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## Just a click away... E-mental health for eating disorders

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## Chapter 3

**Internet and patient empowerment in individuals with symptoms of an eating disorder: A cross-sectional investigation of a pro-recovery focused e-community**

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## Abstract

**Introduction:** Many individuals with eating disorder problems seek information and support online. There are however numerous websites that promote eating disordered behaviors. The website and e-community 'Proud2Bme' was developed as a healthy alternative for pro-eating disorder websites, providing a safe, positive, and pro-recovery focused environment. It offers a wide array of information and personal stories, as well as platforms for interaction such as a forum and chat. The first aim of this study was to investigate whether, and to what extent, empowering processes and outcomes are experienced by participants on Proud2Bme. The second aim was to examine correlates of empowering processes and outcomes.

**Methods:** Participants ( $n = 311$ ) were recruited via an online survey on Proud2Bme. Correlations were examined and *T*-tests and ANOVAs were conducted.

**Results:** Exchanging information, finding recognition, and sharing experiences were the empowering processes most often reported by participants. The most pronounced empowering outcome was feeling better informed. To a smaller degree, increased help-seeking behavior, increased optimism and control over the future, and increased confidence in treatment and the relationship with the therapist were reported. Lower levels of general empowerment, younger age, and more interactive usage patterns of the website were positively associated with the experience of empowering processes and outcomes.

**Discussion:** Offering a platform where individuals can share their experiences and find recognition might be one of the most important ingredients for successful e-health initiatives aimed at improving patient empowerment. Moreover, in the field of eating disorders specifically, such initiatives offer a healthy alternative to the harmful and negative effects of pro-eating disorder websites.

## Introduction

The Internet is a dynamic and continually evolving medium that has become an important source of health information (Kummervold et al., 2008). In 2007, 83.5% of young women in Europe used the Internet for health purposes. The current percentage probably is even higher, given that the number of Internet users continues to grow: between 2007 and 2012 the number of Internet users in Europe has gone from approximately 322 million to 519 million, a 61% increase (Internet world stats, 2012).

By using the Internet as an important means of seeking and retrieving health information and of seeking and providing support, individuals can take a more active and self-managing role in their own healthcare. Health self-management and patient empowerment are closely related concepts. Although the concept of patient empowerment is not a well-defined construct and many definitions exist, most definitions focus on individuals' capacity to make decisions about their health and to have, or take control over aspects of their lives that relate to health (McAllister, Dunn, Payne, Davies, & Todd, 2012). Targeting patient empowerment is important, as it can heighten the quality of care and is of interest in reducing economic costs of healthcare. As stated by Wallerstein in a World Health Organization report (2006), empowerment strategies can lead to outcomes as ends in themselves, but can also serve as intermediate steps to health outcomes. Wallerstein (2006) concluded that targeting patient empowerment can lead to improved self-regulated disease management, more efficient use of health services and improved mental health outcomes.

This article builds on the empowerment construct developed by van Uden-Kraan et al. (2008), who distinguish between empowering processes and outcomes. Empowering processes can be defined processes by which individuals take control over their lives and the management of their disease (Menon, 2002), such as exchanging information and helping others. Empowering outcomes refer to states of feeling psychologically enabled, such as improved acceptance of the illness or an increased sense of optimism and control over the future. Van Uden-Kraan et al. (2008) found that patients with breast cancer, arthritis, and fibromyalgia who participated in online patient support groups experienced a range of empowering processes and outcomes as a result of their participation. Comparable results were found in a group of participants using an online support group for individuals with a chronic physical illness (Bartlett & Coulson, 2011).

The development of empowering strategies as websites and e-communities in the field of eating disorders seems especially important in light of the existence of many pro-eating disorder websites that serve as portals to connect people who suffer from disordered eating, encouraging disordered eating behaviors (Rouleau & von Ranson,

2011). Rouleau et al. (2011) in a review on pro-eating disorder websites concluded that although such websites often contain potentially harmful components, users perceive social support as one of the key functions of pro-eating disorder websites. Indeed, commonly reported reasons for visiting pro-eating disorder websites are a desire for support, interaction with others, and meeting others with an eating disorder (Csipke & Horne, 2007; Wilson, Peebles, Hardy, & Litt, 2006). It is therefore important to develop e-health initiatives that can fulfill these same desires, however in a reliable, healthy, positive, and recovery-focused manner instead of a potentially harmful one.

