Increased cognitive problem reporting after information about chemotherapy-induced cognitive decline
Jacobs, W.; Das, E.; Schagen, S.B.

Published in:
Psychology & Health

DOI:
10.1080/08870446.2016.1244535

Citation for published version (APA):
Increased cognitive problem reporting after information about chemotherapy-induced cognitive decline: The moderating role of stigma consciousness

W. Jacobs\textsuperscript{a,b,*}, E. Das\textsuperscript{a} and S.B. Schagen\textsuperscript{b}

\textsuperscript{a}Department of Communication and Information Science (CIW), Centre for Language Studies, Radboud University Nijmegen, Nijmegen, The Netherlands; \textsuperscript{b}Division of Psychosocial Research and Epidemiology, Netherlands Cancer Institute, Amsterdam, The Netherlands

(Received 28 August 2015; accepted 23 September 2016)

Objective: Information about treatment side effects can increase their occurrence; breast cancer (BC) patients showed increased cognitive problem reporting (CPR) and decreased memory performance after information about cognitive side effects. The current study extends previous research on adverse information effects (AIE) by investigating (a) risk factors, (b) underlying mechanisms and (c) an intervention to reduce AIE.

Design: In an online experiment, 175 female BC patients were randomly assigned to one of three conditions. In the two experimental groups, patients were informed about the possible occurrence of cognitive problems after chemotherapy with (intervention group) or without (experimental group) reassuring information that ‘there are still patients who score well on memory tests’. In the control group, no reference to chemotherapy-related cognitive problems was made.

Main outcome measures: Main dependent measure was CPR. Four moderating and five mediating processes were examined.

Results: CPR increased with higher levels of stigma consciousness in the two experimental groups, but not in the no-information control group.

Conclusion: Merely informing patients about cognitive side effects may increase their occurrence, especially among individuals vulnerable to patient stereotypes. Adding reassuring information is not sufficient to reduce AIE.

Keywords: cognitive problems; nocebo; breast cancer; stereotype threat; information

A substantial group of women treated for breast cancer (BC; 17–75\%) have cognitive problems after chemotherapy, sometimes persisting well into the survivorship period (up to 20 years after therapy). Core impairments of this ‘chemobrain’ phenomenon include memory problems, slowing of information processing speed and executive dysfunction, impacting quality of life and daily functioning (Ahles, Root, & Ryan, 2012; Wefel & Schagen, 2012). So far, research has focused mostly on biological factors as explanatory mechanisms (for a review, see Jansens, Kesler, Ahles, & Morrow, 2014; Wefel & Schagen, 2012), but two recent studies suggest that (mere) information may also contribute to the occurrence of cognitive side effects.

*Corresponding author. Email: w.jacobs@let.ru.nl

© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.
Specifically, communicating that ‘chemotherapy may be associated with cognitive difficulties’ before completing questionnaires and a neuropsychological test increased the reporting of cognitive problems (CPR) and decreased cognitive performance on a verbal memory task for BC patients (Schagen, Das, & van Dam, 2009; Schagen, Das, & Vermeulen, 2012). The processes that drive these effects are still unclear.

The present research introduces the label adverse information effects (AIE) to refer to negative effects of medical information about treatment. Building on nocebo and stereotype threat literature, we extend previous findings in three specific ways, by investigating (a) risk factors; (b) underlying mechanisms; and (c) an intervention to reduce AIE.

What triggers AIE? Explanations from nocebo and stereotype threat research

AIE have thus far been established on cognitive problem reporting (CPR) and neuropsychological test scores. In a first study (Schagen et al., 2009), information about cognitive side effects of chemotherapy increased CPR, but only for BC patients without a history of chemotherapy. This effect was independent of age, education level and negative affect. A second study (Schagen et al., 2012) reported that cancer patients treated with chemotherapy had higher levels of CPR and recalled fewer words on a word-learning test after being informed about the link between chemotherapy and cognition than without such information. AIE findings correspond with studies in the area of mild head injury (MHI) (e.g. Ozen & Fernandes, 2011; Suhr & Gunstad, 2002) that showed increased CPR and diminished performance on neuropsychological tests, when individuals diagnosed with MHI have their attention called to prior head injury. Comparable effects were found for older individuals who were reminded of the expectation that ‘memory performance declines with age’ prior to the neuropsychological tests and self-report measures (Lamont, Swift, & Abrams, 2015).

