment of attachment	Systematic Review	Attachment security may provide a protective buffer	Social context	
Epiphaniou <i>et al</i> (2012)	UK	Lung (50%) Prostate (25%) Thyroid (5%) Other (20%)	Tasks and duties as a carer Benefits and enjoyment Experience with health care professionals and friends and family Challenges, needs and concerns	Interviews	Coping strategies include distraction, emotional release, looking for positive aspects and disengaging from stressful thoughts	Personal resources Finding meaning	

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	Li <i>et al</i> (2014)	China	Prostate (45%) Breast(22%) Prostate and breast (3%) Multiple (9%) Lung (9%) Other (12%)	Mutuality or dyadic effect within couples	Systematic review	Communication and reciprocal influence contribute to carer-patient dyad	Finding meaning Social context	Discovery of growth
22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	Tang <i>et al</i> (2008)	China	Lung (30%) Hepatoma (16%) Colorectal (16%) Gastric (7%) Other (30%)	Demographics QoL Caregiving demands Psychological resources Appraisal Perceived subjective burden	Questionnaire	Appraisal key role in quality of life.	Finding meaning	

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Duggleby <i>et al</i> (2012)	Canada	Breast	Hope	Interviews	Hope was important to them and influenced by partners hope and courage	Gender Social context	
Cormio <i>et al</i> 2014	Italy	Breast (29%), GI (29%), Lung (11%), Genital (7%), other (22%)	Demographics Post-traumatic growth Anxiety and depression Health status	Questionnaire	Carers had higher scores on 'personal strength' than patients.		Discovery of growth

			ECOG status				
Mosher <i>et al</i> 2015	USA	Lung	Coping with physical symptoms Emotional reactions to cancer	Semi-structured interviews	Various strategies for coping identified including avoiding negative emotions.	Finding meaning Social context	
Lambert <i>et al</i> 2015	Canada	Breast (32%), Colorectal (25%) Lung (29%), Prostate (13%)	Appraisal Burden Depression Benefit finding Coping Dyadic support Hopelessness	Questionnaire and exploratory factor analysis	The benefit subscale of the appraisal of caregiving scale correlates with active coping.	Personal resources Finding meaning	
Stamataki <i>et al</i>	UK	GI (19%), Head and neck (16%),	Experiences of being	Semi-structured	Various coping mechanisms	Finding	

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<i>al</i> 2014		gynaecological (10%), Lung (17%), Breast (17%), Brain (9%), Prostate (10%) Lymphomas (3%)	a carer Managing patients illness Impact on life	interviews	and forms of support helped the carers manage the stress.	meaning Personal resources Social context	
Hasson-Oyahon <i>et al</i> 2015	Israel	Colorectal	Attachment Social support Finding meaning	Questionnaire	For male carers avoidance attachment is associated with finding meaning. For females social support is associated with their meaning	Finding meaning Social context	

Kogler <i>et al</i> 2015	Germany	Not reported but mainly bereaved (71%)	Mindfulness Psychological distress QoL Satisfaction with life Meaning in life	RCT and questionnaire	Mindfulness in carers was significantly correlated with higher QoL, life satisfaction, the experience of meaning.	Finding meaning	
Kim <i>et al</i> 2015	USA	Breast 29%, prostate 21%, colorectal 12.5%, non-hodkins lymphoma 8%, lung 7%, other<5%	Caregiving motives Spirituality QoL	Questionnaire	Autonomous reasons for caregiving relate to better long-term mental health among male caregivers. Among women, autonomous motives did not	Gender Social context	

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					predict spirituality or mental health.		
Choi <i>et al</i> (2015)	South Korea	Not stated but terminally ill	Demographics Perceived social support QoL Objective burden of care	Cross-sectional survey	Carers of younger patients more likely to adapt positively. Positive adaptation was related to more visits for care, carers' religiousness, more social support and satisfactory perceived quality of care	Social context	

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49	Elliot <i>et al</i> (2015)	Australia	Prostate	Effect of cancer on way cope How helpful found communication Psychological functioning Satisfaction with relationship Carer burden	Video-taped communication task, semi- structured interview and questionnaires	Resilient couples demonstrated relationship closeness and adaptive cognitive and behavioural coping strategies	Social context	
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Table 3- Codes, themes and theoretical framework

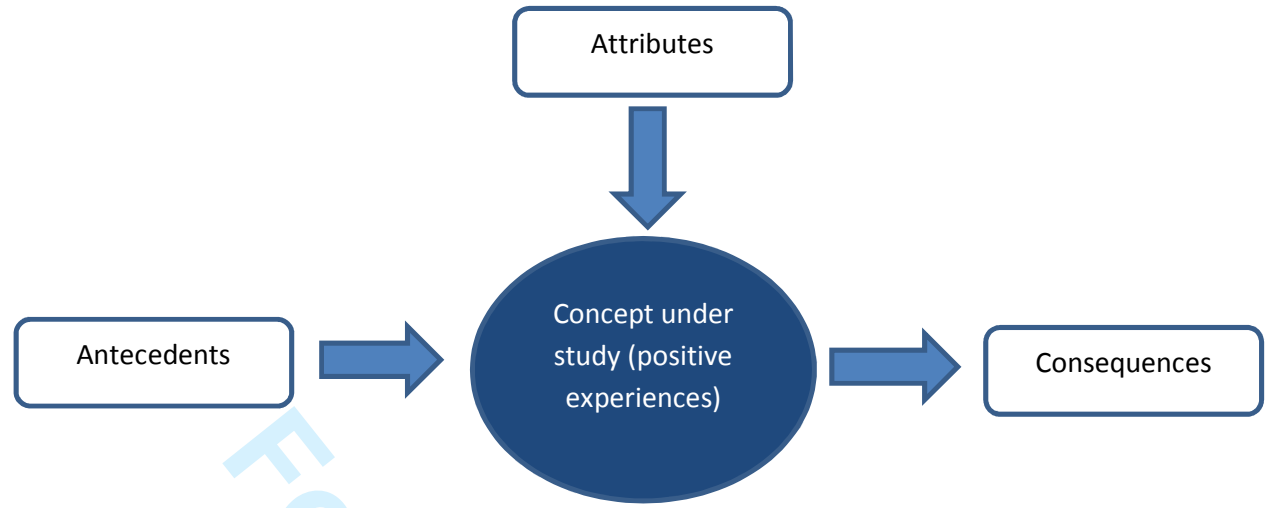
Framework element	Theme	Code
Attribute	Gender	Role, masculinity, appraisal, social expectations, identity, reflection, caring as 'norm'
	Personal resources	Self-esteem, self-efficacy, strength, confidence, mastery, optimism, resilience, mood
	Finding meaning	Positive appraisal, coping, spirituality, emotion management, adjustment, self-awareness, distraction, locus of control
Consequence	Social context	Support, satisfaction with support, perceived support, patient carer dynamic, interventions, relationship quality, attachment, motivation, communication, emotional system
	Discovery of growth	Finding benefits, reward, satisfaction, adjustment, accomplishment, privilege, greater appreciation

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Figure 1. Relevant sections of Rodger's Evolutionary Concept Analysis



For Peer Review

Figure 2. Flow diagram for identifying the literature