In May of 2009, a Dutch website called Proud2Bme (<http://www.Proud2Bme.nl>) was launched as a healthy alternative to pro-eating disorder websites. Proud2Bme offers a wide array of information and provides a social e-community to open up communication about eating disorders with peers, family, and health care professionals. It offers anonymous and low-threshold support and aims to increase empowerment, by raising awareness and creating acknowledgement, as well as enhancing self-management and promoting and facilitating help-seeking behavior. The website has become a popular e-community for individuals with eating problems. To date the effects of visiting a pro-recovery e-community like Proud2Bme on patient empowerment have not been investigated.

The first aim of this study was to investigate whether, and to what extent, specific empowering processes and outcomes are experienced on Proud2Bme. The second aim was to explore potential correlates of empowering processes and outcomes. The following variables were selected as potential correlates: age, eating psychopathology, general empowerment, symptom duration, treatment status, user activity, time since first visit, and interactivity of use. Regarding the latter, it has been found that individuals who do not actively participate (so-called lurkers) in online support groups for HIV/AIDS as well as for breast cancer, fibromyalgia and arthritis, reported less empowerment in terms of social wellbeing and receiving useful information and social support (Mo & Coulson, 2010; van Uden-Kraan, Drosseart, Taal, Seydel, & Van de Laar, 2008).

## **Method**

### **Recruitment, procedure and design**

Proud2Bme was launched in May 2009. Proud2Bme is an interactive e-community aimed at empowering individuals with symptoms of an eating disorder and promoting a positive body image and healthy lifestyle. It offers a wide array of information, personal stories, and experiences about eating disorders, as well as platforms for interaction by means of a forum and group chats, and blogs that cover everything from health, beauty, news, and

entertainment. Everyday, new blogs and input are published on the website. Visitors can furthermore interact with peers, psychologists, dieticians and expert patients. Expert patients are individuals who have experienced eating disorder problems themselves, but who have recovered and who can subsequently use their knowledge and skills to help others who experience eating disorder problems. Daily group chats are moderated by a psychologist, an expert patient or a dietician. Weekly moderated thematic group chats are arranged discussing all kinds of topics, for example binge eating, eating disorders and personality disorders, family problems, and fear of weight gain. All posted input on the website is moderated by employees of our center. This makes Proud2Bme a safe, positive, and pro-recovery environment where individuals can anonymously share their problems and find support and recognition. Because all content is moderated, the quality of the material posted is high and reliable. Any threatening, destructive, or negative comments, tips, or advice are deleted from the website. Visitors to the e-community automatically have access to all content without having to register or login, except for forum- and chat activities, for which one has to follow a simple registration procedure.

Participants were recruited between May and July 2012 by presenting a link on the homepage to an online survey. Any visitor who indicated having eating problems was eligible to participate in the study. No ethical approval was required because this study only included questionnaires and could be completed voluntarily and anonymously: no personal health information could be connected to specific persons (i.e. IP addresses were deleted).

### **Measures (online survey)**

#### *Socio-demographic and descriptive information*

Participants were asked to provide information about socio-demographic characteristics, including age, gender, and level of education. Furthermore participants were asked about their usage patterns on the website, their reasons for visiting the website, their satisfaction with the website, the duration of their eating disorder symptoms (derived by asking participants when (year and month) they first suspected they had an eating disorder problem), as well as their treatment status.

#### *Eating psychopathology*

The Eating Disorder Examination Questionnaire (EDE-Q) (Fairburn & Beglin, 2008) is a self-report questionnaire measuring eating psychopathology. It assesses both the frequency of core eating disordered behaviors and the core attitudinal features of eating psychopathology over the past 28 days. Items assessing the latter are answered on a 7-

point Likert scale and include questions about restraint, concerns about weight, concerns about shape, and concerns about eating. A global mean score of eating psychopathology was calculated by summing and averaging all attitudinal items. Higher scores reflect greater eating psychopathology. The EDE-Q has demonstrated reliability and validity (see Berg et al. (2011) for a review). This study demonstrated the internal consistency of the EDE-Q global score to be excellent ( $\alpha = .94$ ), in line with an earlier study by our research group (Aardoom, Dingemans, Slof Op't Landt, & van Furth, 2012).

