

# ***Ethical Dilemmas in online research & treatment of sexually abused adolescents***

*Ongoing research report, based on Keynote address at the E-Health International Summit in Amsterdam, October 16, 2009*

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Word count including tables and references: 6442

## **Abstract**

**Background:** Although the prevalence of sexual abuse is high among adolescents, many victims do not seek treatment. Internet therapy may provide a low-threshold alternative to regular care.

**Objective:** To evaluate an internet treatment protocol for adolescent victims of sexual intimidation, violation and rape.

**Methods:** The effects of the treatment protocol were evaluated in two studies. The first study was an uncontrolled pretest-posttest pilot. The second study was a baseline-controlled trial, using repeated measurements. To control for spontaneous improvement, participants reported their symptoms both during a baseline control period and during treatment.

**Results:** In the pilot study, treatment completers ( $n=7$ ) reported substantial decreases in trauma symptoms (effect size:  $.9 < d < 1.1$ ). However, there was a large pre-treatment dropout rate (90%) among the potential participants aged between 14 and 18 years old. Dropout appeared to result from the request for biographical information and parental consent during the screening. The second (controlled) study ( $n = 24$ ) confirmed the impact of treatment. Yet, despite attempts to reduce pre-treatment dropout, it remained high (77%).

**Conclusions:** The findings raise important ethical dilemmas. On the one hand it is appealing to allow anonymity in this vulnerable and undertreated population. On the other hand, responsible care providers may need biographical data in order to act if crises occur. The paper discusses the impact of the questions that may arise in online treatment, but also in online self-help programs, but does not claim to have clear-cut answers.

## ***Introduction***

Among adolescents, the prevalence of sexual abuse is high. A recent review comprising 65 studies from 22 countries [1] found that 8% of the men and 20% of the women experienced some form of sexual abuse prior to the age of 19. There is also evidence that a high percentage of these youngsters display posttraumatic stress symptoms, and go on to develop comorbid affective disorders and suicidal ideation [2-3], alcoholism [4] and eating disorders [5]. Furthermore, sexually abused youngsters are at high risk for renewed sexual abuse.

Often, victims of rape or other forms of sexual abuse are unwilling to talk about their experiences [6]. However, disclosure of sexual abuse is critical. In a large survey study among female victims of sexual abuse, Lange et al. [7] established the association between psychopathology and the duration of non-disclosure. Many youngsters are reticent to share their experiences, often because they do not want to involve their family. Furthermore, when they apply for therapeutic help, they often encounter waiting lists [8]. Clearly, there is a need for more accessible psychological help for overcoming traumas of sexual abuse in adolescents.

Internet treatment seems to be a promising and suitable medium to help youngsters. Adolescents appear to share their feelings more easily online than in face-to-face contact [9]. Nikken [10] reviewed the quality and types of Dutch health websites targeting children and adolescents. He identified 50 websites, which predominantly provided psycho-education and brief support. However, none of these websites provided treatment for traumatized adolescents.

To fill this gap, the Rutgers Nisso Group (RNG), a Dutch expert center on sexuality, initiated a project to develop an internet treatment protocol for adolescent victims of sexual intimidation, violation, and rape. Interapy BV, a Dutch mental health institution providing protocolled treatments via the internet, was invited to participate. This article provides a brief description of the online treatment that resulted from this cooperation, and presents two studies that were run to examine its effectiveness.

For the participants, who completed the treatment, the treatment turned out to be effective. However, both studies suffered from a large pre-treatment dropout. Many respondents terminated their participation to the study, most probably because they expected a degree of anonymity that could not be provided. The findings of these studies raise ethical dilemmas in how to deal with anonymity when providing internet treatment to adolescent populations

### ***Online Treatment of Sexually Abused Adolescents***

The treatment protocol is based on an existing cognitive behavioral treatment of posttraumatic stress, which has been proven to be effective in adult populations in several randomized controlled trials [11-15], in online and offline format as well. The treatment comprises ten structured writing assignments [16] that implement three therapeutic interventions: *exposure*, *cognitive reappraisal*, and *social sharing*.

