

# Posttraumatic growth and resilience in adolescent and young adult (AYA) cancer patients: an overview

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*Running head:* Posttraumatic growth and resilience in AYA cancer patients

*Keywords:* posttraumatic growth; resilience; positive outcomes; coping; social support; stress

## **Abstract**

*Purpose:* To provide an overview of the literature on post-traumatic growth (PTG) and resilience among adolescent and young adult (AYA) cancer patients.

*Methods:* A literature search in Embase, PsychInfo, Pubmed, Web of Science, Cochrane Library, and Cinahl was carried out. Thirteen articles met the predefined inclusion criteria.

*Results:* Qualitative interview studies showed that AYA cancer patients report PTG and resilience: PTG is described by AYA cancer patients in terms of benefit finding including changing view of life and feeling stronger and more confident, whereas resilience is described as a balance of several factors including stress and coping, goals, optimism, finding meaning, connection and belonging.

Quantitative studies showed that sociodemographic and clinical characteristics were not associated with PTG. Enduring stress was negatively, and social support positively, associated with PTG. Symptom distress and defensive coping were negatively and adaptive cognitive coping was positively associated with resilience. Both PTG and resilience were positively associated with satisfaction with life and health-related quality of life (HRQoL). Resilience was found to be a mediator in the relationship between symptom distress and HRQoL.

Two interventions aiming to promote resilience, a stress management and a therapeutic music video-intervention, were not successful in significantly increasing overall resilience.

*Conclusion:* Most AYA cancer patients report at least some PTG or resilience. Correlates of PTG and resilience, including symptom distress, stress, coping, social support and physical activity, provide further insight to improve the effectiveness of interventions aimed at

promoting these positive outcomes and potentially buffer negative outcomes.

## **Introduction**

A common trend of incorporating data from adolescent and young adult (AYA) cancer patients into either childhood or older adult populations in research has created a gap in understanding the AYA cancer experience.<sup>1</sup> Adolescence and young adulthood is a complex developmental phase in life defined not only by significant physical changes, but also by critical psychosocial challenges, including transitioning to independence from parents, establishing autonomy and self-identity (personal set of goals and values), engaging in interpersonal relationships (e.g. intimacy, marriage, family forming), along with educational and employment decisions and attainments.<sup>2</sup> A cancer diagnosis during this unique phase of physical and psychosocial growth can disrupt the achievement of developmental milestones and have life-long repercussions. Research shows that AYA cancer patients demonstrate significantly worse health-related quality of life (HRQoL) and greater levels of psychological distress compared to healthy matched peers, due to these challenging circumstances.<sup>3</sup>

Over the past decade, psychosocial research has broadened its scope from the negative aftermath of traumatic events,<sup>4, 5</sup> such as a cancer diagnosis, to the identification of positive outcomes or positive ways in which people's lives have changed as a result of a struggle with adversity.<sup>6, 7</sup> Post-traumatic growth (PTG) is described as the positive psychological change that appears following significantly burdensome or traumatic life events. Specifically, people who have been exposed to trauma reported PTG in relationships, in their outlook on life, in their perception of themselves, in their spiritual beliefs and lastly in their appreciation of life.<sup>8</sup> A vast body of research shows that the majority of people who have been exposed to a potentially traumatic event are resilient.<sup>9</sup> Resilience is the ability to cope with negative emotions that arise from a stressful experience, by identifying and developing resources to function.<sup>10</sup> Many studies on PTG have explicitly or implicitly equated PTG with resilience or

have even gone a step further and considered PTG superior to resilient outcomes.<sup>11</sup> For instance, Carver discriminated between PTG and resilience by defining resilience as a return to the prior level of functioning after difficulty and by relating PTG with not only returning to the prior level but exceeding it.<sup>12</sup> This definition assumes that for PTG to occur, a person has to demonstrate resilience and return to a healthy functioning level before higher, even more efficient functioning levels can be reached. Tedeschi and Calhoun (1995) supported this assumption.<sup>13</sup> They state that positive outcomes after traumatic life events depend on the coming together of several personal variables, resilience being one of them. Hence, for PTG to develop, a person needs to not only be for example optimistic, hardy, and face life crises that represent irreversible changes, but they also need to be resilient in order for a new level of adaptation to be achieved. Westphal and Bonanno (2007) objected to the notion that resilience is often equated with PTG and suggest that PTG and resilience should be viewed as two independent constructs.<sup>14</sup> They have even gone a step further and argued that it is very unlikely for resilient persons to perform the meaning making behaviours that are related to PTG since they do not struggle to the same extent as other, more traumatised persons would. Thus, survivors of trauma that are highly resilient will not engage in the cognitive processing that is essential for PTG to develop.<sup>14</sup> Up to now there is little understanding of the relation between PTG and resilience and no empirical research thus far has tried to shed more light onto this association. Although PTG and resilience can both be seen as outcome as well as a process, the terms cannot be used interchangeably: PTG does not develop as a direct consequence of the traumatic experience but in the aftermath of it and in the struggle to find a new normal,<sup>15, 16</sup> while resilience indicates the ability to cope with negative emotions that arise from a stressful experience and function at normal or close to normal capacity (maintain a stable equilibrium).<sup>17</sup> Nevertheless, there is some evidence that both, PTG and resilience, can function as protective factors counterbalancing the stress-related adverse effects of cancer