*Empowering processes and outcomes as a result of visiting the website*

A questionnaire developed by van Uden-Kraan et al. (2009) was used to assess the experience of empowering processes and outcomes as a result of visiting Proud2Bme, asking individuals how frequently they experienced empowering processes on the website. The questionnaire assesses five types of processes: 'exchanging information' (nine items), 'exchanging social support' (twelve items), 'finding recognition' (four items), 'helping others' (two items), and 'sharing experiences' (two items). Based on an earlier study by van Uden-Kraan et al. (2008), we added a sixth empowering process: 'entertainment' (four items). All items could be answered on a 4-point Likert scale, ranging from 'seldom or never' to 'often'. Example items are: "How often does it happen on Proud2Bme that you experience the sense of 'not being the only one?'" (finding recognition) and "How often does it happen on Proud2Bme that someone pays you a compliment?" (exchanging social support). Mean scores per process were calculated. Consistent with van Uden-Kraan et al. (2009), most empowering process scales showed good internal consistency (Cronbach's  $\alpha$  range .76 - .95), except for the process 'finding recognition' (Cronbach's  $\alpha$  .64). One item ("Does it ever happen that by visiting the website you realize that you are not so bad off after all?") was removed from this subscale, given that this resulted in an acceptable Cronbach's  $\alpha$  of .72.

Empowering outcomes were measured by 38 items in the form of statements that began with 'Through my visit of the website...'. Seven types of outcomes were assessed: 'feeling better informed' (four items), 'improved acceptance of the illness' (five items), 'increased optimism and control over the future' (eight items), 'enhanced self-esteem' (three items), 'enhanced social wellbeing' (two items), 'feeling more confident in the relationship with the therapist' (eleven items), and 'feeling more confident with the treatment' (five items). We added an eighth empowering outcome, 'help-seeking behavior' (three items), given that one of the aims of the website is to promote and facilitate help-seeking behavior. All items could be answered on a 5-point Likert scale ranging from 'completely disagree' to 'completely agree'. Example item are: "Through my visits of Proud2Bme, I feel like I have more (correct) knowledge at my disposal to deal



*better with my illness*" (feeling better informed) and *"Through my visits of Proud2Bme, I am more able to think along with my therapist about my treatment"* (feeling more confident in the relationship with the therapist). Mean scores per outcome were calculated. Most empowering outcome scales showed good internal consistency (Cronbach's  $\alpha$  range .77 - .92). Conversely, the empowering outcome scale 'increased social wellbeing' consisting of only two items demonstrated low internal consistency (Cronbach's  $\alpha$  = .51), and was therefore not taken into account in further analyses.

Given that the original questionnaire was specifically developed for individuals with somatic diseases who participated in online support groups, some minor adaptations in the phrasings were made ('online support group' was changed to 'website', 'illness' to 'eating problems', 'physician' to 'therapist'). Participants without a treatment history would not be presented questions concerning empowering outcomes related to treatment and the relationship with their therapist. Non-interactive users, the so-called lurkers (e.g., those who had never posted any message on the website including the forum and never participated in a chat) would not be presented questions concerning their experiences of empowering processes that required interactive activities online: 'sharing experiences', 'exchanging emotional support', and 'helping others'.

### **General empowerment status**

Besides the experience of empowering processes and outcomes as outlined above, it is informative to assess the participants' general empowerment status as well. The experience of empowering processes and outcomes (for example feeling better informed or having found recognition as a result of visiting the website) does not necessarily tell us something about how empowered participants feel in general. Boevink et al. (2008a) conceptually explored the concept of empowerment in a sample of 56 individuals with chronic psychiatric symptoms. Subsequently, an empowerment questionnaire (Dutch Empowerment Questionnaire (NEV) was developed (Boevink, Kroon, & Giesen, 2008b), consisting of 40 questions which can be answered on a 5-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The questionnaire consists of six subscales: 'professional help' (example item: 'My therapist is there when I need him/her'), 'social support' (example item: 'I am supported by the people that I love'), 'self-will' (example item: 'I am able to deal with my vulnerabilities'), 'a sense of belonging' (example item: 'I feel like I belong to something'), 'self-management' (example item: 'I am able to set limits'), and 'engagement of the community' (example item: 'Society is considerate to individuals with psychological problems'). The questionnaire demonstrated high internal consistency and good concurrent validity (Boevink et al., 2008b). A global measure of general empowerment status was calculated by summing and averaging the score of all

items (range 1-5). Higher scores reflect higher levels of general empowerment. In the current study, only the global scale of this questionnaire was used, which showed high internal consistency (Cronbach's  $\alpha = .93$ ).

### **Statistical analyses**

Pearson's correlations (for normally distributed variables) and Spearman's correlations (for non-normally distributed variables) were calculated between each of the empowering processes and outcomes and age (years), eating psychopathology (EDE-Q), general empowerment (NEV), time since first visit (years), and symptom duration (years). In addition, *T*-tests and ANOVAs were conducted to examine whether experiences of empowering processes and outcomes differed according to one's self-reported eating disorder diagnosis (yes/no), interactivity of use (poster/lurker), treatment status (yes, current/yes, in the past/no), and frequency of website visits (not so frequent/frequent/very frequent). To correct for multiple comparisons, the alpha level of 0.05 was divided by 13 (the total number of empowerment processes and outcomes), rendering an alpha level of 0.004. In case of significant ANOVA *F*-tests, post-hoc analyses with a Bonferroni correction were conducted to further examine group differences. All statistical analyses were performed in SPSS version 19.

## **Results**

### **Sample characteristics**

A total of 318 individuals participated in the online survey. Seven participants were excluded because they indicated not to have eating problems, resulting in a sample size of 311. Some questions addressed towards the end of the online survey were not completed by all participants, and hence part of these data missing is missing. A total of 226 participants (73%) completed the whole online survey. The study sample consisted of mainly women (99.6%), with age ranging from 13 to 40 ( $M = 20.2$ ,  $SD = 5.0$ ). The average symptom duration was 4.6 years (range 0 - 25.3) and the majority of participants reported to be diagnosed with an eating disorder (70.1%). The time since first visit of Proud2Bme ranged from 0 to 38 months, with a mean of 19.8 months (approximately 1.7 years). The majority of participants (76.5%) indicated themselves to be very frequent visitors, visiting the website every day to several times a day. The mean EDE-Q score of participants was 3.4 ( $SD = 1.1$ ), indicating considerable levels of eating psychopathology (Aardoom et al., 2012). More information on demographic, health, and user characteristics can be found in Table 1.

**Table 1. Demographic, health and user characteristics of participants (N=311) <sup>a</sup> in online survey.**

	<i>M (SD)</i>	<i>Range (median)</i>	<i>n (%)</i>
<b>Gender</b> ( <i>n</i> = 250)			
Male			1 (0.4)
Female			249 (99.6)
<b>Age</b> ( <i>n</i> = 250)			
	20.2 (5.0)	13-48 (19)	
<b>Education</b> <sup>b</sup> ( <i>n</i> = 250)			
Low			25 (10.0)
Middle			79 (31.8)
High			145 (58.2)
<b>Diagnosed ED</b> ( <i>n</i> = 311)			
Yes			218 (70.1)
No, but ED symptoms			93 (29.9)
<b>Symptom duration in years</b> ( <i>n</i> = 289)			
	4.6 (4.4)	0-25.3 (3)	
<b>Eating disorder Treatment</b> ( <i>n</i> = 295)			
Yes, currently			133 (45.1)
Yes, in the past (not at the current)			78 (26.4)
No, never			84 (28.5)
<b>Time since first visit in years</b> ( <i>n</i> = 245)			
	1.7 (0.9)	0-3.2 (1.7)	
<b>Eating pathology (EDE-Q)</b> ( <i>n</i> = 252)			
	3.4 (1.1)	0.1-4.8 (3.7)	
<b>Satisfaction with website</b> ( <i>n</i> = 245)			
Very dissatisfied			2 (0.8)
Dissatisfied			3 (1.2)
Neither satisfied nor unsatisfied			14 (5.7)
Satisfied			121 (49.4)
Very satisfied			105 (42.9)
<b>Frequency of website visits</b> <sup>c</sup> ( <i>n</i> = 247)			
Not so frequent			12 (14.9)
Frequent			46 (18.6)
Very frequent			189 (76.5)
<b>General Empowerment (NEV)</b> ( <i>n</i> = 226)			
	2.8 (0.5)	1.3-4.6 (2.8)	
<b>Average duration of website visit</b> ( <i>n</i> = 247)			
Less than 10 minutes			25 (10.1)
10-30 minutes			132 (53.4)
30-60 minutes			57 (23.1)
More than 60 minutes			33 (13.4)
<b>Interactivity of use</b> <sup>d</sup> ( <i>n</i> = 242)			
Posters			211 (87.2)
Lurkers			31 (12.8)

<sup>a</sup> Some questions addressed towards the end of the online survey were not completed by all participants and hence part of these data is missing.

<sup>b</sup> Categorization was based on the Dutch educational system.

<sup>c</sup> Not so frequent = Once a month or less; Frequent = Once a week to several times a month; Very frequent = Daily to several times a day.

<sup>d</sup> Posters = those who had ever posted a message on the website (including forum and chat); Lurkers = Those who had never posted any message on the website (including forum and chat).

Participants on average reported 4.24 (SD = 1.75) reasons for accessing the website. The most popular reason given for accessing the website was wanting to read about personal stories and the experiences of others (83.1%). Other popular reasons were to enjoy or relax (69.2%) or to find information on eating problems (65.2%). Finding help (53.8%), helping others (48.2%), talking to fellow sufferers (43.7%), and finding information on issues such as health and beauty (36.8%) were other reported reasons. The least popular reason, although still given by almost a quarter of this study sample (23.5%), pertained wanting to talk with a professional.

#### *Empowering processes and outcomes*

The most frequently experienced empowering process was ‘exchanging information’, followed by ‘finding recognition’ and ‘sharing experiences’: half of the participants reported experiencing these processes at least regularly (see Table 2). The empowering outcome experienced to the strongest degree was ‘feeling better informed’ (see Table 2). To a lesser degree, participants experienced the outcomes ‘increased help-seeking behavior’, ‘increased optimism and control over the future’, ‘increased confidence in treatment’, and ‘increased confidence in relationship with therapist’. The empowering outcomes ‘improved acceptance of the illness’ and ‘increased self-esteem’ were generally not experienced.

#### **Correlates of empowering processes and outcomes**

Correlations between empowering processes and outcomes are presented in Table 3. The processes ‘amusement’ and ‘exchanging social support’ showed among the highest correlations with a number of outcomes. Results of potential correlates of empowering processes and outcomes are shown in Table 4. General empowerment status was significantly associated with most of the empowering processes and outcomes as a result of visiting Proud2Bme. That is, having a lower general empowerment status was associated with higher levels of reported empowerment as a result of visiting Proud2Bme. Age showed significant negative associations with several empowerment processes, meaning that a younger age was associated with higher self-reported levels of taking control over one’s life and the management of one’s disease. Furthermore, posters reported having experienced entertainment more often than lurkers and also experienced a higher increase in confidence in the relationship with their therapist and a higher increase in the acceptance of the illness relative to lurkers (see Table 4). Thus, active involvement and interaction with others was associated with more empowerment. Shorter symptom duration was only significantly associated with the experience of exchanging information (Spearman’s  $\rho = -.21$ ) and feeling better informed (Spearman’s  $\rho =$

-.26), which were also more often reported to be experienced by very frequent website visitors compared to frequent or not so frequent website visitors ( $F(2,24) = 5.71, p < .004$ ).