Several changes were made to adapt the treatment to sexually abused adolescents. First, an *additional feedback* occasion was included in the exposure module to provide extra guidance at this difficult stage [17-18]. Second, an extra module was added which comprised writing about the impact of the sexual abuse on their body. The participants were encouraged to monitor somatic disturbances (e.g., problems urinating), if any. Third, at the end of treatment, we added instructions to the clients to generate a 'personal toolkit', i.e., a document in which participants listed the elements they found most useful, and in which they formulate how they would use these elements if they should relapse. Finally, we added extra psycho-education concerning the specific problems that they might have encountered, such as shame, social anxiety, or lack of assertiveness.

The full therapeutic procedure was conducted without face-to-face contact. Participants used a common web-browser to follow the therapeutic procedure, including the completion of the questionnaires and the therapeutic assignments.

Several measures were taken to secure the privacy of the participants. First, only the therapist and the participant were given access to the treatments. Participants and therapists were given an account to a private password-protected website. Also, the website included a webmail system, which allowed

participants to contact their therapist outside the treatment regime. Thus, participants who shared an e-mail account with others (e.g., family members) did not have to use this shared account during treatment. Third, all communication with the website was encrypted with the Hypertext Transfer Protocol over Secure Socket Layer. Fourth, the web server was located at a professional Internet host, protected by a firewall, and remotely administered through an encrypted communication channel.

## ***Pilot study***

### ***Methods***

#### ***Design***

The pilot was an uncontrolled pre-post study.

#### ***Recruitment***

The study aimed to recruit a community sample of sexually traumatized adolescents between 14 and 18 years old. Dutch media gave free publicity to the study in response to a press release. Interested users were referred to a public website that provided background information and an application form.

#### ***Screening***

Screening started with standardized self-report instruments administered through the secure website. After the computerized screening, a telephone interview was held in order to check whether all questions were understood, and to obtain additional information if needed. Those who were eligible were asked to return a printed and signed informed consent form. In accordance to Dutch law, this form had to be signed by the respondent's parents.

To establish whether the respondent experienced sexual abuse in the past, the *Vragenlijst Seksuele Trauma's Adolescenten* was used (*Childhood Unwanted Sexual Experiences Questionnaire*). This anamnestic instrument is based on a similar adult questionnaire, but adapted for adolescents [19-20]. It provides information about the type of the abuse, severity, feelings of guilt and shame, degree of disclosure, location, and the relationship with the perpetrator.

To enter the study, respondents had to be between 14 and 18 years old. Respondents were excluded if the sexual abuse was ongoing in the family (i.e., ongoing incest); if there was another than PTSD DSM-4 diagnosis which was prevalent; if the applicants were in treatment elsewhere; if there were indications of psychosis, dissociation, suicidal ideation, automutilation, anorexia nervosa (severe underweight, BMI < 18), use of neuroleptics, prior admission into a psychiatric hospital, or substance abuse. Excluded respondents received personalized referrals to agencies providing face-to-face treatment in their region.

The *Interapy Biographic Questionnaire* [21] was used to establish age, level of education, and experience with internet. Risk of psychosis was determined by means of the Dutch *Screening Device for Psychotic Disorder* (SPDP; [22]). The *Somatoform Dissociation Questionnaire-5* [23] was used to determine the degree of dissociation. Suicidal ideation was determined with the Dutch adaptation of the *Suicidality Questionnaire* [24]. The Dutch adaptation of the *Self Harm Inventory* [25] was used to establish the presence and degree of automutilation. Substance abuse was determined by the *Substance and Medication List* developed by Interapy.

### **Outcome measures**

- *Posttraumatic stress* was measured using the Dutch adaptation of the *Children's Responses to Trauma Inventory* (CRTI; [26]). This list consists of 34 items, divided in 4 subscales: Intrusion, Avoidance, Arousal and non-trauma-specific reactions (such as guilt, sadness, and somatic complaints).
- *Impairment/Empowerment*. At the end of each treatment module, participants expressed the degree in which their symptoms interfered with their functioning on a scale from 1 (low) to 10 (high). Similarly, participants monitored their *empowerment*, i.e., the degree to which they could cope with their symptoms.

### **Client satisfaction**

At posttest, participants answered questions regarding their satisfaction with the duration and transparency of the treatment, the clearness of the questionnaires, the explanations, and the assignments. In addition, they indicated how comfortable they felt with their therapist.