Little is known about the mechanisms that are at play in AIE, but we propose that theoretical explanations from both nocebo and stereotype threat research could be relevant. The nocebo effect occurs for an inert or active treatment or medication when the expectation of negative symptoms results in increased experience of these symptoms (Faasse & Petrie, 2013). For example, individuals may report more pain after verbal suggestions for pain increase (Petersen et al., 2014). Nocebo literature has suggested that expectations, associative learning and suggestion may trigger the nocebo effect. Most studies in this domain have focused on biochemical factors and brain processes involved following negative expectations about for example, pain (e.g. Koyama, McHaffie, Laurienti, & Coghill, 2005). Research on the role of suggestion has mostly explicitly varied probability or severity estimates, but not examined effects of merely adapting or reframing patient information without adding beneficial information about the treatment.

A research domain that appears especially promising to further explore the role of information in aversive responses following treatment is the stereotype threat literature. Stereotype threat is implied when performance, for example, on a math test, is impaired after individuals are provided with stereotypical information about their group prior to the test (Steele, 1997; Steele & Aronson, 1995). These effects are proposed to occur because the threat of being judged or negatively stereotyped may interfere with performance in several ways, for instance, by decreasing motivation or increasing negative emotions (Kit, Tuokko, & Mateer, 2008). Stereotype threat has been researched extensively in the area of racial and gender stereotypes; we propose it may also apply...
to AIE. Specifically, activation of a stereotype or schema about a category – such as ‘cancer patients have chemobrain’ – may unconsciously lead to behaviour in correspondence with that stereotype for individuals who are part of the group under threat.

The present research tests whether stereotype threat assumptions also apply to AIE. Research from different fields shows that stereotypes can play a role in the medical domain in general and in cancer patients in particular. Individuals diagnosed with cancer may experience stereotypical expectancies or some levels of (social) stigma, i.e. ‘the specific sense of being different from others as a consequence of being assigned to the patient role’ (Koller et al., 1996, p. 988). In the present research, we examine the role of implicit association activation in the occurrence of AIE using a Word Completion Task. Specifically, we examine whether reading information about cognitive problems after chemotherapy treatment activates: (a) implicit stereotypical associations with cognitive problems, e.g. being ‘dumb’ or ‘demented’, and whether (b) information about cognitive problems after chemotherapy activates or deactivates implicit associations related to the patient category (RQ1).

Related to the first goal of the present study, several other relevant underlying processes of AIE were examined. An extensive body of literature on stereotype threat outside the clinical setting suggests that stereotype threat effects operate through various cognitive, emotional and motivational mechanisms (for an overview, see Kit et al., 2008 and Schmader & Beilock, 2011). Although these studies have not revealed conclusive evidence regarding underlying processes, they have shown that reduced feelings of self-efficacy (Kit, Mateer, Tuokko, & Spencer-Rodgers, 2014; Spencer, Steele, & Quinn, 1999), increased worry about performance (Steele, Spencer, & Aronson, 2002), increased (Jamieson & Harkins, 2007; Smith, 2004) or decreased (Kit et al., 2008; Smith, 2004) motivation and effort can play a role in stereotype threat effects. Building on these findings, we examined whether information about cognitive side effects increases or decreases patients’ motivation levels (Jamieson & Harkins, 2007; Kit et al., 2008), affected patients’ worry about their performance (Steele et al., 2002) and affected their feelings of self-efficacy (Spencer et al., 1999), and whether these factors also predicted CPR (RQ2).

**Risk factors of AIE: who is most vulnerable?**

A second goal of this study was to examine risk factors for AIE. Although one would expect that individuals for whom the information is not personally relevant (not treated with chemotherapy) should not be vulnerable for information about cognitive decline after chemotherapy, previous studies among patients with and without chemotherapy showed mixed findings regarding which patients are most at risk (Schagen et al., 2009, 2012). The present research aims to examine whether these divergent findings may be reconciled by including risk factors for stereotype threat that have been identified in research on racial and gender stereotypes (see for a review Kit et al., 2008). First, stigma consciousness – i.e. ‘the extent to which individuals are chronically self-conscious of their stigmatized status’ (Brown & Pinel, 2003, p. 627) will be examined as a risk factor. Research has shown that individuals differ in their vulnerability to race or gender stereotypes depending on their perception of how much they are stereotyped by others and how much they are affected by it. Especially individuals high in stigma consciousness may be negatively affected by stereotype threat (Brown & Pinel, 2003).
Second, research shows stronger stereotype threat effects when the domain or group under threat is personally relevant (Aronson et al., 1999). Translated to AIE, an individual high in domain identification, (i.e. how greatly patients value their cognitive performance) may be more likely to be negatively affected by threatening information regarding their performance than an individual low in domain identification. Likewise, individuals who highly identify with the group under threat and who consider category membership to be an important part of their identity (i.e. to what extent an individual identifies with other cancer patients) may be more affected when their group status is threatened than low identifiers (Spears, Doosje, & Ellemers, 1997; Steele et al., 2002).

The present study includes both patients with and without chemotherapy experience and additionally assessed individual differences in identification with the patient category, identification with the cognition domain and stigma consciousness, with the goal to explore if previous divergent findings regarding the role of previous experience with chemotherapy can perhaps be explained by a third variable, specifically varying levels of stigma consciousness, domain or group identification (RQ3).

Reducing AIE: intervention possibilities

A third goal of the present study was to provide a first test of an informational intervention aimed at reducing AIE among cancer patients. Nocebo and placebo research point to the importance of enhancing positive expectancies in order to decrease nocebo effects, but experimental studies that specifically examine effects of adapting or reframing patient information are scarce. There are some examples of studies that focused on enhancing placebo or preventing nocebo by varying patient information or by suggestion, but these studies mostly manipulated probability or severity estimates or provided additional benefit information about the treatment (e.g. Heisig, Shedden-Mora, Hidalgo, & Nestoriuc, 2015).

Research outside the clinical domain has found several ways to diminish stereotype threat effects, for example, by forewarning (Johns, Schmader, & Martens, 2005), by allowing individuals to affirm a valued personal characteristic – in accordance with self-affirmation theory (Steele, 1988) – or by providing them with a positive identity (McGlone & Aronson, 2007; Sherman et al., 2013).

Finally, research on doctor–patient communication suggests that patients’ expectations about treatment can be altered by providing positive information about the treatment – for example, stating ‘that a therapy is ‘good’, ‘safe’ or ‘effective’, and giving support or reassurance’ – can positively influence health outcomes (Di Blassi, Harkness, Ernst, Georgiou, & Kleijn, 2001, p. 758; Verheul, Sanders, & Bensing, 2010). Because the latter findings directly pertain to the medical context and could be effectively implemented in a short information letter about the relationship between chemotherapy and cognitive complaints, the current study examined whether adding reassuring and positive information to the threatening medical information would diminish AIE (RQ4).

Method

Design and participants

Patients were recruited online, by posting a link on 15 Dutch forums and websites, both related and unrelated to (breast) cancer (May–June 2011). With approval of the website owners or moderators, a recruitment text with a request to participate in an online
questionnaire about ‘complaints and symptoms that can be experienced by cancer patients after diagnosis and treatment’ was posted together with the survey link. Because no names or other identifying information was requested, no signed consent form was required. A total of 236 cancer patients\textsuperscript{1} responded by filling out the questionnaire and were randomly assigned to one of three groups (experimental, intervention or control) in the online experiment. After opening the survey link, the following general introduction text was presented to all participants (in Dutch): ‘Dear reader, Welcome to this survey. When you click on “next” the questionnaire will start. This questionnaire is about complaints and symptoms that cancer patients can experience after different treatments. We would like to ask you to carefully complete this survey. There is no time limit, you can take as much time as you like. Please complete the questionnaire in one go. Completing the questionnaire will take about 25 min. Your data will be treated confidentially and anonymously. Thank you for your cooperation’. Although this introduction text and the recruitment text accompanying the survey link were directed at individuals with a cancer diagnosis in general, and did not differentiate between individuals with and without chemotherapy experience, the vast majority of the respondents were women who had been treated in the past for BC ($n = 202$ of 236 participants). Due to this imbalance, we decided to create a homogeneous sample, by excluding the small number of patients with other diagnoses ($n = 15$) and males ($n = 7$), as well as patients who at the time of the assessment received chemotherapy ($n = 14$). Also, as ‘CPR’ was the main outcome measure in this study, the analysis were done for those who completed the questions regarding this main dependent variable ($n = 175$). The cases that were excluded from the analysis ($n = 25$) were equally distributed among the three conditions, $\chi^2(2, N = 200) = .40, p = .82$. From the original sample of 236 participants, a total of 61 cases were thus excluded from analysis.

Of the final sample of 175 BC patients, 76\% were treated with and 24\% did not undergo chemotherapy. The three groups of the final sample were equally distributed with regard to all relevant demographic and clinical variables (Table 1).

\textbf{Procedure and materials}

Participants were randomly assigned to one of three conditions by computer. The first experimental group ($n = 56$) received the following introduction (in Dutch): ‘Before you start, please carefully read the information below. For many cancer patients, chemotherapy is an important part of their treatment. We know from experience that some patients receiving chemotherapy experience complaints regarding their memory ability and their ability to concentrate. The goal of this study is to gain more insight in this relationship. This study is important to reveal how such complaints could be prevented in future. In this study you will be, among others, asked whether or not you experience cognitive complaints. In addition, there is a short test that measures cognitive performance’ (experimental group) (Schagen et al., 2009, 2012). The second experimental group (intervention group) received the same information plus two positive and reassuring sentences: ‘Before you start, please carefully read the information below. For many cancer patients, chemotherapy is an important part of their treatment. We know from experience that some patients receiving chemotherapy experience complaints regarding their memory ability and their ability to concentrate. However, there are also many patients who do not experience these complaints. In this study you will be, among others, asked whether or not you experience cognitive complaints. In addition, there is a short test that measures cognitive
performance. We know that patients with memory- and concentration problems often still perform well on this test’ ($n = 59$) (Di Blassi et al., 2001; Johns et al., 2005). The control group received a one-sentence neutral introduction without any reference to chemotherapy or cognitive difficulties: ‘Thank you for your cooperation’ ($n = 60$) (Schagen et al., 2009, 2012). This procedure resembles common medical practice, in which patients are sometimes informed about the possibility of cognitive side effects, and other times are not informed about this possibility.

After reading the experimental text, all groups completed an online questionnaire. The dependent variable of interest was CPR. The questionnaire measuring CPR was derived from earlier research in this domain (Schagen et al., 2009, 2012). This survey was part of a more extensive project on short- and long-term effects of being informed about the cognitive side effects of cancer treatment on CPR and cognitive performance.

**Measures**

**Dependent measures**

CPR was measured with 10 five-point Likert scale items (very often–never) of the subscales ‘absent-mindedness’ and ‘names and words’ of the Cognitive Failure

<table>
<thead>
<tr>
<th>Table 1. Demographic and clinical variables.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
</tr>
<tr>
<td>Age mean (SD)</td>
</tr>
<tr>
<td>Chemotherapy % ($n/N$)</td>
</tr>
<tr>
<td>Endocrine treatment % ($n/N$)</td>
</tr>
<tr>
<td>Currently</td>
</tr>
<tr>
<td>Past</td>
</tr>
<tr>
<td>Radiotherapy % ($n/N$)</td>
</tr>
<tr>
<td>Currently</td>
</tr>
<tr>
<td>Past</td>
</tr>
<tr>
<td>Time since diagnosis, yrs (SD)</td>
</tr>
<tr>
<td>BC diagnosis +/- other % ($n/N$)</td>
</tr>
<tr>
<td>Breast</td>
</tr>
<tr>
<td>Breast and lung</td>
</tr>
<tr>
<td>Breast and skin</td>
</tr>
<tr>
<td>Breast and gynaecological</td>
</tr>
<tr>
<td>Breast and else</td>
</tr>
<tr>
<td>Employed % ($n/N$)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Temporarily not</td>
</tr>
<tr>
<td>Education level% ($n/N$)</td>
</tr>
<tr>
<td>Low</td>
</tr>
<tr>
<td>Medium</td>
</tr>
<tr>
<td>High</td>
</tr>
<tr>
<td>Pre-existing knowledge % ($n/N$)</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Some</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>
Questionnaire (Broadbent, Cooper, FitzGerald, & Parkes, 1982; Ponds, Roozendaal, & Jolles, 2004; Schagen et al., 2012; \(\alpha = .89\)). This scale is a standard questionnaire to assess CPR. Participants indicated how often (in general) they experienced memory problems, e.g. ‘How often do you find you forget appointments?’.

**Implicit cognition stereotype and patient category activation** was measured by asking patients to complete 28 word fragments of which four fragments could be completed relating to a ‘cognition stereotype’ and 8 to a ‘patient category’, e.g. _ANCER can be completed as CANCER or DANCER. The other words were neutral words, e.g. SH(EE)P or SH(AR)P (Das, Bushman, Bezemer, Kerkhof, & Vermeulen, 2009). The number of word fragments completed relating to cognition or to being a patient were summed separately to two sum scores. Higher scores denote higher levels of stereotype activation. All words were pretested before use in this study (\(n = 33\)).

**Motivation level** was measured by two five-point Likert scale items (strongly disagree–strongly agree) (Seibt & Förster, 2004; \(r = .73, p = .00\)) assessing whether participants are motivated to perform well on a memory task. For example, ‘I am motivated to do well on a memory task’.

To measure **self-efficacy**, participants rated on four five-point Likert scale items (strongly disagree–strongly agree) derived from the translated self-efficacy scale, their ability to do well on a memory test (Spencer et al., 1999; \(\alpha = .82\)). For instance, ‘I think I have the cognitive ability to perform well on a memory task’.

**Self-reported worry about performance** was measured by three five-point Likert scale items (strongly disagree–strongly agree), assessing level of worries when thinking of a memory task (\(\alpha = .79\)), e.g. ‘I am worried about my performance on a memory task’.

**Moderators**

**Stigma consciousness** was assessed by eight five-point Likert scale items (strongly disagree–strongly agree) derived from the Stigma Consciousness Questionnaire (Brown & Pinel, 2003; \(\alpha = .83\)). Items were translated to Dutch and adapted for use in a cancer population. Participants indicated ‘the extent to which they expect to be stereotyped by others’ (Pinel, 1999, p. 114) and are personally influenced by these (cancer) patient stereotypes, e.g. ‘Most other people have a lot more negative thoughts about cancer patients than they actually express’.

**Domain identification** was assessed with six five-point Likert scale items (strongly disagree–strongly agree) derived from the Mathematics Identification Questionnaire (Brown & Josepks, 2000) and the Domain Identification Questionnaire (Smith & White, 2001; \(\alpha = .84\)). These items assessed the extent to which participants identify with the domain of ‘cognition’ and the level of importance of their thinking ability to their self-identity, e.g. ‘My cognition (thinking ability) is important to me’.

**Group identification** to the category ‘cancer patient’ was measured by three five-point Likert scale items (strongly disagree–strongly agree) derived from Doosje, Ellemers and Spears (1995) and Spears et al. (1997), and three five-point scale items of the collective self-esteem scale (Luhtanen & Crocker, 1992; \(\alpha = .65\)). These items were adapted to examine the perceived importance of patient identity to self-image (Schmader, 2002), e.g. ‘Being a cancer patient is an important part of my self-image’.

**Chemotherapy experience** was measured by asking participants to indicate whether they currently or in the past underwent chemotherapy or not (no/yes).
**Covariates**

Pre-existing knowledge about chemotherapy-induced cognitive problems (prior to the experiment) was measured by two five-point Likert scale items (not at all–totally) \( (r = .46, p < .001) \); e.g. ‘To what extent are you familiar with the fact that some patients experience memory and concentration problems after cancer treatment’.

Affect was measured by six five-point Likert scale items (strongly disagree–strongly agree) taken from the Positive and Negative Affect Schedule PANAS (Watson, Clark, & Tellegen, 1988; \( \alpha = .82 \)). Participants indicated the extent to which they experienced a specific emotion at that moment (e.g. irritable); higher scores indicate more positive affect (Schagen et al., 2009).

Other cancer-related symptoms were measured by four five-point Likert scale items (very often–never) derived from the Depression and Anxiety questionnaire (De Jonghe, Huyser, Swinkels, Sno, & Schalken, 1990; \( \alpha = .71 \)), concerning the frequency of experiencing pain, fatigue, decreased endurance and sleeping problems. These questions were previously used in studies on the cognitive side effects of chemotherapy (e.g. Schagen et al., 1999, 2009). Higher scores indicate a higher frequency of symptoms during the previous weeks.

**Statistical analyses**

Data were analysed with SPSS Version 20.0 (SPSS, Inc, IL, USA) using one and two way analyses of (co)variance with group (experimental, intervention, control) and chemotherapy experience (yes, no) as independent factors and stigma consciousness, domain identification and group identification as continuous moderators (see Aiken & West, 1991 for this specific analysis). Using this procedure, tests of differences between respondents with different levels of the moderator can be performed without using a median split. All observations are thus included in the analysis (e.g. Royston, Altman, & Sauerbrei, 2006). Because no moderating effects were observed for chemotherapy experience, domain and group identification (all \( F \)'s \( \leq 1.52 \)), only the analyses with stigma consciousness are reported below. See the online supplemental material for a detailed overview of all results (\( p \)-values, means and standard deviations). Correlations were examined; when potential confounds were significantly related to the dependent variable, these variables were included as covariates in the main analyses. Bootstrapping procedures were used to test for mediation (Preacher & Hayes, 2008).

Levene’s tests were conducted for all dependent variables; findings are only reported for significant Levene’s test scores. Effect sizes were calculated with partial eta squared, with effect sizes of .01–.06 considered as small, .06–.14 as medium and above .14 as large (Cohen, 1988).

**Results**

**Implicit stereotype and category activation**

First, we examined whether reading information about cognitive problems after chemotherapy activated: (a) implicit stereotypical associations with cognitive problems (e.g. being ‘dumb’ or ‘demented’) and whether (b) information about cognitive problems after chemotherapy activated implicit associations related to the patient category (RQ1). There was no significant main effect of group or interaction effect, but the ANOVA on activation
of the cognition stereotype with group (experimental, intervention, control) and stigma consciousness (continuous) as predictor revealed a main effect of stigma consciousness, \( F(5,141) = 6.26, p = .01, \eta^2_p = .04 \). Individuals high in stigma consciousness had higher levels of associations with cognitive problems, \( t(1, 145) = 2.42, p = .017, b(SEb) = .27 (.11), \beta = .20 \).

A similar ANOVA on activation of the patient category words showed no main effect of group or interaction effect, but again revealed a main effect of stigma consciousness in the opposite direction, \( F(5,141) = 6.68, p = .01, \eta^2_p = .05 \). Individuals low in stigma consciousness showed higher levels of patient category activation, \( t(1, 145) = -2.44, p = .016, b(SEb) = -.42 (.17), \beta = -.20 \).

**Cognitive problem reporting**

Further, we examined whether reading information about cognitive problems after chemotherapy treatment influenced CPR. Also, stigma consciousness was examined as risk factor (RQ3) and it was investigated whether adding reassuring and positive information to the threatening medical information could diminish the AIE (RQ4). The ANOVA on CPR with group (experimental, intervention, control) and stigma consciousness (continuous) as predictors revealed no main effect of group (\( F(5,141) = .06, p = .941, \eta^2_p = .00 \)). There was, however, a significant main effect of stigma consciousness on CPR (\( F(5,141) = 23.67, p < .001, \eta^2_p = .14 \)), indicating that individuals with higher levels of stigma consciousness more frequently reported cognitive problems. In addition, the interaction effect of group and stigma consciousness on CPR was significant (\( F(5,141) = 3.32, p = .039, \eta^2_p = .05 \)). For individuals in the experimental and intervention condition, the frequency of CPR increased with higher levels of stigma consciousness, \( t(1,45) = 4.01, p < .001, b(SEb) = .57 (.14), \beta = .51 \) and \( t(1,45) = 3.60, p = .001, b(SEb) = .53 (.15), \beta = .47 \). For patients in the control condition there was no relationship between stigma consciousness and CPR, \( t(1,51) = .75, p = .45, b(SEb) = .11 (.14), \beta = .11 \) (see Figure 1).

![Interaction effect of experimental condition and stigma consciousness on CPR controlling for affect and other cancer-related symptoms.](image-url)
Other risk factors were also examined. Similar ANOVAs with chemotherapy experience, domain and group identification (RQ3) as moderators revealed no additional significant interaction effects (all $F$’s $\leq$ 1.52).

**Worry, motivation and self-efficacy**

We examined whether information about cognitive side effects increases or decreases patients’ motivation levels, affected patients’ worry about their performance and affected their feelings of self-efficacy, and whether these factors also predicted CPR (RQ2). The ANOVA on worry with group (experimental, intervention, control) and stigma consciousness (continuous) as predictors showed a marginally significant effect of experimental condition on worry ($F(5,141) = 2.60, p = .078, \eta^2_p = .04$). Individuals in the experimental group showed marginally significant higher levels of worry ($M = 2.94, SD = .80$) than individuals in the control group ($M = 2.58, SD = .83$) ($p = .07$). The levels of worry in the intervention condition ($M = 2.84, SD = .78$) and the other two conditions were similar ($p$’s $\geq .32$).

There was a main effect of stigma consciousness ($F(5,141) = 6.90, p = .01, \eta^2_p = .05$): individuals with higher levels of stigma consciousness reported higher levels of worry, $t(1,145) = 2.57, p = .011, b(SEb) = .25 (.10), \beta = .21$. No interaction was found. The ANOVAs on motivation and self-efficacy with group and stigma consciousness as predictors showed no main or interaction effects ($F$’s $\leq 2.64$).

**Controlling for potential confounds**

To verify the robustness of our main findings, we reran the ANOVAs of our main findings regarding CPR and stigma consciousness (RQ3 and RQ4), this time controlling for potential confounds. Other cancer-related symptoms and affect were significantly related to CPR. Both variables were included as covariates in an ANCOVA on CPR. This analysis showed again no main effect of experimental group. The main effect for stigma consciousness remained significant ($F(7,139) = 10.22, p = .002, \eta^2_p = .07$), as did the interaction effect of group and stigma consciousness on CPR ($F(7,139) = 4.06, p = .02, \eta^2_p = .06$). The same pattern of findings was observed; for individuals in the experimental and intervention condition, the frequency of CPR increased with higher levels of stigma consciousness, $t(3,43) = 3.11, p = .003, b(SEb) = .50 (.16), \beta = .44$ and $t(3,43) = 2.49, p = .017, b(SEb) = .36 (.15), \beta = .32$. For patients in the control condition there was no relationship between stigma consciousness and CPR, $t(3,49) = .24, p = .81, b(SEb) = .03 (.14), \beta = .03$ (see Figure 1).

Similar ANCOVAs with chemotherapy experience, domain and group identification (RQ3) as moderators showed again no additional significant interaction effects (all $F$’s $\leq 1.10$). Finally, when covariates were included in the model, bootstrapping procedures (Preacher & Hayes, 2008), showed no evidence for mediation by the proposed mediators.

**Discussion**

Information about the association between cognitive difficulties and chemotherapy increased CPR especially for individuals who consider themselves to be stereotyped as...
cancer patients by others. These findings extend previous research on AIE for BC patients (Schagen et al., 2009, 2012) and show that concepts from social psychological research, such as stereotype threat and stigma consciousness, may also be of importance in the clinical domain.

Being highly aware of cancer patient stereotypes and of one’s own stigmatised status (Brown & Pinel, 2003) may constitute a risk factor for negative effects of treatment information. These findings correspond with stereotype threat research, which had suggested that information is more likely to have negative effects among individuals who consider the information as relevant to their self-concepts (e.g. Schmader, 2002). Our findings suggest that the extent to which someone expects to be stereotyped as a cancer patient by others is more important than other factors related to the relevance of a stereotype, such as chemotherapy experience, group and domain identification. In the present research, these factors did not play a significant role in the prediction of cognitive complaints.

Although one would expect individuals with actual chemotherapy experience to be affected only by information about the potential relationship between chemotherapy and cognitive problems, previous research showed inconsistent findings (Schagen et al., 2009, 2012). In the current study, BC patients with and without chemotherapy experience were equally affected by information about chemotherapy-associated cognitive problems, which suggests that it is not the actual experience with chemotherapy that is important in increasing AIE.

The significant effect of stigma consciousness and the absence of interaction effects of domain and group identification may point to the importance of social effects of diminished cognitive functioning and the fear of social consequences of being assigned to the cancer patient role. What might play a role here is that the (self-) threatening information in this study (cognitive decline after cancer) is not as visible as ‘being a woman’, but is hidden (Quinn, 2006). Patients high in stigma consciousness may be more afraid of disclosing a stigmatised identity to others than patients low in stigma consciousness. One essential difference between domain and group identification and stigma consciousness is that stigma consciousness focuses on the judgement or view by others and the extent to which an individual values being considered a cancer patient by others, whereas domain or group identification focuses on the importance of the domain or group for the patients themselves. Hence, (worrying about) social or stigmatising factors may play a role in being at risk for AIE concerning cognitive problems after a cancer diagnosis and treatment.

This corresponds with the findings of Koller et al. (1996) that experienced social stigma was associated with negative affect and symptom reporting of cancer patients. Individuals who consider themselves to be highly stigmatised as a cancer patient by others may be more strongly affected by negative information about their group, and more motivated to disprove the stereotype. This may also explain why the intervention developed in this study was unsuccessful. The intervention was primarily directed at reassurance and at increasing patients’ self-confidence regarding cognitive performance. Future studies should examine interventions directed at diminishing worries about the social consequences of cognitive difficulties and cancer. The null-findings here may also be explained by linguistic or negation bias, i.e. the idea that language reflects and implicitly communicates stereotypical expectancies. Both texts may have created the expectation of ‘problems’ (Burgers, Beukeboom, & Sparks, 2012). As previous research
showed that small linguistic variations (i.e. negations or affirmations) can impact the health message (Burgers et al., 2012), it might be interesting to test whether these variations can change the effect of information on CPR.

We did not find evidence for the activation of stereotypical cognition or patient category associations after reading the experimental information. However, patients high in stigma consciousness had overall more stereotypical associations about cognition such as being ‘dumb’. In addition, these patients showed deactivated levels of the patient category. As especially patients high in stigma consciousness were more prone to AIE, these findings point to the possibility that stigma conscious patients do not want to be regarded as a patient and, as a result, try hard to disprove stereotypical expectations. Future studies should further examine this line of reasoning.

A limitation of the current study is that patients were recruited online and that, although we collected information about diagnosis and treatment, checking this self-reported information and obtaining more information about patients’ medical history was impossible. Information about cancer stage or treatment regimen was not obtained. Future studies should include this information and study AIE in a more controlled setting. In addition, the influence of expectancies of cognitive side effects prior to treatment and effects of the experimental texts on expectancy levels should be measured. Nocebo and placebo research shows the importance of enhancing positive expectancies, however, it has not been investigated often whether an intervention (in text) designed at changing expectations could reduce AIE. Finally, future studies should use a text for the control condition comparable in length to the other two experimental conditions.

Although the present study shows that informing patients about cognitive side effects of chemotherapy may have negative effects for a subgroup of patients, informing patients on treatment (side effects) also has several positive outcomes. For example, patients with fulfilled information needs have in general less depression and anxiety and report a better health-related quality of life (Husson, Mols, & Van de Poll-Franse, 2010). Moreover, because of informed consent procedures, health practitioners are required to inform patients about medical procedures and side effects of treatment and medication. So the main question is not if treatment information needs to be communicated to patients, but how to inform each individual patient about treatment side effects. Although we found no positive effects of our intervention, we did demonstrate that information can have a differential impact on experienced side effects as a function of patient characteristics, which points to the importance of ‘patient-centered information provision’ (Husson et al., 2010, p. 11). Wells and Kaptchuk (2012) suggest a ‘contextualized informed consent procedure’, which takes into account ‘possible side effects, the patient being treated and the particular diagnosis involved’, in order to prevent ‘the increase of side effects through expectancy mechanisms due to informing patients about side effects of medication’ (p. 1). Future research should further examine information-based interventions to prevent these AIE in communicating about side effects in general and about cognitive side effects of cancer treatment in particular. Effective psychological and pharmacological interventions to diminish cognitive problems in cancer patients are still scarce. Although several interventions seem promising, such as cognitive rehabilitation or physical activity interventions (see for a review Chan, McCarthy, Devenish, Sullivan, & Chan, 2015), the current approach might be an addition to these other approaches and could, for example, be integrated in psycho-educational material or cognitive rehabilitation programmes.
Finally, it is important to track changes in CPR and to examine possible contributing psychological factors before, during and after treatment, as research shows that pre-treatment worry may contribute to CPR during treatment (Berman et al., 2014). Also, women newly diagnosed with BC might react differently to information about side effects than women several years after treatment. Future studies should examine CPR and the duration of the information effects in a prospective design, to create a more naturalistic situation and to determine the severity of the effect of the patient information.

Conclusion

This study made a first attempt to identify risk factors for AIE regarding chemotherapy-associated cognitive problems. Information about the cognitive side effects of chemotherapy increased the frequency of CPR for BC patients high in stigma consciousness. Informing women with BC about long-term (cognitive) side effects of treatment without creating these side effects becomes increasingly important as BC survival rates increase and more women return to work after BC treatment. Over the past years, cognitive changes after cancer treatment have gained attention in research (Wefel, Kesler, Noll, & Schagen, 2015), which may also have raised patients’ awareness of the association between cognition and cancer treatment. In the future, it may be increasingly important to develop effective interventions in the clinical setting in order to find a way to inform patients about cognitive side effects without worsening them.

Supplemental material

Supplemental data for this article can be accessed online here: http://dx.doi.org/10.1080/08870446.2016.1244535

Disclosure statement

No potential conflict of interest was reported by the authors.

Note

1. Please note that although the present N of the original sample is the exact same number as the N in Schagen et al., 2012, this is coincidental as we recruited a new, independent sample for the current study.

References


Wells, R. E., & Kaptchuk, T. J. (2012). To tell the truth, the whole truth, may do patients harm: The problem of the nocebo effect for informed consent. The American Journal of Bioethics, 12, 22–29. doi:10.1080/15265161.2011.652798