**Table 2: Empowering processes and outcomes experienced by survey participants as a result of visiting the website Proud2Bme.**

	<i>n</i>	<i>M (SD)</i>	<i>Median</i>
<b>Empowerment Processes<sup>a</sup></b>			
Exchanging information	243	3.26 (0.51)	3.33
Finding recognition	243	3.08 (0.69)	3.00
Sharing experiences	208	2.61 (0.98)	3.00
Exchanging social support	209	2.26 (0.74)	2.00
Entertainment	243	2.26 (0.74)	2.00
Helping others	209	2.10 (0.81)	2.00
<b>Empowerment Outcomes<sup>b</sup></b>			
Feeling better informed	237	3.67 (0.85)	3.75
Increased help-seeking behavior	228	3.39 (1.01)	3.33
Increased optimism and control over the future	231	3.33 (0.62)	3.38
Increased confidence in treatment	109	3.32 (0.64)	3.40
Increased confidence in relationship with therapist	109	3.25 (0.64)	3.27
Improved acceptance of illness	237	2.89 (0.96)	3.00
Increased self-esteem	231	2.73 (0.96)	3.00

<sup>a</sup> Answered on a 4-point Likert scale: 1 = Seldom to never; 2 = Sometimes; 3 = Regularly; 4 = Often

<sup>b</sup> Answered on a 5-point Likert scale: 1 = Completely disagree; 2 = Disagree; 3 = Neither agree nor disagree; 4 = Agree; 5 = Completely agree

Mixed results were found regarding levels of eating psychopathology. Higher levels of eating psychopathology were associated with more frequent experiences of finding recognition and increased help-seeking behavior, but also associated with lower increased self-esteem (see Table 4). Participants who had never been in treatment reported to feel better informed because of Proud2Bme compared to participants who did receive treatment in their past, however, the former group reported less increased help-seeking behavior and less improved acceptance of the illness than individuals who were currently in treatment. Finally, shorter time since first visit of the website was significantly associated with the experience of feeling better informed (Spearman's  $\rho = -.21, p < .004$ ).

## Discussion

The first aim of this study was to investigate whether, and to what extent, specific

empowering processes and outcomes were experienced as a result of visiting a pro-recovery website called 'Proud2Bme' for individuals with eating problems. The second aim was to explore potential correlates of empowering processes and outcomes. Visiting Proud2Bme was associated with becoming an active partner in the management of one's eating disorder problems. Visitors reported experiencing a range of empowering processes and outcomes as a result of visiting the website. Regarding empowering processes, participants most frequently reported exchanging information, finding recognition, and sharing experiences. These findings are highly comparable to findings of two studies focusing on online support groups for patients with breast cancer, fibromyalgia, and arthritis (Bartlett et al., 2011; van Uden-Kraan, Drossaert, Taal, Seydel, & Van de Laar, 2009). Our results are also in line with a study by McCormack (2010), who found that the primary function of an online support group for individuals with anorexia nervosa was to encourage others, along with providing informational support and sharing personal experiences. In terms of empowering outcomes, visiting Proud2Bme was positively associated with participants' feeling of being informed, in line with findings of van Uden-Kraan et al. (2009). To a smaller degree, participants reported that visiting the website resulted in increased help-seeking behavior, increased optimism and control over the future, and increased confidence in treatment and the relationship with their therapist. Overall, results seem to suggest that initiatives like Proud2Bme are a promising tool for the empowerment of individuals with eating disorder symptoms, encouraging and helping them to take control over their lives and the management of their disease.

Overall, participants did not report increased self-esteem or acceptance of the illness as a result of visiting the e-community, which is in contrast to the findings of van Uden-Kraan et al. (2009). This discrepancy might be explained by the fact that low self-esteem is one of the core characteristics of eating disorders (Fairburn et al., 2003) whereas for breast cancer, fibromyalgia, and arthritis it is not. Furthermore, individuals with an eating disorder generally experience shame because they feel responsible for creating and maintaining their eating problem (Troop, Holbrey, & Treasure, 1998). This may be different from individuals with somatic disorders, who might have less difficulty with accepting their problems and who ask for help more easily.

The second aim of the study was to examine potential correlates of empowering processes and outcomes. Note that although correlations do not imply causality, significant correlations are discussed and speculated on in light of possible underlying causes of these relations in an attempt to interpret study results. The processes 'amusement' and 'exchanging social support' showed among the highest correlations with a number of outcomes, which may indicate that these processes are important in order to

**Table 3: Pearson correlation coefficients for empowering processes and outcomes.**

	7. Empowering outcome feeling better informed	8. Empowering outcome improved acceptance illness	9. Empowering outcome increased confidence in treatment	10. Empowering outcome increased optimism and control over the future	11. Empowering outcome increased self esteem	12. Empowering outcome increased confidence in relationship with therapist	13. Empowering outcome increased help-seeking behavior
1. Empowering process exchanging information	.49** (n=237)	.32** (n=237)	.30** (n=109)	.38** (n=231)	.30** (n=231)	.31** (n=109)	.25** (n=228)
2. Empowering process finding recognition	.30** (n=237)	.25** (n=237)	.20* (n=109)	.19** (n=231)	.11 (n=231)	.29** (n=109)	.20** (n=228)
3. Empowering process entertainment	.33** (n=237)	.35** (n=237)	.40** (n=109)	.41** (n=231)	.42** (n=231)	.40** (n=109)	.22** (n=228)
4. Empowering process exchanging social support	.27** (n=206)	.43** (n=206)	.29** (n=98)	.41** (n=201)	.40** (n=201)	.26** (n=98)	.29** (n=199)
5. Empowering process helping others	.20** (n=206)	.35** (n=206)	.23* (n=98)	.37** (n=201)	.34** (n=201)	.15 (n=98)	.16* (n=199)
6. Empowering process sharing experiences	.18** (n=206)	.36** (n=206)	.19 (n=98)	.33** (n=201)	.31** (n=201)	.17 (n=98)	.21** (n=199)

\* =p < .05

\*\* p < .01

**Table 4: Correlates of empowering processes and outcomes as a result of visiting the website Proud2Bme, corrected for multiple comparisons ( $\alpha = .004$ ).**

	Age	Eating psychopathology (EDE-Q)	General empowerment (NEV)	Interactivity of use <sup>A</sup>	Treatment status <sup>B</sup>
	Spearman's $\rho$ (n)	Spearman's $\rho$ (n)	Pearson r (n)	t (df)	F (df)
<b>Empowerment processes:</b>					
Exchanging information	-.21 (243)*	.08 (243)	-.11 (226)	0.05 (240)	4.19 (2,240)
Finding recognition	-.29 (243)*	.27 (243)*	.01 (226)	-2.71 (240)	2.62 (2,240)
Sharing experiences	-.18 (208)	.06 (208)	-.24 (198)*	-	5.46 (2,205)
Exchanging social support	-.22(209)*	.07 (209)	-.19 (198)	-	4.41 (2,206)
Entertainment	-.29 (243)*	.03 (243)	-.25 (226)*	-2.88 (240)*	1.74 (2,240)
Helping Others	-.11 (209)	-.10 (209)	-.34 (198)*	-	3.47 (2,206)
<b>Empowerment Outcomes:</b>					
Feeling better informed	-.21 (237)*	-.03 (237)	-.13 (226)	-0.67 (235)	6.88 (2,234)* Yes current > Yes past Yes past < No never
Increased help-seeking behavior	.03 (228)	.22 (228)*	-.08 (226)	-2.61 (226)	5.63 (2,225)* Yes current > Yes past Yes current > No never
Increased optimism and control over the future	-.10 (231)	-.08 (231)	-.44 (226)*	-0.90 (229)	0.90 (2,228)
Increased confidence in treatment	-.09 (109)	-.10 (109)	-.41 (109)*	-2.74 (107)	-
Increased confidence in relationship with therapist	-.08 (109)	.03 (109)	-.30 (109)*	-3.52 (107)*	-
Improved acceptance of the illness	-.10 (237)	-.09 (237)	-.35 (226)*	-2.90 (235)*	10.59 (2,234)* Yes current > Yes past Yes current > No never
Increased self-esteem	-.01 (231)	-.26 (231)*	-.47 (226)*	-0.05 (229)	1.32 (2,228)

\* =  $p \leq .004$

<sup>A</sup> Posters = those who had ever posted a message on the website (including forum and chat); Lurkers = those who had never posted any message on the website

<sup>B</sup> Yes current = Yes, currently in treatment; Yes past = Yes, received treatment in the past but currently not in treatment; No never = Never received treatment

Note: EDE-Q = Eating Disorder Examination Questionnaire; NEV = Dutch Empowerment Questionnaire



experience empowering outcomes. Lower levels of general empowerment status were significantly associated with higher levels of reported empowering processes and outcomes as a result of visiting Proud2Bme, which may suggest that the website especially empowers those who seem to need it the most (e.g., less empowered individuals). Younger age was associated with higher self-report levels of experienced empowering processes, possibly because the e-community Proud2Bme focuses on adolescents which for example may lead to younger individuals being better able to find recognition in the posted stories. Results furthermore suggest interactivity to be a potential important aspect of improving empowerment.

Interestingly, shorter time since first visit of Proud2Bme was associated with the empowering outcome feeling better informed, which might suggest that participants can experience empowerment because of their website visits rather quickly. This might also suggest that the reason for visiting Proud2Bme changes over time and that Proud2Bme thus seems to provide in different needs as time goes. Another interesting finding was that participants who had never been in treatment reported lower levels of increased help-seeking behavior and improved acceptance of the illness relative to participants who were currently in treatment. One may expect the website to have less impact on individuals who were already in treatment, given that these individuals may already be more empowered as a result of their treatment. It is valuable to realize that both the so-called underserved individuals who seek help late or even never access treatment (Moessner & Bauer, 2012), as well as individuals who are currently undergoing treatment reported experiencing empowerment. In addition, approximately half of the participants who were currently in treatment reported having sought help as a result of visiting the website. This suggests that by providing a safe, positive, and recovery focused environment, E-health initiatives such as Proud2Bme may help to bridge the gap between the need for treatment and actual treatment.

Results of this study should be considered in light of the following limitations. First, the cross-sectional design of this study does not permit inferring causal relationships. Patient empowerment could have been enhanced by external factors, although we explicitly asked participants how they felt empowered by their visits to the website. Yet participants might not be completely capable of assessing which specific factors in their lives influenced them to feel a certain way. Although challenging, future research should ideally investigate the effects of E-health initiatives on patient empowerment by means of prospective studies. Second, the present study sample may not necessarily be representative for the entire group of individuals visiting the website (selection bias). There is a possibility that only individuals who perceive the website as empowering completed the survey, or that the website is only empowering for those who visit the

website frequently. Although with respect to the latter, results demonstrated an association for frequency of website visits with only two empowering processes and none of the empowering outcomes. Third, the retrospective design of this the current study comes with the risk of recall bias. Recall bias could have resulted both in over- and underestimation of true patient empowerment. This study is also limited by the use of solely subjective self reported assessments. Finally, this study did not investigate possible disempowering effects of visiting Proud2Bme.

In conclusion, results of this study demonstrated that a broad range of visitors reported experiencing empowering processes and outcomes as a result of visiting Proud2Bme, encouraging and helping them to take control over their lives and the management of their disease. Furthermore, results suggested Proud2Bme to have a potential in bridging the gap between the need for treatment and the actual treatment received, by means of providing a safe, positive, and recovery focused environment. This study can provide a relevant contribution to the process of developing best practices in E-health. That is, offering a platform on which individuals can share their experiences and find recognition may be one of the most important ingredients for successful e-health initiatives aimed at improving patient empowerment. Our results suggest that the success of e-communities not only depends on the level of qualitatively good information, but also on the possibility of interactive involvement and on being a 'fun place' where individuals can enjoy their selves. The constantly changing content of the website through the active involvement of many volunteers, might contribute to the success of Proud2Bme. In the field of eating disorders specifically, e-health initiatives as Proud2Bme not only have the potential to increase empowerment in individuals with symptoms of an eating disorder, but also offer a healthy alternative to the harmful and negative effects of pro-eating disorder websites.