## **Results**

### ***Participant flow***

Publicity resulted in 112 applications for treatment. Among the applicants, sexual abuse varied from intimidation, enforced exhibition of genitals, to forced sexual acts and rape. Several applicants suffered repeated abuse by the same perpetrator. Figure 1 shows the high dropout prior to the screening, during the screening, and in the period between screening and telephone intake. Thirty applicants were excluded, most of them because of age (older than 18), ongoing incest, suicidal ideation, or because of concurrent treatment). This resulted in a further reduction of the number of participants to 14, of whom 6 did not return their informed consent. Finally, 8 participants started treatment, all females between 15 and 18 years. One participant did not complete treatment and the posttest.

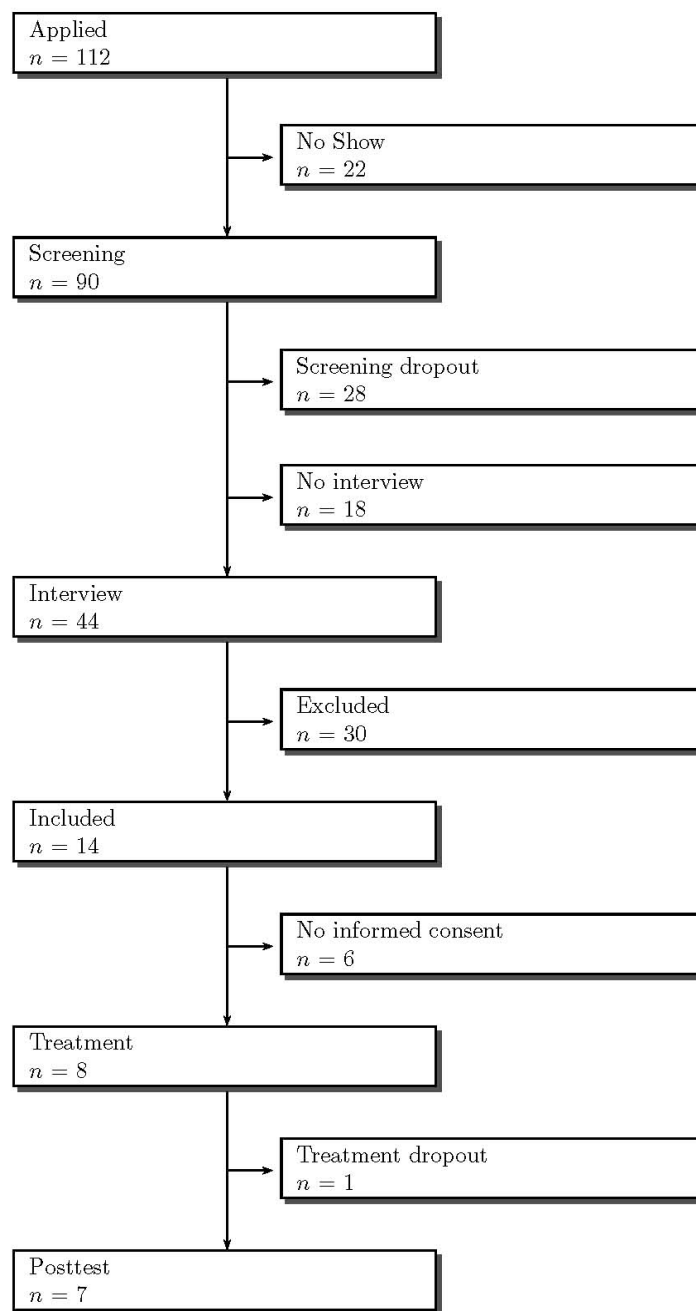


Figure 1. Flow of Participants in the Pilot Study.



### **Treatment effects**

As shown in Table 1, the CRTI-scores suggested substantial improvements, with high effect sizes (Cohen's  $d$  [27]:  $.9 < d < 1.1$ ). Monitoring of impairment and empowerment showed high effect sizes as well (reduction of impairment:  $d = 1.2$ ; increase in empowerment:  $d = 1.4$ ). However, as a consequence of the small sample size and thus low statistical power: all paired  $t$ -tests were non-significant at  $\alpha=0.05$ .

Table 1. Average Trauma Scores at Pre-Treatment and Post-Treatment on the Children's Responses to Trauma Inventory (n=7).

Subscale (range)	Pretest		Posttest		Effect size
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	Cohen's <i>d</i>
Intrusion (7-35)	17.7	3.8	13.1	4.4	1.0
Avoidance (11 – 55)	22.6	4.7	17.9	5.1	1.1
Arousal (6 – 30)	16.4	3.2	13.1	2.7	1.0
Non-specific symptoms (5-35)	28.0	8.1	20.9	6.5	.9
Total (34 – 170)	101.0	18.0	76.4	20.6	1.0

### **Client Satisfaction**

As the details and data of the evaluations were reported by Wijnker and Michels [28], we limit ourselves to the main observations. All participants considered the treatment as being very satisfactory, and they showed a very high appreciation of their therapists. All participants indicated that they would recommend the treatment to others in positions similar to their own.

### **Initial discussion: the pilot study**

The most striking finding of the pilot was the extremely high pre-treatment dropout. Of the 82 applicants not excluded by the researchers, 90% withdrew from the study before they had a chance to get acquainted with it. There was no pre-treatment dropout among the included adolescents, who were 18 years and thus not required to obtain their parents' permission. The obligation to inform their parents seemed to create the main barrier for most of the younger adolescents.

Seven out of the eight who started treatment completed treatment. The outcome and evaluations of these seven completers were very positive.

Given the results of the pilot study, we concluded that the treatment appeared promising, but that we had to find ways to deal with the pre-treatment withdrawal caused by the fear to inform parents or give up anonymity.

## ***Study 2: Controlled study***

### ***Methods***

#### ***Design: within controlled pre-post***

In the second study, we aimed to control for spontaneous improvement through a controlled design. Under Dutch law, in a randomized group design participants up to 18 years must obtain consent from both parents. Since the treatment could be viewed as effective for adults and for the adolescents who did complete treatment in the pilot study, the ethical committee of the department of Clinical Psychology of the University of Amsterdam allowed us to define the study as a treatment evaluation study with a baseline-control period of non-intervention rather than an experimental study.

#### ***The treatment protocol and recruitment***

The treatment protocol was identical to the one used in the pilot study. Participants were again made aware of the treatment and the study by free publicity, but were also referred by general physicians and mental health agencies.

#### ***Screening***

The screening procedure was similar to that of the pilot study. However, if participants refused to participate in the telephone interview, the interview was conducted through online chat.

The exclusion criteria were largely the same as in the pilot study. There were three exceptions. First, the upper age level was expanded to 25 years. This

change was applied since we received signals from the field that older adolescents and even young adults belonged to the target population. Second, participants aged 16 and older could participate without informing their parents, since the second study was accepted as a treatment evaluation. Third, the symptoms of the participants had to meet the criteria of PTSD, i.e., they had to score at or above the clinical cut-off (24) of PTSD of the Impact of Event Scale (IES [29-31], described below).

### **Outcome measures**

- The Dutch adaptation of the IES was used to measure the degree of traumatization. The IES consists of 15 items, and comprises the subscales Intrusion (8 items) and Avoidance (7 items).
- To establish the degree of depression, the Dutch adaption of the *Depression subscale of the Symptom Checklist (SCL-90 [33])* was used.
- As in the pilot study, participants rated their degree of *Impairment* and *Empowerment* on a scale ranging from 1 (*low*) to 10 (*high*), immediately after the completion of each phase during the baseline-control period and the treatment period.

### **Statistical analyses**

Change scores were calculated for the baseline-control period and the treatment period. The differences between these change scores were tested using two sided paired *t*-tests. Effect sizes were expressed in Cohen's *d* by dividing the mean difference scores with the standard deviation of the first assessment. Net effect sizes were calculated by subtracting the effect size of changes in the control period from the effect sizes of changes in the treatment period. All dropouts completed the posttests of both periods. Hence, there was no need to implement the intention-to-treat protocol through data imputation.

## **Results study 2**

### **Participants flow**

As shown in Figure 2, the second study also suffered from considerable pre-treatment dropout. Twenty-four percent ( $n = 37$ ) of the applicants ( $N = 155$ ) did not start the screening. Since we have no data of these respondents we cannot establish the reasons for their dropout. Of those who started the

screening ( $n = 118$ ), 31% ( $n = 37$ ) did not complete it. These participants provided some data that enabled us to establish which questions made them stop the screening. