

Patiënten Weten Beter: Verhalen

over Patiëntenervaringen met

Ziekenhuiszorg

June 2013

Felix Klein

s1106945

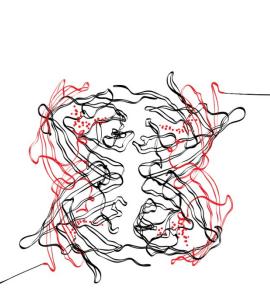
Bachelor Psychology 3rd year

University of Twente

Course: Bachelor thesis

Supervisors: Dr. C.H.C. Drossaert

Dr. A.M. Sools



UNIVERSITEIT TWENTE.

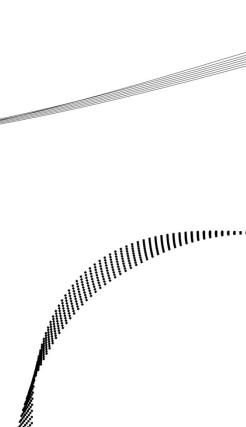


Table of Contents

Abstract	4
Samenvatting	5
1 Introduction	6
2 Methods	11
2.1 Participants	11
2.2 Instruments	11
2.3 Data analysis	12
3 Results	13
3.1 Who writes about their experiences as a patient on the websit	e?13
3.1 Benefits of written, online narrative research	17
3.1.1 Attitude towards Writing	17
3.1.2 Duty	18
3.1.3 Insight	18
3.1.4 Discovery of meaning	19
3.1.5 Emotional Response	
3.1.6 Closure	20
3.1.7 Relief	21
4 Discussion	24
4.1 Limitations	29
4.2 Suggestions for Further Research	29
4.3 Conclusion	30
Acknowledgements	31
References	32
A	25

1.	Website Patiënten Weten Beter	. 35
2.	Questions Website	. 36

Abstract

Background- Implementing patient-centered care in the Dutch health care system is currently an important goal. Patient-centered care focuses on the patient and the individual's particular healthcare needs. The main goal of patient-centered care is to help the patients to become active participants in their care. The University of Twente conducted in cooperation with the Rathenau Institute research over experiences of patients with the health care system. From the 20th April 2012 till the 19th March 2013 a total of 94 participants wrote down their experiences with the Dutch health care system on the website www.patientenwetenbeter.nl. In this bachelor thesis research about who is most likely to participate in this study was conducted. Furthermore additional benefits in the patient's health and an increase in satisfaction of writing about their experience are analyzed.

Methods- The participants were asked to fill out a short questionnaire regarding socio-demographic variables about the writer. Then descriptive analysis was conducted on the basis of the gained data. Furthermore, the writers were asked to answer how their experience writing their story was. The answers regarding the writing experience were classified from the researchers into themes and subthemes on the basis of an open thematic analysis.

Results- Most of the writers were female, well-educated, between the ages of 26 and 70 years old, visited the hospital more than 10 times and wrote about ambivalent experiences. The following themes were found in the answers "Positive assessment of writing", "Negative assessment of writing", "Duty", "Insight", "Higher regard for health", "Change for next patient", "Reliving of emotion", "Self-awareness of emotion", "Closure" and "Relief".

Conclusion- All in all was the sample more heterogeneous than previously expected. Although more women than men participate in this study and this might have led to a greater number of answers in the theme emotional response. Our findings indicate that the benefits of the Patiënten Weten Beter study (PWB-study) are similar to those gained through expressive writing. In total 8 out of the 10 themes regarding the benefits of expressive writing were also found in the literature study. The two themes, which were not found in prior studies, are "Attitude towards writing" and the theme "Duty". It can be concluded that benefits similar to those of expressive and therapeutic writing might be possible to reach with a much simpler set-up.

Samenvatting

Achtergrond- De invoering van een patiënt centrale zorg in de Nederlandse ziekenhuiszorg is een belangrijk doel van de overheid. Patiënt centrale zorg is gericht op de patiënten en hun specifieke behoeften in het ziekenhuis zorg. Het belangrijkst doel van patiënt centrale zorg is het steunen van patiënten in hun ontwikkeling naar een actieve deelnemer in hun zorg. De Universiteit Twente heeft coöperatie met het Rathenau instituut een onderzoek over ervaringen van patiënten met de ziekenhuiszorg uit gevoerd. Deze bachelor thesis gaat over the positieve invloed van het schrijven over hun ervaring op de gezondheid en tevredenheid van de schrijvers. Bovendien zijn de deelnemers op hun kenmerken onderzocht worden.

Methode- Van de 20de april 2012 tot de 19ste maart 2013 schreven in totaal 94 deelnemers over hun ervaring met de Nederlandse ziekenhuiszorg op de website <u>www.patientenwetenbeter.nl</u>. Naar het beëindigen van hun verhaal, worden de deelnemers gevraagd hun schrijf ervaring in te schatten. Bovendien, hebben de schrijver en korte enquête over hun socio-demografische variables ingevuld. De antwoorden met betrekking tot de schrijf ervaringen zijn dan in thema's en sub-thema's geclassificeerd worden op basis van een thematische analyse.

Resultaten- De meerderheid van de schrijvers was vrouwelijk, hoog opgeleid, tussen 26 en 70 jaar oud, was meer dan 10 keer in het ziekenhuis en heeft over ambivalente verhalen geschreven. De volgende thema's kamen te voorschijn: "Positive assessment of writing", "Negative assessment of writing", "Duty", "Insight", "Higher regard for health", "Change for next patient", "Reliving of emotion", "Self-awareness of emotion", "Closure" and "Relief".

Conclusie- De steekproef was heterogener dan ervoren verwacht. Desondanks waren er meer vrouwen dan manen in dit. De baten van de Patiënten Weten Beter studie (PWB-studie) blijken soortgelijk te zijn op de baten van expressief en therapeutisch schrijven. In totaal 8 van 10 thema's zijn ook terug te vinden in voorafgaand onderzoek met betrekking tot de baten van expressief schrijven Alleen de thema's "Attitude towards writing" en "Duty" zijn niet terug te vinden.. Op basis van dit onderzoek kan worden geconcludeerd dat baten soortgelijk aan expressief en therapeutisch schrijven kunnen met een veel simpelere opbouw bereikt worden.

1 Introduction

Health care systems all over the world are trying to change towards a more patient-centered care (Damman, Hendriks, & Sixma, 2009; Groene, 2011). In the Netherlands the implementation of patient-centered care in the health care system became an important goal as well (Raad voor de Volksgezondheid en Zorg (RVZ), 1998). This shift towards client centeredness can be seen in all aspects of the Dutch health care system (Schoot, 2005). Patient-centered care focuses on the patient and the individual's particular healthcare needs. The main goal of patient-centered care is to help the patients to become active participants in their care (Reynolds, 2009). Supporting this style of patient-centered care is that informed and deciding patients seem to have a higher chance of healing and are more satisfied (Richards, 1999). Additional benefits of patient-centered care are an improved patient satisfaction, a higher physician satisfaction, and fewer malpractice complaints (Oates, Weston, & Jordan, 2000).

In spite of this development toward patient-centeredness there is still a big gap between what the patient expects and what is offered in hospitals (Raad voor de Volksgezondheid en Zorg (RVZ), 2003). The "Raad voor de Volksgezondheid en Zorg" (2003) advises strongly to treat patients as consumers in the Dutch health care system. This is defined as putting the needs of the patient central.

In order to adapt a patient-centered style of health care the patient's expectations, experiences, and opinions have to become a central aspect of research (Sitzia & Wood, 1997). Specifically the aspects of health care, which lead to patient satisfaction, have to be determined. Major advantages in measuring patient satisfaction are: Firstly understanding patients' experiences of health care, secondly promoting cooperation with treatment, thirdly identifying problems in health care, and finally evaluation of health care (Fitzpatrick, 1984).

One way of measuring patient satisfaction is the consumer quality index (CQ-index) (Bos, Sturms, Schrijvers, & van Stel, 2012), which is used to asses patients views of the health care system. The CQ-index is the Dutch national standard to measure healthcare quality from the perspective of healthcare users (Damman, 2010). The CQ-measurement instruments are directed at what patients believe to be important quality-aspects of care and how often these aspects are adhered. Further

aspects are the accessibility of health care and how the patients assess their received treatment (Delnoij & Hendriks, 2008). The index is measured via a multiple-choice questionnaire, in which the participants are given a Likert scale in order to articulate their answers.

A limitation of these questionnaires is that they are often not very specific and therefore not applicable for a deep analysis into how to improve health care. A second problem is that only questions, which are specifically asked, can be answered. Furthermore, dissatisfaction is usually only expressed when an extreme negative event occurs(Klein & Boals, 2001). This kind of research therefore fails at researching the specific needs of the patient (Brown, 2007). Out of these problems came the need for a more qualitative and therefore more patient-centered approach to patient satisfaction research (Avis, Bond, & Arthur, 1997). A further advantage of qualitative research in health care is that it helps in understanding emotions, perceptions and actions of people, who suffer from a medical condition (Holloway, 2005). Most of the qualitative studies regarding health care chose an interview-based approach (Pope, van Royen, & Baker, 2002). These studies appear to be more patient-centered than quantitative research, because they analyses every participant separately and is therefore much more detailed.

To overcome the barriers of quantitative patient satisfaction research the University of Twente conducted in cooperation with the Rathenau Institute research over experiences of patients with the health care system. The Patiënten Weten Beter study (PWB-study), collects since 2012 patient's stories via the website www.patientenwetenbeter.nl (Annex 1. Website Patiënten Weten Beter). The goal of the PWB-study is helping in providing a client-centered framework of the Dutch health care system and providing a place for the patients to be heard. The study is directed at researching patient satisfaction and analyzing the additional benefits of writing in this study. One of the benefits of narrative research might be the possibly added therapeutic effect gained through the writing. The writing in narrative research could provide similar effects than expressive writing (Smyth, 1998). In this case the writing differs from expressive writing, because the writing takes place without a supervisor or therapist, there is only one session of writing and not three or more, and it takes place online. Nevertheless, similar outcomes than with expressive writing might be possible.

Expressive writing is defined as the "client('s) expressive and reflective writing, whether self-generated or suggested by a therapist/researcher" (Wright & Chung, 2001). Expressive writing usually take place under professional supervision and is repeated three or more times (Kacewicz, Slatcher, & Pennebaker, 2007). It is found to have a significant impact on the persons health and well-being if the person writes about a upsetting experience (Pennebaker, 1997). Participants who write about traumatic, stressful or emotional events are found to have an increase in physical and psychological health compared with those who write about neutral topics (Baikie & Wilhelm, 2005). Furthermore, expressive writing has been closely linked with increased insight, self-reflection, optimism, sense of control, and self-esteem in the patient (Esterling, L'Abate, Murray, & Pennebaker, 1999). Another factor how it sometimes effects participants is bringing closure to unresolved issues (Connolly Baker & Mazza, 2004). It has furthermore been linked with an improvement in healthiness and emotional well-being (Lepore & Smyth, 2002). Known disadvantages of expressive and therapeutic writing are an "initial increase in negative mood and a lack of support, information and objective views from others" (McArdle & Byrt, 2001). A further disadvantage of expressive writing is that it does not facilitate helpful coping information (Lowe, 2006).

There are different theories about the mechanisms through which expressive writing is effective. One of the first theories trying to explain of expressive writing was the inhibition theory. This theory is in line with Freud's psychoanalysis and states that expressive writing is beneficial through the expressions of inhibited thoughts about an upsetting event (Frattaroli, 2006). The Cognitive-Processing Theory states however that "the act of making sense of an event, of gaining insight about a trauma, and of organizing and integrating an upsetting experience into one's self-schema is the mechanism" through which expressive writing functions (Pennebaker, 1993). Integrated thoughts and feeling can then be constructed into a coherent narrative and it is then easier to summarize or forget them (Pennebaker & Seagal, 1999). Another explanation is given by the exposure model. Through confronting, describing, and the reliving of thoughts and feelings about the negative experience do these thoughts become extinct(Klein & Boals, 2001). This leads to a kind of closure related to the incident (Lepore, 1997). The exposure model is similar with the inhibition theory in the way that the act of reliving and confronting the incident leads to the benefits of expressive writing.

The Self-Regulation Theory states that expressive writing allows people to observe themselves expressing and controlling their emotions. This leads to a stronger sense of self-efficacy for emotional regulation and therefore to feeling more in control over their stressors(Lepore & Smyth, 2002). Mediators through which expressive writing leads to health benefits may be self-affirmation and cognitive-processing and discovery of meaning (Creswell et al., 2007). Self-affirmation is thereby defined as a positive reflection of a valued self-domain. Cognitive processing includes thinking about the positive aspects of the negative experience. Discovery of meaning includes a positive change in the response of the negative experience (Creswell et al., 2007). These mediators are very much oriented on Pennebaker's (1993) Cognitive-Processing theory. Self-affirmation is basically integration of an upsetting experience into one's self-schema and the mediator "discovery of meaning" is similar to Pennebaker's "act of making sense of an event".

The PWB-study may help in providing a broader and better framework for the quality assessment of the health care system. Narrative research is especially applicable in rather new fields of study (Boulton, Fitzpatrick, & Swinburn, 1996), because the possible answers are not predetermined like in quantitative research. This makes narrative research more patient-centered than quantitative research. The second goal of the PWB-study regards the effects of expressive writing.

In order to assess the relevancy of the findings research about the experience of writing has to be done. For example people over 65, who are responsible for more than half of the hospital visits per year (CBS, 2013), use the internet significantly less (CBS, 2013) and are therefore less likely to post their story. It has been indicated that online counseling clients are typically female (Chester & Glass, 2006), which might be comparable to participating in online, narrative research. Furthermore, Smyth (1998) proposes that men benefit more from written disclosure, because they are less likely than women to naturally disclose information as a result of traditional sex roles. This hypothesis is opposed to the view of (Frattaroli, 2006), who failed to find a difference in effect between men and women. Men seem to be more interested in seeking out information than in seeking emotional support and are less likely to express negative emotions online (Lieberman, 2008). All of these studies suggest that women are more likely to participate in online, narrative writing. Patients participating in expressive writing are likely to have finished college (Frattaroli, 2006) and are therefore rather educated. Most

feedback questionnaires in hospitals are only filled in when a negative experience was made (Klein & Boals, 2001). This might also reflect on online narrative writing. With the goal of assessing if the sample is representative, research over who is most likely to tell their story has to be done. It is possible that some of the benefits will be explained through the characteristics of the sample.

The goal of this study is to analyze how expressive writing in the Dutch health care system may help increasing the patient's health and satisfaction. Through the qualitative approach of this study is it possible to come to more differentiated and personal conclusion in contrast with a quantitative approach.

On the basis of the literature mentioned above a mostly positive impact from writing the story on the website **www.patientenwetenbeter.nl** is to be expected, because the advantages of expressive writing seem to outweigh the disadvantages. On the one hand the patients might be likely to find closure concerning bad experiences in the health care system and on the other hand the belief that they might influence improvement in the treatment of future patients. Another probable effect seems to be increased insight in the own story (Klein & Boals, 2001).

In conclusion, the descriptive statistic part of the study might elaborate on the following topics. Firstly the benefits of the PWB-study might be explained with the composition of the sample. Secondly there might be different benefits for different people. Thirdly the question, which people can be reached with this kind of research, can be answered.