and thereby improving HRQoL of patients.<sup>18, 19</sup> It may therefore be argued that interventions to improve psychological adaptation after cancer are not just about preventing, reducing, and/or treating psychological distress but also about increasing resilience and promoting PTG.<sup>20</sup> Until now, there has been little examination of PTG and resilience outcomes in AYA cancer patients. This review study aims to provide an overview of the literature on PTG and resilience experiences, correlates and interventions among AYA cancer patients to inform future research.

## **Methods**

### ***Search strategy***

A computerized search of the literature through Embase (1974 - present), PsychInfo (1806 - present), Pubmed (1946 - present), Web of Science (1945 - present), Cochrane Library, including Cochrane Central Register of Controlled Trials (CENTRAL) and Cinahl (1981-present, EBSCOhost) was carried out by two researchers (SG and OH) on November 30<sup>th</sup> 2016. The search strategy combined the terms ('neoplasm' or 'cancer') and ('adolescent' or 'young adult') with other key terms related to positive psychosocial outcomes including ('posttraumatic growth' or 'relating to others' or 'new possibilities' or 'spiritual change' or 'life appreciation' or 'personal strength' or 'empowerment' or 'emotional growth' or 'resilience' or 'benefit finding' or 'positive health'). The reference lists of all identified publications were examined to find relevant publications not identified via the search strategy. There were no limits with regard to the year of publication. The search yielded 264 unique hits.

### ***Selection criteria***

We used an inclusive approach with regard to the AYA cancer patient age definition. Several

AYA age definitions are used globally, ranging from 12 years<sup>21</sup> to 39 years<sup>22</sup>, based on physical and psychological developmental phase and accompanied care system (pediatric vs. adult oncology), aspects of tumor pathology or biology, or on health outcomes.<sup>23</sup> All studies that presented results of patients who were within the age range of 12 to 39 years at time of cancer diagnosis were included. Furthermore, studies were included: (i) if PTG or resilience (according to the definition of the researchers) was assessed; (ii) if the publication was an original article published in English (no poster abstract, letter to the editor or systematic review paper). Studies were excluded if: (i) they focused solely on pediatric and/or adult cancer patients; (ii) the study included patients of all ages but did not present the AYA patient data separately. The described inclusion and exclusion criteria were applied to the initial 264 hits. SG and OH screened all titles and abstracts, 38 articles met the criteria. After careful independent review by SG and OH, 13 articles meeting our selection criteria and were included in our review. Figure 1 presents the flow-chart of the selection procedure.

### ***Quality assessment***

The methodological quality of the 13 included studies was independently assessed by two reviewers (SG and OH) based on established criteria for systematic reviews (Table 1).<sup>24</sup> The quality of a study can be described in terms of internal (methods) and external validity (representativeness and generalization). To cover both validity aspects the quality criteria were divided into 4 categories: assessment of outcomes, study population, study design and presentation of results. In case of disagreement, which occurred mostly due to differences in interpretation of items, were discussed in a consensus meeting. For each quality criterion a study met, 1 point was assigned (highest possible score of 12 points). If a study did not meet our criterion or was described insufficiently or not at all, 0 points were assigned. Studies scoring 9 points or more were arbitrarily considered to be of 'high quality'. Studies scoring

between 6-8 points were rated as 'adequate quality'. Studies scoring <6 points were rated as 'low quality'.

## **Results**

### ***Study characteristics***

In total, 13 studies were included, all published between February 2007 and February 2015. Qualitative (n=3), quantitative (cross-sectional cohort, n=8) as well as intervention studies (n=2) were present. The main findings are summarized in Table 2.

### ***Methodological quality and issues***

The quality scores ranged from 3 to 10.5 points (Table 2), and the mean quality score of all studies was 7.8 points. The Kappa inter rater agreement was 0.66 (standard error of 0.16), indicating a good strength of agreement between the two independent reviewers.<sup>25</sup> Three studies were of low, four of high and six of adequate quality. General limitations of the included studies were patient response rates under 75% (n=10), small patient sample sizes (n=7) and lack of longitudinally gathered data (n=8) or group comparisons (n=6). A complicating factor for data extraction was that PTG and/or resilience were often secondary outcomes in most of the quantitative studies, resulting in a limited presentation of the results for these outcomes. We will discuss the main results of the included studies according to their study design.

### ***Qualitative studies***

Three qualitative semi-structured interview studies were included in this review.<sup>26-28</sup> These



studies showed that AYAs with cancer have the capacity to be resilient<sup>26</sup> and almost all patients included in the studies reported some form of PTG.<sup>27, 28</sup>

AYAs with cancer described resilience as a balance of several factors including a) coping and stress; b) goals, purpose and planning; c) optimism; d) meaning and gratefulness; and e) connection and belonging.<sup>26</sup> The balance of these factors could be promoted by increasing specific skills (including benefit-finding, goal-setting, stress management).<sup>26</sup> For example, AYA cancer patients who were able to find meaning, stay positive, set goals, control stress, seemed to consider themselves resilient, but in periods of extreme anxiety or transition (for example when they did not know what to expect), they felt their resilience diminished. Similarly, AYA cancer patients who persisted in negative emotions or who could not build purpose or meaning perceived themselves as little resilient. AYA cancer patients stated that levels of resilience shifted with specific experiences, moods and skills.

The other two interview studies focused on PTG which was described more in terms of benefit finding.<sup>27, 28</sup> Two recurrent themes emerged for the adolescent cancer experience: 1) loss of control, which resulted in anger or frustration and treatment non-adherence; and (2) benefit finding including improved bolstered relationships and improved personal attributes. All AYA cancer patients interviewed, except one, stated that they experienced at least one positive facet of being diagnosed with and treated for cancer.<sup>27</sup> This was supported by the results of another study, showing that AYAs with cancer perceived that their view of life had been changed in a positive way.<sup>28</sup> They felt stronger through having survived cancer. They felt this had equipped them with the confidence and the faith that they could deal more effectively with other stressful situations.

### *Quantitative studies*

Eight cohort studies, all with a cross-sectional design,<sup>18, 29-35</sup> and two intervention studies were included in this review.<sup>36, 37</sup>

### *Measures*

Different questionnaires were used to assess PTG and resilience. Most of the questionnaires were not specifically developed for AYAs with cancer, however in most cases the reported psychometric properties were good.

Four of the five studies focusing on PTG used the Posttraumatic Growth Inventory (PTGI)<sup>29-31</sup> or its short form.<sup>32</sup> The PTGI is a well-validated 21-item questionnaire including factors of New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life.<sup>38</sup> The questionnaire measures how successful individuals, coping with the aftermath of trauma, are in rebuilding or strengthening their perceptions of their self and others, and the meaning of events. A recent study showed that the PTGI was clear, appropriate, and relevant for AYAs with cancer.<sup>39</sup> One study used the personal growth scale of the Psychological Well Being Scale (PWBS). A theoretical model shows that psychological well-being consists of six specific dimensions of health: Autonomy, Environmental Mastery, Personal Growth, Positive Relations With Others, Purpose in Life, Self-Acceptance.<sup>40</sup> The personal growth scale is not validated among AYAs with cancer and it is limited by only measuring one aspect of PTG.

Two of the five studies focusing on resilience used the Haase Adolescent Resilience in Illness Scale (HARS),<sup>30,33</sup> that measures how adolescents with an illness think or feel about managing their health after diagnosis of the disease.<sup>10</sup> The Ego-Resiliency Scale was used in one study<sup>34</sup> and is based on the concept of ego-resiliency or the ability to adapt ones level of emotional control up or down appropriate to the conditions.<sup>41</sup> Another study assessed resilience with the Resilience Scale (RS),<sup>18</sup> which had the best psychometric properties to measure resilience among adolescent populations.<sup>42</sup> The RS focuses on psychological qualities rather than deficits (e.g. personal competence and acceptance of self and life).<sup>43</sup> The

last study used the Connor-Davidson Resilience Scale (CD-RISC),<sup>29</sup> measuring five dimensions of resilience: (1) personal competence; (2) trust in one's intuition, tolerance of negative emotions, and strengthening effects of stress; (3) secure relationships and positive acceptance of change; (4) control; (5) spiritual effects.<sup>44</sup>

#### *PTG/resilience levels of AYAs with cancer compared to healthy controls*

Mean PTG and resilience levels of AYAs with cancer are described per study in Table 2. Two studies compared the levels of PTG of AYAs with cancer with those of healthy controls.<sup>32, 35</sup> In the first study, the in-treatment group of AYA cancer patients scored significantly lower compared to age-matched healthy controls and off-treatment AYA cancer patients on PTG as measured by the personal growth subscale of the psychological well-being scale (PWBS).<sup>35</sup> In the other study, PTG levels as measured by the Posttraumatic Growth Inventory (PTGI) of AYA cancer patients did not differ from healthy controls matched on age, gender, educational level and partnership status.<sup>32</sup>

With respect to resilience, one study found that AYA cancer patients had a significantly lower resilience score compared to gender- and age-matched healthy controls on the Ego Resilience scale.<sup>34</sup>

#### *Correlates of PTG/resilience*

Six studies examined the correlates of PTG or resilience.<sup>29, 30, 35, 18, 33, 34</sup> Sociodemographic and clinical characteristics were not associated with PTG. PTG scores did not vary by age, gender, stage/severity of the disease,<sup>29, 30</sup> race, relationship status, and treatment status, except for the PTGI subscale of 'New Possibilities', of which the score was slightly lower in Caucasian patients compared to non-white patients.<sup>30</sup> In another study, personal growth scores of the PWBS were compared between the in- and off-treatment AYA cancer patient age groups 15-20, 21-29 and 30-39 years, but no significant differences were found.<sup>35</sup>

Some evidence was found for an association between psychosocial factors and PTG. Stress (negative) and social support (positive) were significantly associated with PTG.<sup>29</sup> A significant interaction was found between physical activity and social support, indicating a strong positive association between social support and PTG in inactive persons and a weaker association for active persons.

There is a lack of studies examining the clinical and sociodemographic correlates of resilience among AYAs with cancer. Only one study showed that age, time since diagnosis and school grade were not correlated with resilience.<sup>33</sup> This same study found that usage of a cognitive coping strategy to be associated with higher levels of resilience and usage of a defensive coping strategy to be associated with lower levels of resilience. However, no significant association between coping style and resilience was found in another study.<sup>34</sup> In this study a significant negative association between expectations of the future and resilience, and significant positive associations between resilience and openness to experience and impulse control was found. In addition, cancer symptom distress was negatively associated with resilience.<sup>18</sup>

#### *Association PTG/resilience with other outcomes*

Three studies examined the association between PTG or resilience and other outcome measures.<sup>18, 30, 31</sup> No significant relationship between PTG and overall posttraumatic stress (PTS) severity was observed.<sup>30</sup> However, curvilinear relationships between re-experiencing (a PTS symptom) and two of five PTG indicators (New Possibilities, Personal Strengths) were found, indicating some degree of distress related to the cancer experience was needed to develop PTG.<sup>30</sup> Another study found that PTG was positively associated with both general and health-related life satisfaction.<sup>31</sup>

Resilience was found to be a mediator in the relation between HRQoL and cancer symptom distress, indicating that resilience might play a role in limiting the adverse effects of cancer symptoms on HRQoL.<sup>18</sup>

### *Intervention studies*

Two intervention studies were included.<sup>36, 37</sup> The Promoting Resilience in Stress Management (PRISM) intervention consisted of two long or four short skill-based modules focused on managing stress (stress management/coping and goal setting) and building resilience (cognitive restructuring and benefit-finding).<sup>36</sup> Although a small effect size was found, the scores before and after intervention did not differ significantly. The second intervention, a Therapeutic Music Video (TMV) aimed to (a) increase protective factors like hope-derived meaning, courageous coping, spiritual feelings, family environment and social integration; (b) diminish risk factors like defensive coping and illness-related distress; and (c) increase levels of resilience and self-transcendence.<sup>37</sup> AYAs with cancer were randomly allocated to either the TMV-intervention or a low dose audio book control group, both under supervision of a therapist, and completed 6 sessions over three weeks. Overall resilience did not differ significantly between the two groups directly post-intervention, nor 100 days later. However, positive coping, social integration, and family environment were improved after the TMV intervention.

## **Discussion**

This study aimed to provide an overview of the studies conducted on PTG and resilience in AYA cancer patients. The included qualitative studies, showed that most AYA cancer patients have the capacity to be resilient or showed some form of PTG. Cross-sectional cohort studies found no significant differences in PTG and resilience between AYA cancer patients and

healthy controls, except for two studies showing that (on-treatment) patients had lower levels compared to healthy controls. Sociodemographic and clinical characteristics were not associated with PTG or resilience, except for race. Social support was positively and enduring distress negatively correlated with PTG. Symptom distress and defensive coping were negatively and adaptive cognitive coping was positively associated with resilience. PTG and resilience were found to be of significant influence on general and health-related life satisfaction and HRQoL of AYA cancer patients. The two resilience interventions did not result in significant improvements in overall resilience levels of AYA cancer patients.

### ***Prevalence of PTG and resilience: theoretical considerations***

Overall, the results of the qualitative and quantitative studies suggest that AYAs with cancer experience at least some degree of PTG and resilience. This is in line with a study showing that almost 85% of childhood cancer survivors report at least one positive aspect of their cancer journey,<sup>45</sup> and another study showing that up to 87% of the adult cancer survivors report PTG.<sup>46</sup> The studies included in our review found no or only small differences in PTG and resilience scores between AYA cancer patients and healthy controls. However, prevalence rates of PTG or resilience are difficult to determine because of the heterogeneity of the study samples. The interpretation of these results is further complicated by the fact that for both, PTG and resilience, different definitions, theoretical frameworks and assessment tools were used.<sup>47, 48</sup> Most researchers adopted the model of Tedeschi and Calhoun<sup>38</sup> for analyzing PTG in the aftermath of cancer and relied on the associated PTGI assessment tool. However, this tool was derived from research on war, natural disasters or other types trauma and not cancer.<sup>48</sup> The extent of PTG experienced might be affected by the nature of the trauma.<sup>49</sup> Cancer is different compared to other traumas in terms of the internal nature of the crisis, the multiple stressors, and future-focused fears.<sup>50</sup> Cancer often has a nuanced onset

(routine screening examinations), continues through cancer diagnosis and treatments, and it goes on for many years with the fear of future recurrences or disease progression. The PTGI does not assess the specific nature of the cancer experience. AYA cancer patients and healthy controls may have different reference points and are therefore not easily comparable.

With regard to resilience three general ways have been used to describe it: as a baseline characteristic, as an outcome itself or as a mechanism to improve (positive) outcomes.<sup>51</sup>

Among AYAs with cancer, resilience is described as the process of finding or developing resources to manage stressors and reach positive outcomes,<sup>10</sup> and the two most commonly used frameworks are the Resilience in Illness Model<sup>52</sup> and its adolescent version.<sup>10</sup> This framework comprises of health-protective (e.g. social integration and courageous coping) and risk factors (e.g. illness related distress and defensive coping) and outcomes. Future research should explore the best framework for studying resilience and an assessment tool should be developed that assesses all components of resilience.

In addition, future research should focus on examining the relation between PTG and resilience, because this could have important implications for both preventive interventions as well as trauma counselling.

### ***Correlates of PTG and resilience***

PTG and resilience may not occur in all AYA cancer patients, identification of correlates creates opportunities to improve these outcomes. Sociodemographic and clinical factors were not associated with both outcomes. However, one of the included studies in our review found a difference between in-treatment AYA cancer patients who had lower PTG scores compared to both off-treatment AYA cancer patients and healthy controls,<sup>35</sup> which is congruent with studies among adult cancer survivors.<sup>20</sup> According to the Tedeschi and Calhoun definition, PTG needs time to appear in the aftermath of a traumatic event. It implies that moving beyond

the daily demands of cancer and threat to one's health or life provides room for greater processing of growth. Other cancer and treatment characteristics show contradictory associations with PTG and resilience among pediatric and adult cancer survivors.<sup>6, 7, 20, 53, 54</sup> In case of PTG this is not unexpected, as the PTGI, the most commonly used PTG assessment tool, does not explicitly refer to the medical nature of trauma and may therefore not be completely adequate to capture the full spectrum of positive reactions in cancer.<sup>48</sup> With regard to the sociodemographic variables, most studies showed no relationship between gender and positive outcomes in adults with cancer, although there is also evidence that women report higher levels of PTG.<sup>20, 55, 56</sup> There is some evidence indicating that racial or ethnic minority groups tend to report higher levels of PTG.<sup>20</sup> Several studies observed higher socioeconomic status (income and educational level) was associated with higher PTG or resilience,<sup>57-60</sup> however other studies found no relationship.<sup>20</sup> The choice of one or another questionnaire may have conditioned the emergence of specific variables that better fitted with the tool itself, resulting in a relevant risk of outcome bias.<sup>48</sup> More studies, using an appropriate definition, theoretical framework and assessment tool, must be conducted to identify sociodemographic and clinical correlates of PTG and resilience.

Psychosocial factors were more often found to be correlates of PTG and resilience. An adaptive coping strategy (cognitive or problem-oriented coping) was associated with higher levels of resilience among AYA cancer patients. This coping mechanism is used for protection of self in new dangerous situations, till sufficient resources are available for developing context-specific adaptive coping skills. Adaptive coping strategies such as acceptance, religious coping, and positive reinterpretation were also positively associated with PTG in adult cancer patient studies.<sup>53, 54, 61, 62</sup> Non-adaptive ways of coping (e.g. defensive coping) can be changed into adaptive coping if the AYA cancer patient has enough time to



mobilize or create other protective factors to diminish the impact of cancer and its treatment. In their relatively short lives, most AYA cancer patients may not have experienced many major life events. As such, their coping skills to handle new traumatic situations may not have been optimally developed yet, which makes AYAs in more need of some support with coping.

Social support was positively correlated with PTG. Social support including acceptance and empathic conversations may strengthen AYA cancer patients to process their trauma, facilitate coping and increase adjustment.<sup>63, 64</sup> Ongoing support encourages AYA cancer patients to communicate openly about and cognitively process their cancer through self-disclosure.<sup>8</sup> Nevertheless, AYA cancer patients often indicate problems with maintaining normal, pre-cancer relationships with family and friends, informing others about their disease, maintaining school and/or work and other activities, and dealing with feeling different.<sup>10</sup> Studies have shown that support received from other AYA cancer patients is incredibly important for this age group.<sup>63</sup> Ways to enhance social support should be explored. Though, (online) peer support groups and age-specific information portals for AYA cancer patients have been shown to significantly reduce feelings of social isolation, improve knowledge, self-efficacy, problem-solving skills and effective interpersonal interactions.<sup>65</sup>

Stress was negatively associated with PTG,<sup>29</sup> indicating that low levels of distress experienced after cancer treatment has ended can stimulate processing of the cancer experience, allowing growth. This finding, however, is incongruent with the PTG theory of Tedeschi and Calhoun<sup>38</sup> suggesting that traumatic events may serve as promoters for the development of PTG because stress facilitates peoples' cognitive process for rebuilding their views of themselves, their environment and their future.<sup>8</sup> A study among childhood cancer survivors indeed found a positive correlation between posttraumatic stress and PTG.<sup>45</sup> Another study included in this

review found a curvilinear relationship between posttraumatic stress (re-experiencing) and PTG (new possibilities and personal strengths),<sup>30</sup> suggesting that there may be an optimal level of (posttraumatic) stress that strengthens PTG. When the posttraumatic stress levels increase beyond that point, a person may be overwhelmed by the stress, and adaptation and PTG may be negatively affected.<sup>66</sup> The results of this study indicate that re-experiencing may help to adapt psychologically. More research is needed to determine the threshold by which stress levels become too high to allow PTG to take place.

### ***Interventions***

Searching for potential ways to enhance PTG or resilience among AYA cancer patients is important, as the results of this review show that both are associated with better HRQoL and higher levels of satisfaction with life. Based on the correlates of PTG and resilience found in this review, coping mechanisms and/or social support are potential targets for intervention. Until now there are no interventions that are convincingly successful in promoting PTG or resilience among AYA cancer patients. However, both described resilience interventions were underpowered and participants were not screened for low resilience levels before the start of the intervention. Furthermore, both interventions were brief in nature which may be insufficient to learn and incorporate new skills. The PRISM intervention seems promising as the intervention is based on important correlates of positive outcomes: stress management and coping skills. Future studies with sufficient power should further explore the efficacy of this intervention, whereby social support also should be considered as an important element.

### ***Implications for practice and future research***

As a result of the lack of one standard definition, theoretical framework, and assessment tool, for both PTG and resilience, research is still inconclusive in identifying correlates and mediators of PTG and resilience.

Development of future interventions should be informed by the specific needs and capacities of AYAs with cancer. Future studies should investigate whether PTG and resilience can simply be encouraged by prompting AYA cancer patients to describe positive experiences that have resulted from cancer. An intervention among adult breast cancer survivors where survivors were asked to write about positive experiences (feelings and thoughts) related to their cancer, showed that those who wrote down positive feelings reported less health care professional visits and lower levels of distress than survivors who wrote down facts of their experience.<sup>67</sup> The correlates of PTG and resilience may inform researchers and healthcare professionals on key elements to target in future interventions. For example, healthcare professionals may be able to recognize protective (social support) or risk factors (stress) and enable coping by supporting adaptive coping strategies. Health care professionals can also assist with problem solving, giving information in small amounts, listening, and showing empathy.<sup>68</sup> Among adult cancer patients, two cognitive-behavioral interventions, including elements of relaxation exercises, conflict resolution and emotional expression, and coping skills training had positive effects on PTG.<sup>69, 70</sup>

### ***Limitations***

This review has several limitations which should be mentioned. First, the small number of included studies and the heterogeneity of study samples and designs, makes it impossible to draw definitive conclusions about prevalence rates and correlates of both outcomes. In addition, different instruments were used to assess PTG or resilience, which could have resulted in contradictory study findings. There is a lack of a unifying description and therefore

subsequent operationalization and measurement of both constructs. Researchers should explore the best ways to measure PTG and resilience and determine cut-off values for these instruments, making it easier to distinguish those who adjust well from those who could probably benefit from a PTG or resilience promoting intervention. The quality of the included studies was moderate to high (except for the qualitative studies). However, three shortcomings that need attention for future studies are the patient response rates under 75%, the small patient sample sizes and cross-sectional study designs.

To conclude, most AYA cancer patients report some degree of resilience or PTG. The factors associated with PTG and resilience found in this review, including stress, coping and social support, provide tentative insight to improve the effectiveness of interventions aimed at promoting these positive outcomes and potentially buffer more negative outcomes.

**Acknowledgements:** Dr. Olga Husson (KUN2015-7527) is supported by a Social Psychology Fellowship from the Dutch Cancer Society.

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**Figure 1:** Prisma flow-chart of selection procedure

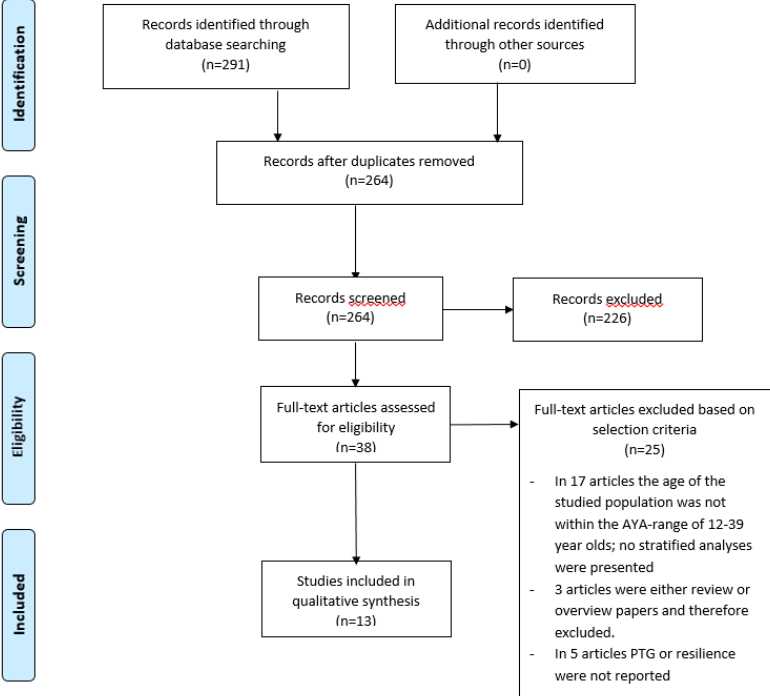


Table 1 Quality scores of included studies (positive with respect to)

	Rosenberg, 2014	Wicks, 2010	Wallace, 2007	Zebrack, 2014	Salsman, 2014	Monteiro, 2013	Seitz, 2010	Love, 2010	Wu, 2015	Wu, 2012	Smorti, 2012	Rosenberg, 2015	Robb, 2014
<b>Assessment of PTG / resilience</b>													
1. A valid quality questionnaire is used for measuring PTG or resilience	0	0	0	1	1	1	1	1	1	1	1	1	0,5
<b>Study population</b>													
2. A description is included of at least two socio-demographic variables (e.g., age, employment status, educational status)	1	1	1	1	1	1	1	1	1	1	0	1	1
3. A description is included of at least two clinical variables of the described patient population (e.g., tumour, stage at diagnosis)	0	1	1	1	1	1	1	1	0	1	0	1	1
4. Inclusion and/or exclusion criteria are described	1	1	1	1	1	1	1	1	1	1	1	1	1
5. Participation and response rates for patient groups have to be described and have to be more than 75%	1	0	0	1	0	0	0	0	0	0	1	0	0
6. Information is given about the ratio of respondents versus non-respondents (0.5 point for reasons of non-response, 0.5 point for comparison of the responding vs. non-responding group)	0.5	0,5	0	0,5	0	0	0,5	0	0,5	0	1	0,5	0,5
<b>Study design</b>													
7. The study size is consisting of at least 50 patients (arbitrarily chosen)	0	0	0	1	1	0	1	1	0	1	0	0	1
8. The collection of data is longitudinally gathered	1	0	0	1	0	0	0	0	0	0	0	1	1
9. The process of data collection is described (e.g., interview or self-report etc.)	1	1	1	1	1	0,5	1	1	1	1	1	1	1
<b>Results</b>													
10. The results are compared between two groups or more (e.g., healthy population, groups with different treatment or age) and/or	0	0	0	0	1	1	1	1	0	0	1	1	1

results are compared with at least two time points (e.g., longitudinally versus post-treatment).													
11. Mean, median, standard deviations or percentages are reported for the most important outcome measures	0	0	0	1	1	1	1	1	1	1	1	1	1
12. Statistical proof for the findings is reported	0	0	0	1	1	1	1	1	1	1	1	1	1
Total	5,5	4,5	4	10,5	9	7,5	9,5	9	6,5	8	8	9,5	10

Table 2 Overview of all included studies

Author, year, country	Design	Sample	Age at time cancer diagnosis (years)	Age at time study (years)	PTG/resilience measure	Scores of positive outcome measures in studied population	Main results/conclusion	Quality
<b>Qualitative studies</b>								
Rosenberg, 2014, USA	Qualitative	17 AYAs requiring chemotherapy and diagnosed 14-60 days before study enrollment	14-22	15-23 (M=17)	Semi-structured interview at baseline and 3-6 months later to inform development of resilience promoting intervention	n.a.	AYAs perceived resilience as a balance that may be promoted by learned skills in stress-management, goal-setting and benefit-finding.	Low
Wicks, 2010, New Zealand	Qualitative	10 AYAs	12-19	16-22	In-depth semi-structured interviews into the “adolescent cancer experience”	n.a.	Nine out of ten patients experienced a benefit finding after cancer.	Low
Wallace, 2007, UK	Qualitative	6 female AYAs	12-16	14-19	Semi-structured interviews focused on altered appearance	n.a.	All patients experienced benefit finding after cancer.	Low
<b>Quantitative studies – PTG</b>								
Zebrack, 2014, USA	Cross-sectional	165 AYAs in-treatment	14-39 (M=22.8)	15-40	PTGI: 21-item questionnaire with five subscales with total score range of 0-105 points. Cronbachs $\alpha=0.95$	Mean PTG score was 67.3 (SD=24.3)	PTGI total score did not vary by gender, race, relationship status, age, severity of disease. No significant relationship between PTG and PTS was noticed at the 12-month follow-up. A curvilinear relationship between re-experiencing and two of the five PTG-subcales was observed.	High
Salsman, 2014, USA	Cross-sectional	335 AYAs within 0-60 months post treatment	18-39 (M=31.8)	18-44	PTGI-SF: 10-item version of the PTGI with range of 0-50 points $\alpha=0.92$	Mean PTG score was 27.75 in patient group versus 27.22 for healthy controls (p=0.74)	Amount of PTG did not differ significantly between AYA cancer patients and the healthy controls	High
Monteiro, 2013, Portugal	Cross-sectional	36 AYAs: 11 were in-treatment, 25 off-treatment	15-39	20-38 (M=28.5)	Personal Growth subscale of the PWBS: 14-item scale with range of 14-84.	Mean personal growth score of the	Cancer patients on-treatment scored significantly lower on personal growth than the off-treatment and healthy control groups.	Adequate



					Cronbachs $\alpha=0.83$	in-treatment AYAs was 65.81(SD=6.35), of the off-treatment AYAs was 72.77(SD=7.89) and in healthy controls 71.27(SD=8.90)		
Seitz, 2010, Germany	Cross-sectional	820 long-term AYA cancer survivors	15-18	18-42 (M=30.4, SD=6)	PTGI Cronbachs $\alpha=0.89$	Scores of PTG were not reported	PTG is positively associated both general and health-related life satisfaction	High
Love, 2010, Canada	Cross-sectional	64 AYA cancer survivors	18-38	20-39 (M=28.8)	PTGI Scores range 1-6 Cronbachs $\alpha=0.90$	Mean overall PTG score was 4.06(SD=1.08)	PTG scores did not vary by age, gender, stage/severity of the disease. Stress ( $\beta=-0.04$ ) and social support ( $\beta=0.46$ ) were significantly associated with PTG ( $R^2=0.24$ ). This association was stronger in physically inactive AYAs	High
<b>Quantitative studies – Resilience</b>								
Wu, 2015, USA	Cross-sectional	40 AYAs in-treatment	13-20 (M=16.4)	13-20 (M=16.4)	RS: 25-item questionnaire with score range of 25-175. A score >147 indicates highly resilient, 121-146 medium resilient and <121 little resilient. Cronbach's $\alpha=0.93$	Mean resilience score was 134.62 (SD=25.43)	Cancer symptom distress had a significant negative influence ( $\beta=-0.44$ ) on resilience. Resilience mediates (buffer) the relationship between cancer distress symptoms and quality of life	Adequate
Wu, 2013, Taiwan	Cross-sectional	131 AYAs receiving chemotherapy	11-19 (M=14.7)	11-19 (M=14.7)	HARS: 13-item version with range of 13-78. Cronbachs $\alpha=0.85$	Mean resilience was 61.40(SD=10.28)	Age, time since diagnosis and school grade were not associated with resilience. Cognitive coping mechanisms are associated with higher levels of resilience, and defensive coping with more worries and less resilience.	Adequate
Smorti, 2012, Italy	Cross-sectional	32 AYAs with bone cancer who were in complete remission after treatment	Not presented	11-20 (M=15.2)	Expectations for Future scale: 9-item scale with range of 9-45. Cronbach's $\alpha=0.78$ . Ego-Resiliency Scale:	Mean resilience score of AYAs was 26.94(SD=4.51) versus	AYA with cancer scored significantly lower on resilience than the healthy controls. Expectations of the future and resilience were significant and negatively correlated, openness to experience and resilience were significant and positively correlated.	Adequate

					10-item scale with range 10-40 points. Cronbachs $\alpha=0.79$	31.13(SD=4.27) in healthy controls (p=<0.001)		
<b>Intervention studies - Resilience</b>								
Rosenberg, 2015, USA	Intervention (pre-post design)	15 AYAs diagnosed with cancer at least two weeks before study	12-25	14-25 (M=16.2)	CD-RISC: 10-item with range 0-40. Cronbachs $\alpha=0.85$ Measured at baseline and follow-up	Mean resilience score at baseline was 26.2. Mean score at follow up after intervention was 28.4 (p=0.195)	The intervention was feasible and well-accepted by AYAs, however efficacy could not be determined	High
Robb, 2014, USA	Intervention (RCT)	113 AYAs undergoing hemopoietin stem cell transplantation	11-24 (M=17.3)	11-24 (M=17.3)	HARS: 15-item version with range 1-6 Cronbach's $\alpha=0.81$ . Measured at baseline (T1), post-intervention (T2) and 100 days post-transplant (T3)	Mean resilience score at baseline was 5.1(SD=0.6)	Overall resilience did not differ significantly between the two groups at T2 (p=0.35), nor at T3 (p=0.29), although the intervention group reported better courageous coping (p=0.03) at T2 and better social integration p=0.028) and family-environment (p=0.008) at T3	High

CD-RISC: Connor-Davidson Resilience Scale; HARS: Haase's Adolescent Resilience Scale; M: mean; n.a.: not applicable; PTGI: Posttraumatic Growth Inventory; PTGI-SF: Posttraumatic Growth Inventory Short Form; PTS: posttraumatic stress; PWBS: Psychological Well Being Scale; RIM: Resilience in Illness Model; RS: Resilience Scale; YLOT: Youth Life Orientation Test