The narrative approach in studying patient satisfaction might be useful for the following reasons. First narrative research helps in giving a voice to the patients. Secondly narrative research might have similar beneficial effects than expressive writing. Thirdly the effects of a narrative online-study have not been researched yet, although the similarity to expressive writing may indicate positive effects.

This led to the following research questions:

- 1. Who writes about their experiences as a patient on the website www.patientenwetenbeter.nl?
- 2. What benefits experience writers, who participate in written, online narrative research?

2 Methods

2.1 PARTICIPANTS

From the 20th April 2012 till the 19th March 2013 a total of 94 participants wrote down their experiences with the Dutch health care system on the website <u>www.patientenwetenbeter.nl</u>. This website was part of a research conducted by the Rathenau Instituut and the University of Twente regarding the improvement of health care system from the perspective of the patients and which roll technology should play in that. The focus group consisted of patients in the Netherlands.

2.2 Instruments

The participants were gained via newspaper advertisement, via online-advertisement and via patient's organizations. The study was conducted on the website www.patientenwetenbeter.nl. This website encourages visitors to write about their experience with the health care system and publishes these stories for others to read. It is possible to comment on these stories and the goals of the study are also explained on the website. The stories were part of a different research and were not discussed in this study. After finishing writing their story about their experience with the health care system, the writer was asked to fill out a short questionnaire with open and multiple-choice questions (Annex 2. Questions Website). The questionnaire contained questions about socio demographic variables about the writer, such as sex, age, education, income, number of hospital visits and experiences with the health care system. In total there were 8 questions on the website regarding the demographic variables. All of the questions were asked in the Dutch language.

Furthermore, the participants were asked to write down their experience with the health care system. "How did you experience the writing of your story?" ("Hoe heeft u het schrijven van uw verhaal ervaren?"). The answers to this question were gathered and analyzed in this study in order to answer the second research questions.

2.3 Data analysis

Firstly the socio demographic data was analyzed via a descriptive analysis. Secondly he answers regarding the writing experience were classified from the researcher into themes and subthemes on the basis of an open thematic analysis. Thematic analysis is used in order to identify, analyze, and report patterns or themes identified in the data. It helps furthermore in organizing and describing the data set in detail (Braun & Clarke, 2006). In this case it was possible for a theme to have sub-themes. Furthermore, the researcher selected quotations in order to clarify the themes and sub-themes, which were identified. It was possible for one answer to be divided into two or more quotations. The minimum length of one quotation was one word and the maximum length was an entire answer. An example for an answer, which was divided into 2 quotations, is:

"Nodig en bevrijdend. Het is goed om frustratie van je af te schrijven."

The quotation "Nodig [...]" was in this case classified into the theme duty and "[...] bevrijdend. Het is goed om frustratie van je aft e schrijven." was scored as part of the theme relief. The code-tree was gained through an inductive analysis of the data. An inductive analysis leads according to Patton (2005) to the development of themes and sub-themes. Themes are thereby defined as reoccurring unifying concepts or statements about the subject of inquiry (Boyatzis, 1998). The answers were also scored independently by the second researcher Johannes Knuewer. The second researcher was only given the answers, not the selective fragments. He was then asked categorize the answers into the themes and sub-themes. First the allocation of the answers into fragments was discussed, until a consensus was reached where each quotation begins and where it ends. Then the classification of each quotation into themes was discussed. As a result the theme duty was added, the other themes and sub-themes were refined and some of the answers were scored differently. If there was a discrepancy in their opinion about the classification, the quotation was discussed until a consensus was reached.

3 Results

3.1 WHO WRITES ABOUT THEIR EXPERIENCES AS A PATIENT ON THE WEBSITE?

In the following the socio demographic variables are described and analyzed in order to gain knowledge, about who is most likely to write about their experience on the website.

The sample in this research was quite heterogeneous, although most of the writers were female (Table 1). Patients out of all age groups participated in this research with most of the writers were between the ages of 26 and 70 and with more people older than 70 than people younger than 26 (Table 1). Most of the stories addressed an ambivalent experience and there was only a small difference between the number of negative and positive experiences with a slight leaning towards negative experiences (Table 2). The writers seemed to be well educated. Almost half of them finished MBO, HAVO or VWO and more than half of the writers finished even HBO, WO or a post academic education (Table 1). Half of the participants visited the hospital more than 10 times (Table 1). The living situations and the income of the writers seem to be very diverse with most of the writers living with a partner (Table 1).

Table 1. Characteristics of the writers (n=94)

Characteristics		n	Percentage*
Sex (n=80)	Female	61	76%
	Male	18	23%
Age (n=80)	<25	3	4%
	26-40	20	25%
	41-55	19	24%
	56-70	24	30%
	Older than 70	14	18%
Highest degree (n=78)	None/ lager/ VMBO	3	4%
	MBO,HAVO, VWO	36	44%
	HBO/WO/Post academic	41	53%
Living situation (n=79)	Single without children	16	20%
,	Single with children	6	8%
	With partner, without children	20	25%
	With partner, children living at	20	25%
	home		
	With partner, children living not at home	12	15%
	Living with (grand-)parents/family	3	4%
	None of the above, namely	2	3%
Monthly after deductions family	500-1000	10	13%
income(in €) (n=78)	1000-2000	13	17%
	2000-3000	13	17%
	3000-4000	12	15%
	>4000	5	6%
	No comment	19	24%
	No idea	6	8%
Country of origin (n=83)	native	77	93%
	foreigner ¹	6	7%
Number of times in the hospital in	0 times	2	3%
the last. 5 years (n=73)	1 time	9	12%
•	2-5 times	24	33%
	5-10 times	7	10%
	More than 10 times	31	43%

^{*} Percentage calculated with valid n.

1 Foreigner, if writer himself or one of his parents was born in a non-western country (Vietnam, Suriname, Indonesia, South-Africa, Myanmar, Brazil)

Table 2. Characteristics of the story (n=100)

Was the experience positive or negative? (n=80) Mostly negative Mostly positive Both positive and negative Neutral neither positive nor	23 19 33	29% 24%
Both positive and negative Neutral neither positive nor	33	
Neutral neither positive nor		
•	_	41%
magatina)	5	6%
negative)		
Characteristics hospital		
Which type of institution is central to the <i>One hospital</i> story? (n=90)	70	71%
More than one hospital	20	20%
Academic of peripheral hospital? (n=85) Peripheral	62	73%
Academic	20	24%
Both peripheral and academic	3	4%
In which province was the hospital? (n=92) Zuid-Holland	22	24%
Noord-Holland	21	23%
Noord-Holland Noord-Brabant	18	20%
Somewhere else in the	27	29%
Netherlands	21	2770
Foreign country ¹	4	4%
Which other organizations are mentioned? Board of complaint/inspection	6	6%
(n=13)# Health insurance firms	5	5%
Patient organization	2	2%
Characteristics treatment/experience	n	%
Does it concern one admission or a admission	60	63%
polyclinic admission? (n=95) Polyclinic admission	35	37%
When did the medical treatment take place? < 1 year ago	42	51%
(n=83) 1-5 years ago	32	39%
Longer than 5 years ago	8	10%

[#] Variable is based on given data ## Variable is filled in by respondent and extended with given data 1 Belgium (2x), Germany, Spain.

Table 2. Characteristics of the story (n=100) (continuing)

Characteristics persons in story		n	%
Which role does the writer have in the story?	Writer is the patient	78	79%
(n=100)##	Writer is the parent of the patient	7	7%
	Writer is partner of patient	5	5%
	Writer is child of patient	4	4%
	Other ³	5	5%
What is the age of the patient? (n=76)##	0-1 year	2	3%
	1-18 years	1	1%
	19-40 years	20	26%
	41-55 years	17	22%
	56-70 years	22	29%
	Older than 70 years	14	18%
Which professions of the nursing staff are mentioned? 2 (n=100)#	Specialist/ doctor-assistant	85	85%
	Nurse	47	47%
	Supporting (e.g. assistant)	16	16%
	$Paramedic (e.g.\ physiotherapist)$	16	16%
	General practitioner	42	42%
	Employee of Medicare/	6	6%
Which other persons (except the writer, the	homecare		
patient and the nursing staff) are mentioned?	Child of patient	15	15%
(n=100)#	Different older patient	7	7%
	Partner of patient	17	17%
	Different patient	9	9%
	Friends/ acquaintance	7	7%
	Parents of patient	4	4%
	Family remaining	8	8%
	Grandparents of patient	2	2%
	Other ⁴	2	2%

[#] Variable is based on given data
Variable is filled in by respondent and extended with given data
2 Regarding that more than one answer was possible, do the percentages not add up till 100%
3 Knowledge (3x), sister-in-law, sister
4 Pastor, companion in misfortune

3.1 Benefits of written, online narrative research

In the following obtained themes and sub-themes are defined and explained with the help of distinctive quotes. The following themes were found "Positive assessment of writing", "Negative assessment of writing", "Duty", "Insight", "Higher regard for health", "Change for next patient", "Reliving of emotion", "Self-awareness of emotion", "Closure", and the theme "Relief". The two sub-themes "Positive assessment of writing" and "Negative assessment of writing" were both classified as part of the theme "Attitude towards writing". The two sub-themes "Higher regard for health" and "Change for next patient" were classified as part of the theme "Discovery of meaning". The two sub-themes "Reliving of emotion" and "Self-awareness of emotion" were classified under the theme "Emotional Response".

3.1.1 ATTITUDE TOWARDS WRITING

The theme "attitude towards writing" is categorized into two sub-themes, namely "positive and negative assessment of writing". This theme does not concern answers about the effects of the writing process, but only feedback if the writers liked or did not like the writing process. Assessment refers to the act of categorizing the writing into positive or negative. The answers are therefore more related to the valence of the writing for the patient.

A positive assessment or evaluation of the writing experiences can be found in many of the answers. The positive assessment is often only one word. The adjectives, which are most used to describe the writing positively are "goed", "pretig", "fijn" and "prima".

The second sub-theme was "negative assessment of writing". This sub-theme occurred significantly less than positive assessment of writing; although some writers mentioned being confronted with negative emotions (see 3.1.5 Emotional Response). In the quotations scored as negative the writers often describe writing as "lastig" and "negatief".

3.1.2 DUTY

The next theme is "duty". Many writers wrote that they had to write their story and that it was necessary for others to know their story. This theme is defined as a sort of a felt moral obligation to society to tell their story. Examples for this are:

"[...] moest gezegd worden." and "[...]Ook zie ik het als een plicht dit soort zaken wereldkundig te maken".

Further adjectives, which are used to express the feeling of duty, are "nodig" and "noodzakelijk". The themes "duty" and the "belief to change something for the next patient" (see 3.1.4 Discovery of meaning) have a strong interrelated connection. Some writers seem to think that it is their duty to prevent things that happened to them from happening again.

3.1.3 Insight

Another reoccurring theme is "insight". Some answers indicate that the writing helps the writer in clarifying the event they write about. The act of insight is defined as restructuring the thoughts over the event and gaining a deep, precise understanding of the event. One example is:

"Verduidelijkend voor mezelf".

This theme includes the notion that through the writing process the patients start thinking about the event and thus gain insight into different connections. Furthermore, the theme insight includes the processing of information in the story e.g.

"[...] dingen van je afschrijven help bij de verwerking".

The writer states in this case that the writing supports him in processing the event. This theme has almost always a positive connotation. Most answers that relate to the concept of insight also emphasize the positive impact of the gaining of insight e.g.

"fijn. vervelende dingen van je afschrijven help bij de verwerking.".

3.1.4 DISCOVERY OF MEANING

"Discovery of meaning" is defined as a positive change as a response to an experience. The theme "discovery of meaning" includes two sub-themes namely the "belief to change something for the next patient" and "placing a higher value on one's health". The "belief to change something for the next patient" is a reoccurring theme in the stories. Many participants state that their reason for writing down their story was trying to improve the conditions for future patients. The following quotation is an example for this:

"Eindelijk een kans dat mijn ervaringen in het ziekenhuis gehoord kunnen worden om verbeteringen door te voeren."

Through improving the situation for the following patient the writer finds a reason why the incident happened to him. Another way through which the patient seems to discover meaning is that they believe the incident led to placing a higher value on their own life. This particular sub-theme occurred very rarely. An example for this theme is:

"[...] Het maakt ook dat ik me extra goed realiseer dat ik volop moet genieten van m'n goede gezondheid!".

3.1.5 EMOTIONAL RESPONSE

The theme "emotional response" can be categorized into two sub-themes, namely "reliving the emotion" and "self-awareness of emotion". Many of the writing experiences include the notion of reliving the emotions of the incident. "Reliving the emotion" is defined as experiencing the same feelings and thoughts during the disclosure like in the original experience. One example is:

"Ik had het niet gedacht, maar de herbeleving wekt toch gevoelens op."

"Reliving the emotion" is thereby the act of placing oneself in the same situation and re-experiencing your response. "Self-awareness of emotion" on the other hand is the act of introspectively recognizing one's emotions. In contrast to the theme "reliving the emotion" the emotion in the theme "self-awareness of emotion" has to be identified and reflected upon. One example is the following quotation:

"Confronterend. Het is half mei gebeurd, maar ik heb er nog zeer regelmatig 'last' van: ben nog steeds heel boos en verdrietig om wat er gebeurd is.".

Another example for the theme "self-awareness of emotion" is:

Het maakte me nu kwader dan op het moment zelf. [...]".

In this example the writer compares feeling during the writing with the feeling he or she had when the actual event took place. The emotions, the writers become aware of most frequently, are anger, fear and sadness.

3.1.6 CLOSURE

The theme "closure" is defined as the act of leaving the subject of the story behind and learning to live with the past. An example for the theme "closure" is:

"Ik ben een beetje mijn woede over de eerste non-behandeling kwijt."

The metaphor of given the story away is thereby used quite often. A reoccurring part of the closure theme is seeing the writing as sort of a finalization of the incident e.g.

"Het was als een soort afronding van een moeilijke periode die op een positieve manier beëindigd wordt."

In this theme the writer indicates that through the writing the patient sort of processes and therefore puts an end to the particular story. This theme is similar to the theme "relief" mentioned below in the way that both themes are concerned with conclusion of the event. The theme "relief" differs in so far from "closure" that the act of leaving the event behind is associated with lightening the mood and positive feelings. "Closure" is thereby sort of the end of the event and "relief" is the alleviation of leaving the event behind.

3.1.7 Relief

The theme "relief" is sort of the act of freeing oneself of the incident and leaving it behind.

The writer experiences thereby a feeling of reassurance and relaxation, because the writer released himself from the negative emotions related to the event. The metaphor of given or writing the story away is thereby used quite often. For example in these answers:

"[...] bevrijdend. Het is goed om frustratie van je af te schrijven." and "Een opluchting en dat ik mn verhaal kwijt kan."

Another reoccurring part of the "relief" theme is seeing the writing as sort of a finalization of the incident e.g.

"Een soort opluchting,dat ik het op deze manier kwijt kan. [...]"

The experience of relief was most regarding the relief from feelings and emotions such as frustration and anger. Furthermore, relief is sometimes directed on the action of leaving the part of his or her life behind, which was the concern of his or her story.

Table 3. Frequency table of themes with corresponding quotes

Theme	Subtheme	Quotation
Attitude towards writing (42,3%)	Positive assessment of writing (35,6%)	Goed om nog eens na te denken over hoe het proces nu precies verlopen is.
		Prima
	Negative assessment of writing (6,7%)	Overwegend negatief
		lastig
Duty (3,5%)		[] moest gezegd worden.
		Nodig []
Insight (4,5%)		Verhelderend []
		Verduidelijkend voor mezelf
Discovery of meaning (14,6%)	Belief to change something for the next patient (13,4%)	Eindelijk een kans dat mijn ervaringen in het ziekenhuis gehoord kunnen worden om verbeteringen door te voeren.
		[] goed in de zin dat mensen hier hopelijk van kunnen leren.
	Higher regard for health (1,2%)	[] Het maakt ook dat ik me extra goed realiseer dat ik volop moet genieten van m'n goede gezondheid!

Table 3. Frequency table of themes with corresponding quotes (continuing)

Theme	Subtheme	Quotation
Emotional response (21,2%)	Reliving of emotion (13,4%)	Ik had het niet gedacht, maar de herbeleving wekt toch gevoelens op
		Hmm, het onmachtige gevoel kwam weer helemaal terug. Ik werd er eigenlijk wel wat emotioneel door. Maar het voelt goed om het hier te kunnen schrijven.
	Self-awareness of emotion (7,8%)	Bij het schrijven van het korte verhaal voel ik weer opnieuw de woede en het verdriet.
	(,,,,,,	Confronterend. Het is half mei gebeurd, maar ik heb er nog zeer regelmatig 'last' van: ben nog steeds heel boos en verdrietig om wat er gebeurd is.
Closure (2,1%)		Het was als een soort afronding van een moeilijke periode []
		Ik ben een beetje mijn woede over de eerste non-behandeling kwijt.
Relief (13,3%)		[] bevrijdend. Het is goed om frustratie van je af te schrijven.
		Een opluchting en dat ik mn verhaal kwijt kan.

4 Discussion

This study tried to answer, who writes about their experiences as a patient on the website www.patientenwetenbeter.nl and what the benefits for writers, who participate in written, online narrative research, are. In the following the expectations of who is most likely to participate are compared to actual results. Furthermore, these results are compared with patients in a Dutch hospital in order to analyze how the characteristics of the group of participants differ from a random group of Dutch patients. Additionally, the possible influence of the sample on the occurrence and characteristics of the themes is discussed.

The amount of women in this research was greater than the average amount of women in a Dutch hospital (CBS, 2013). This was expected, because the literature study showed that women are more likely to participate in this online, narrative story than men. Expressive writing might have different effects on women compared to men. It has been indicated that expressive writing might be more effective for men than for women (Smyth, 1998). The answers in this research including an emotional response could be influenced by the high number of women. Women are significantly more likely to write about feelings like fear and sadness (Mohammad & Yang, 2011; Zakowski et al., 2003).

Most of stories in this study addressed an ambivalent experience and the number of mentioned negative and positive experiences was similar, although a higher number of stories concerning negative experiences than positive experiences was expected based on the literature research. Stories containing moderate expression of negative emotions and high expression of positive emotions have been linked with greater health benefits in other studies(Rivkin, Gustafson, Weingarten, & Chin, 2006). Pennebaker (1997) states that the greatest health benefits come from writing about upsetting experiences, some studies come to the conclusion that writing about positive emotions has the greatest effect (Burton & King, 2009), and furthermore, there are studies, which conclude that writing about upsetting experiences, writing about positive experiences and writing about neutral experiences has the same effect (Sharsky, 1997). This shows that it still not sure, which kind of experience are best to write about, in order to get the greatest health benefits.

The average age of the writers was slightly below the average age of patients in Dutch hospitals, but higher than expected. This could have influenced the results in the way that older people are more satisfied with the nursing staff than younger people(CBS, 2013) and are therefore more likely to write positive reviews. Furthermore, it has been indicated that older people refer more to the present and future (Tausczik & Pennebaker, 2010), which suggests that they feel a greater sense of closure. This could have influenced the outcome in the theme "closure". Nevertheless, the hypothesis that older people would not be reached via the website, because of their lower affinity with the internet, was disproven.

The level of education of the writers in this study appears to be higher than the average level of education of patients in a Dutch hospital as mentioned above. Emotional disclosure might have greater effects on people with a higher education (Junghaenel, Schwartz, & Broderick, 2008). It has been shown that patients, who only finished basis education tend to be less satisfied with their treatment than patients with a higher education (CBS, 2013). Nonetheless has there been research, which indicates that the level of education has no influence on the benefits of expressive writing (Frattaroli, 2006). A higher education has been linked with an increased ability of understanding and insight (Barnett, 1994). The higher level of education might have led to a greater number of answers regarding the theme "insight".

Although the writing in the PWB-study differs from the usually used methods of expressive writing and therapeutic writing on numerous accounts, most mechanisms for expressive writing and therapeutic writing found in the literature were also found in this study. In total 10 different themes, which might be responsible for the benefits of expressive writing, were found. 8 of these 10 themes have been found in prior studies. These findings imply that benefits similar to those of expressive writing are possible with a much simpler method. In the following each theme will be discussed separately.

The theme "attitude towards writing" was found to be the most frequent theme in the answers. This theme relates to the assessment of the writing process after the writing. One reason for the frequency might be that it is one of the easiest answers to give with the lowest amount of reflectiveness. Most of the writers evaluated the writing thereby positively. No research has been done

yet regarding to which extent the appraisal of the writing process influences the benefits of expressive writing. This factor is important, because on the one hand people, who have a positive attitude towards writing, are more likely to participate in this kind of narrative research and on the other hand the benefit of expressive writing might be influenced by believing in its benefits (Frattaroli, 2006). Therefore people, who evaluate the writing positively might have greater benefits, and on the contrary people, who evaluate the writing negatively, might gain less through the writing process.

A reoccurring theme, which was found in this study, was the theme "duty". Many writers stated that they had to tell their story, some in order to help future patients. The theme duty is thus strongly connected with the discovery of meaning's sub-theme the belief to change something for the next patient. Nevertheless, not all writers link the fact that they see it as a duty with a discovery of meaning. This theme has not been mentioned in prior research regarding the mediators of expressive writing. One reason for this might be that the theme duty is mostly specifically related to expressive writing, where the stories are processed in order to change something. In this case that is the belief that through writing their story they can help in improving the health care system.

An important theme found in this study was the theme "insight". Written experiences with words that imply insight are shown to have greater health benefits with people, who are trying to adjust to HIV(Rivkin et al., 2006). Furthermore, expressive writing and clarity have been closely associated. Clarity is likely a result of gained insight (Pennebaker, 2004). Writing can also lead to an increase in self-understanding and clarification (Connolly Baker & Mazza, 2004). The cognitive processing theory states that expressive writing helps the writers in reorganizing their thoughts and feelings into a more coherent and meaningful narrative (Pennebaker & Seagal, 1999). In order to reach a coherent narrative the writer has to gain insight into his own thoughts and feelings. Gaining of insight is therefore a possible mediator for the benefits of expressive writing.

Some of the answers stated that the writing led them to a "discovery of meaning" of the described event. Pennebaker and Chung (2007) found that most writers state that the writing leads to a greater "meaningfulness in their lives". It has furthermore been shown that the discovery of meaning indicates a successful reconciliation of the traumatic event (Bower, Kemeny, Taylor, & Fahey, 2003; Westling & Mann, 2005). Finding benefits in the event may lead to a discovery of meaning in one's

life (Hemenover, 2003). It has furthermore been show that the discovery of meaning in the experience leads to a less rapid course of illness in men infected with HIV (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). The belief to change something for the next patient may lead to self-enhancing views, which protect against effects of threatening events such as stress. It has been show that this protection positively affects mental and physical health (Taylor et al., 2000). This hypothesis is supported through the findings of Bonnano, Rennicke and Dekel (2005), which states that people with higher positive self-views seem to have less stress and a lower biological responses to stress.

The theme "reliving of emotion" was a reoccurring theme in the answers. Some writers describe the act of reliving the incident as their primary experience triggered by the writing of their story. The theme of reliving is also an important part of the exposure theory. This theory states that through reliving thoughts and feelings about a negative experience these thoughts and feelings become extinct (Nicholls, 2009). Gaining closure has been associated with repeated exposure to the incident, including thoughts and behavior (Lepore, 1997).

The theme "self-awareness of emotion" was a reoccurring theme in the answers. Rivkin et al. (2006) found out that expressive writing usually leads to an increase in self-awareness. Self-awareness is furthermore a factor in learning to effectively regulate emotions (Watkins, 2004). Expressive writing specifically increases emotional awareness (Thatcher & Day, 2012; Warner et al., 2006). Furthermore, the suppression of emotion, which is neutralized by the self-awareness of emotion, has been linked with negative effects on physical health, such as an increased heart rate (Esterling et al., 1999). This theme is in line with the inhibition-theory. This theory states that through writing about of inhibited thoughts about an upsetting event the writer becomes aware of these thoughts and this in turn leads to the health benefits of expressive writing (Frattaroli, 2006). The definition of the theme self-awareness in this study differs therefore from the definition in the other studies. In this study self-awareness was always related to emotion and never to thoughts. In the other studies the theme self-awareness contained answers regarding the reflection of their own thoughts.

The theme "closure" was found in some of the answers. Thatcher and Day (2012) concluded from their study that expressive writing increases the chance of closure. Closure leads furthermore to a new perspective on future events (Spera, Buhrfeind, & Pennebaker, 1994). Moreover does written

disclosure sometimes facilitate emotional closure (Snyder, Gordon, & Baucom, 2004). All of these three studies, regarding closure, found that closure leads to the act of moving on. Nevertheless it is important to mention that this theme occurred very rarely in contrast with these three studies.

The theme "relief" was a reoccurring theme in the answers regarding the writing experience. Gellaitry, Peters, Blomefeld and Horne (2010) and Unsworth, Rogelberg and Bonilla (2010) found the theme "relief" to be frequent in their research. Writing over a traumatic experience can bring relief (Carroll, 2005). In Carroll's study (2005) most of the writers stated that relief was the result of dealing with the incident. This was not the case in this study, although it is a plausible explanation. In this study most writers connect the theme relief with the metaphor of giving the story away or leaving incident behind.

Themes, which were not found in this study, but were expected occur in the answers were the themes "confronting of a trauma" and "self-affirmation". The theme "confronting of a trauma" is an important part of the exposure model of expressive writing (Klein & Boals, 2001). The theme "confronting" is defined as facing the trauma and dealing with it. The themes found in this study, which are most similar to the "confronting of thoughts", are the theme "self-awareness of emotion" and the theme "reliving of emotion". The difference between these themes is that "self-awareness of emotion" and "reliving of emotion" are only concerned with the emotions of the writer and not with the entirety of his thoughts. A reason why the theme "confronting of a trauma" was not found in this research might that all writers decided on their own that they wanted to participate. The participants are therefore likely to have been confronted with the topic of their story, because it would have been otherwise unlikely that they decided to participate in this research. Therefore part of the confrontation might have taken place before the writing process. Additionally, it is likely that most of the participants did not experience a trauma, which they could confront.

The theme "self-affirmation" was also not found in this study. Self-affirmation is defined as a positive reflection of a valued self-domain (Creswell et al., 2007). The only theme, which is connected to the theme "self-affirmation", is the "belief to change something for the next patient". This theme covers only a very specific aspect of the theme "self-affirmation". One reason why almost no notion of

self-affirmation found in the answers might be that most of the writers only participated once and therefore were not able to judge their development over a longer period of time.

4.1 LIMITATIONS

A limitation of this study is the process of selection of the writers via the website. This process of selection fails to reach some patients and leads to giving some groups of patients a greater importance. For example patients without an internet access are not given a voice in this research. In order to minimalize and understand the effects of the selection process the influence of the sample on the themes and the benefits of expressive writing had to be examined. It might be possible that through different kind of advertising or a different kind of research people, who were not reached in this study, could be reached. The people, who were reached by this study, seem to benefit greatly nonetheless.

4.2 Suggestions for Further Research

Through the results of this study many mechanisms, which might explain the benefits of expressive writing, were found. Two of the ten themes found in this research have not been linked with expressive writing before. These two themes are the attitude towards writing and the theme duty. Future research has to be done in order to confirm that these two themes reoccur under similar circumstances and that these two themes mediate the benefits of expressive writing. Following research should furthermore link the descriptive variables with found themes in order to assess the influence of group of respondents on the results. In this way connections between gender or the valence of the story and the different mechanisms through which expressive writing might lead to health benefits can be analyzed more easily. On the basis of this research one can conclude that a further advantage of narrative research is the benefits similar to expressive writing. Therefore it is advised for further research to take a qualitative, narrative methodology into consideration. Future research should furthermore be directed at how the health benefits are achieved.

4.3 CONCLUSION

In summary this study found a large number of similarities between the effects of participating in the PWB-study and expressive and therapeutic writing. This fact is astonishing, because of the much simpler set-up of the PWB-study. Expressive writing usually take place under professional supervision and is repeated three or more times. All of this was not the case in this study. Furthermore, two new themes were found, which might impact the healing process, namely "Attitude towards writing" and "Duty". In how far they are responsible for some of the benefits of expressive writing has to be determined. All in all the PWB-study seemed to reach many different groups of people, but some populations are underrepresented. For these groups a different approach might make sense. For most of the people, who participated in this study, the writing seemed to be beneficial nevertheless.

ACKNOWLEDGEMENTS

This bachelor-thesis has been written with the great support of quite a few people. I am hereby articulation my gratitude for their help and feedback throughout the development and execution of my bachelor thesis. Firstly I would like to thank my supervisors Dr. C.H.C. Drossaert and Dr. A. M. Sools. Without their assistance this bachelor thesis would not have been possible. Secondly I would like to thank Johannes Knuewer, who was the second researcher in this study. He spent a lot of time with the coding of the answers into themes, discussing our findings. His tireless work and the offering of a fresh perspective greatly improved the outcome of this study. Thirdly I would like to thank my housemates, who supported me morally throughout the whole process.

References

- Avis, M., Bond, M., & Arthur, A. (1997). Questioning patient satisfaction: an empirical investigation in two outpatient clinics. *Social Science & Medicine*, 44(1), 85-92.
- Baikie, K. A., & Wilhelm, K. (2005). Emotional and physical health benefits of expressive writing. *Advances in Psychiatric Treatment*, 11(5), 338-346.
- Barnett, R. (1994). *The Limits of Competence: Knowledge, Higher Education and Society*. Bristol: Society for Research into Higher Education & Open University Press.
- Bonanno, G. A., Rennicke, C., & Dekel, S. (2005). Self-enhancement among high-exposure survivors of the September 11th terrorist attack: Resilience or social maladjustment? *Journal of Personality and Social Psychology*, 88(6), 984.
- Bos, N., Sturms, L., Schrijvers, A., & van Stel, H. (2012). The consumer quality index (CQ-index) in an accident and emergency department: development and first evaluation. *BMC Health Services Research*, 12(1), 284.
- Boulton, M., Fitzpatrick, R., & Swinburn, C. (1996). Qualitative research in health care: II. A structured review and evaluation of studies. *Journal of evaluation in clinical practice*, 2(3), 171-179.
- Bower, J. E., Kemeny, M. E., Taylor, S. E., & Fahey, J. L. (2003). Finding positive meaning and its association with natural killer cell cytotoxicity among participants in a bereavement-related disclosure intervention. *Annals of Behavioral Medicine*, 25(2), 146-155.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*: SAGE Publications, Incorporated.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Brown, C. R. (2007). Where are the patients in the quality of health care? *International Journal for Quality in Health Care*, 19(3), 125-126. doi: 10.1093/intqhc/mzm009
- Burton, C. M., & King, L. A. (2009). The health benefits of writing about positive experiences: The role of broadened cognition. *Psychology and Health*, 24(8), 867-879.
- Carroll, R. (2005). Finding the words to say it: the healing power of poetry. *Evidence-based Complementary and Alternative Medicine*, 2(2), 161-172.
- CBS. (2013). Statistisch Jaarboek 2013 (2013 ed.). Den Haag: Centraal Bureau voor de Statistiek; Den Haag.
- Chester, A., & Glass, C. A. (2006). Online counselling: A descriptive analysis of therapy services on the Internet. *British Journal of Guidance & Counselling*, 34(2), 145-160.
- Connolly Baker, K., & Mazza, N. (2004). The healing power of writing: Applying the expressive/creative component of poetry therapy. *Journal of Poetry Therapy*, 17(3), 141-154.
- Creswell, J. D., Lam, S., Stanton, A. L., Taylor, S. E., Bower, J. E., & Sherman, D. K. (2007). Does self-affirmation, cognitive processing, or discovery of meaning explain cancer-related health benefits of expressive writing? *Personality and Social Psychology Bulletin*, *33*(2), 238-250.
- Damman, O. (2010). Public Reporting about Healthcare Users' Experiences: the Consumer Quality Index: Nivel.
- Damman, O., Hendriks, M., & Sixma, H. J. (2009). Towards more patient centred healthcare: A new Consumer Quality Index instrument to assess patients' experiences with breast care. *European Journal of Cancer*, 45(9), 1569-1577.
- Delnoij, D., & Hendriks, M. (2008). De CQ-index: het meten van klantervaringen in de zorg. *TSG*, 86(8), 440-446.
- Esterling, B. A., L'Abate, L., Murray, E. J., & Pennebaker, J. W. (1999). Empirical foundations for writing in prevention and psychotherapy: Mental and physical health outcomes. *Clinical psychology review*, 19(1), 79-96.
- Fitzpatrick, R. (1984). Satisfaction with health care. *The experience of illness. London: Tavistock*, 154-175.
- Frattaroli, J. (2006). Experimental disclosure and its moderators: a meta-analysis. *Psychological bulletin*, 132(6), 823.

- Gellaitry, G., Peters, K., Bloomfield, D., & Horne, R. (2010). Narrowing the gap: The effects of an expressive writing intervention on perceptions of actual and ideal emotional support in women who have completed treatment for early stage breast cancer. *Psycho-Oncology*, 19(1), 77-84.
- Groene, O. (2011). Patient centredness and quality improvement efforts in hospitals: rationale, measurement, implementation. *International Journal for Quality in Health Care*, 23(5), 531-537.
- Hemenover, S. H. (2003). The good, the bad, and the healthy: Impacts of emotional disclosure of trauma on resilient self-concept and psychological distress. *Personality and Social Psychology Bulletin*, 29(10), 1236-1244.
- Holloway, I. (2005). Qualitative research in health care: McGraw-Hill International.
- Junghaenel, D. U., Schwartz, J. E., & Broderick, J. E. (2008). Differential efficacy of written emotional disclosure for subgroups of fibromyalgia patients. *British journal of health psychology*, *13*(1), 57-60.
- Kacewicz, E., Slatcher, R. B., & Pennebaker, J. W. (2007). Expressive Writing: An Alternative to Traditional Methods* *Low-cost approaches to promote physical and mental health* (pp. 271-284): Springer.
- Klein, K., & Boals, A. (2001). Expressive writing can increase working memory capacity. *Journal of Experimental Psychology General*, 130(3), 520-533.
- Lepore, S. J. (1997). Expressive writing moderates the relation between intrusive thoughts and depressive symptoms. *Journal of Personality and Social Psychology*, 73, 1030-1037.
- Lepore, S. J., & Smyth, J. M. (2002). *The writing cure: How expressive writing promotes health and emotional well-being*: American Psychological Association Washington, DC.
- Lieberman, M. A. (2008). Gender and online cancer support groups: issues facing male cancer patients. *Journal of cancer education*, 23(3), 167-171.
- Lowe, G. (2006). Health-related effects of creative and expressive writing. *Health education*, 106(1), 60-70.
- McArdle, S., & Byrt, R. (2001). Fiction, poetry and mental health: expressive and therapeutic uses of literature. *Journal of Psychiatric and Mental Health Nursing*, 8(6), 517-524.
- Mohammad, S. M., & Yang, T. W. (2011). *Tracking sentiment in mail: how genders differ on emotional axes*. Paper presented at the Proceedings of the 2nd Workshop on Computational Approaches to Subjectivity and Sentiment Analysis (ACL-HLT 2011.
- Nicholls, S. (2009). Beyond expressive writing evolving models of developmental creative writing. *Journal of health psychology, 14*(2), 171-180.
- Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *Fam Pract*, 49, 796-804.
- Patton, M. Q. (2005). Qualitative research *Encyclopedia of Statistics in Behavioral Science*: Wiley Online Library.
- Pennebaker, J. W. (1993). Putting stress into words: Health, linguistic, and therapeutic implications. *Behaviour research and therapy*, 31(6), 539-548.
- Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science*, 8(3), 162-166.
- Pennebaker, J. W. (2004). Writing to heal: A guided journal for recovering from trauma & emotional upheaval: New Harbinger Publications Oakland.
- Pennebaker, J. W., & Chung, C. K. (2007). Expressive writing, emotional upheavals, and health. *Foundations of health psychology*, 263-284.
- Pennebaker, J. W., & Seagal, J. D. (1999). Forming a story: The health benefits of narrative. *Journal of clinical psychology*, 55(10), 1243-1254.
- Pope, C., van Royen, P., & Baker, R. (2002). Qualitative methods in research on healthcare quality. *Quality and Safety in Health Care*, 11(2), 148-152.
- Raad voor de Volksgezondheid en Zorg (RVZ). (1998). Naar een meer vraaggerichte zorg (Towards increased demand-orientedness). Zoetermeer: Raad voor de Volksgezondheid.
- Raad voor de Volksgezondheid en Zorg (RVZ). (2003). Van patiënt tot klant (From patient to client).
- Reynolds, A. (2009). Patient-centered Care. Radiologic Technology, 81(2), 133-147.

- Richards, T. (1999). Patients' priorities: Need to be assessed properly and taken into account. *BMJ: British Medical Journal*, *318*(7179), 277.
- Rivkin, I. D., Gustafson, J., Weingarten, I., & Chin, D. (2006). The effects of expressive writing on adjustment to HIV. *AIDS and Behavior*, 10(1), 13-26.
- Schoot, T. I. R. W. L. (2005). Recognition of client values as a basis for tailored care: the view of Dutch expert patients and family caregivers. [Article]. *Scandinavian Journal of Caring Sciences*, 19(2), 169-176. doi: 10.1111/j.1471-6712.2005.00327.x
- Sharsky, M. (1997). Emotional consequences of written expression of traumatic and positive experiences. ProQuest Information & Learning.
- Sitzia, J., & Wood, N. (1997). Patient satisfaction: a review of issues and concepts. *Social Science & Medicine*, 45(12), 1829-1843.
- Smyth, J. M. (1998). Written emotional expression: Effect sizes, outcome types, and moderating variables. *Journal of Consulting and Clinical Psychology*, 66(1), 174-184.
- Snyder, D. K., Gordon, K. C., & Baucom, D. H. (2004). Treating affair couples: Extending the written disclosure paradigm to relationship trauma. *Clinical Psychology: Science and Practice*, 11(2), 155-159.
- Spera, S. P., Buhrfeind, E. D., & Pennebaker, J. W. (1994). Expressive writing and coping with job loss. *Academy of Management Journal*, *37*(3), 722-733.
- Tausczik, Y. R., & Pennebaker, J. W. (2010). The psychological meaning of words: LIWC and computerized text analysis methods. *Journal of Language and Social Psychology*, 29(1), 24-54
- Taylor, S. E., Kemeny, M. E., Reed, G. M., Bower, J. E., & Gruenewald, T. L. (2000). Psychological resources, positive illusions, and health. *American Psychologist*, 55(1), 99-109.
- Thatcher, J., & Day, M. C. (2012). Athletes' experiences of expressive writing about sports stressors. *Psychology of Sport and Exercise*.
- Unsworth, K. L., Rogelberg, S. G., & Bonilla, D. (2010). Emotional expressive writing to alleviate euthanasia-related stress. *The Canadian Veterinary Journal*, *51*(7), 775.
- Warner, L. J., Lumley, M. A., Casey, R. J., Pierantoni, W., Salazar, R., Zoratti, E. M., . . . Simon, M. R. (2006). Health effects of written emotional disclosure in adolescents with asthma: A randomized, controlled trial. *Journal of Pediatric Psychology*, 31(6), 557-568.
- Watkins, E. (2004). Adaptive and maladaptive ruminative self-focus during emotional processing. *Behaviour research and therapy*, 42(9), 1037-1052.
- Westling, E., & Mann, T. (2005). Effects of cognitive processing and discovery of meaning on medication adherence in HIV-positive adults. *Unpublished manuscript, University of California, Los Angeles*.
- Wright, J., & Chung, M. C. (2001). Mastery or mystery? Therapeutic writing: A review of the literature. *British Journal of Guidance and Counselling*, 29(3), 277-291.
- Zakowski, S. G., Harris, C., Krueger, N., Laubmeier, K. K., Garrett, S., Flanigan, R., & Johnson, P. (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *British journal of health psychology*, 8(3), 271-286.

Annexes

1. Website Patiënten Weten Beter



2. QUESTIONS WEBSITE

EXTRA VRAGEN

Nu volgen 8 korte vragen over het verhaal en uw ervaring met het schrijven. Het invullen hiervan duurt ongeveer 5 minuten.

Als u de vragen liever niet invult ga dan naar "opslaan en verder" onderaan de pagina

- 1. Hoe heeft u het schrijven van uw verhaal ervaren?
- 2. Hoe groot acht u de kans dat uw wens ook gerealiseerd gaat worden? Geef een cijfer van 1 (zeer kleine kans) tot 10 (zeer grote kans) toelichting
- 3. Wat is er voor nodig om de wens die u uitsprak aan het einde van uw verhaal ook echt te laten uitkomen?
- 4. Hoe waardeert u. alles overziend, uw verhaal?
- Overwegend positief
- Overwegend negatief
- Gemengd: positief en negatief
- Neutraal: niet specifiek positief of negatief
- 5. Wanneer speelde de gebeurtenis in uw verhaal?
- In de afgelopen 12 maanden
- Tussen 1 en 5 jaar geleden
- Langer dan 5 jaar geleden
- 6. Vink aub aan welke van onderstaande onderwerpen van toepassing zijn op uw verhaal Er zijn meerdere opties mogelijk
- kundigheid zorgverlener(s)
- informatie door zorgverlener(s)
- bejegening door zorgverlener(s)
- afstemming tussen zorgverleners onderling
- vertrouwen
- respect
- privacy
- veiligheid
- inspraak
- bureaucratie
- technologie
- service/klantgerichtheid
- anders, namelijk

- 7. Hieronder volgen enkele vragen over de aandoening of ziekte die in uw verhaal centraal staat.
- a. Welke ziekte of aandoening staat centraal in uw verhaal?
- b. Betreft het de ziekte van uzelf of van een ander?
- Ziekte van mezelf
- Ziekte van een ander, namelijk
- 8. Tenslotte volgen nog enkele vragen over het ziekenhuisbezoek:
- a. Heeft uw verhaal betrekking op een opname (minstens 1 overnachting in het ziekenhuis) of een poliklinisch bezoek (geen overnachting)?
- Een opname
- Poliklinisch
- b. Op welke afdeling of welk vakgebied heeft uw verhaal betrekking? (bijvoorbeeld chirurgie, oncologie, kindergeneeskunde, etc.)
- c. Over welk soort ziekenhuis gaat uw verhaal?
- Een academisch ziekenhuis
- -Een regulier ziekenhuis
- d. In welke provincie ligt het ziekenhuis waar uw verhaal zich afspeelt?
- Limburg
- Noord-Brabant
- Zeeland
- Gelderland
- Utrecht
- Zuid-Holland
- Noord-Holland
- Overijssel
- Drenthe
- Friesland
- Groningen
- Flevoland
- Het ziekenhuis lag in het buitenland, namelijk...

Vragen over uw achtergrond (persoonsgegevens van de schrijver)

Wij zouden het erg op prijs stellen als u tot slot enkele persoonlijke gegevens invult, zodat we kunnen vergelijken op welke punten verhalen van elkaar verschillen en overeenkomen. Deze gegevens zullen anoniem en vertrouwelijk behandeld worden. Ze zullen niet doorgegeven worden aan derden. Mocht u er bezwaar tegen hebben, dan kunt u ervoor kiezen de gegevens niet in te vullen of vragen over te slaan.

- 1.Sekse
- Man
- Vrouw

2. Leeftijd:

- 3. Wat is het hoogste diploma dat u behaalde?
 - geen onderwijs
- lager onderwijs
- voorbereidend beroepsonderwijs (VMBO)
- middelbaar beroepsonderwijs (MBO)
- voorbereidend wetenschappelijk onderwijs (HAVO en VWO)
- hoger beroepsonderwijs (HBO)
- hoger wetenschappelijk onderwijs (universiteit)
- postacademisch (bijvoorbeeld notariaat, doctorstitel, artsexamen)
- Anders, namelijk
- 4. Hoe is uw huidige woonsituatie?
 - Alleenstaand zonder kinderen
 - Alleenstaand met thuiswonende kinderen
 - Alleenstaand met zelfstandig wonende kinderen
- Samenwonend/getrouwd zonder kinderen
- Samenwonend/getrouwd met thuiswonende kinderen
- Samenwonend/getrouwd met zelfstandig wonende kinderen
- Inwonend bij (groot)ouder(s)/familie
- Inwonend met (kind(eren) bij (groot)ouder(s)/familie
- Anders, namelijk
- 6. Wat is uw maandelijks netto-gezinsinkomen?
- < 500 euro
- 500-1000 euro
- 1000-2000 euro
- 2000-3000 euro
- 3000-4000 euro
- > 4000 euro
- Dat zeg ik liever niet
- Geen idee
- 7. Nationaliteit

Ik ben geboren in (land):

Mijn moeder is geboren in (land):

Mijn vader is geboren in (land):

- 8. Hoe vaak bent u in het ziekenhuis geweest in de afgelopen 5 jaar?
 - 0 keer
- 1 keer
- 2-5 keer
- 5-10 keer
- Vaker dan 10 keer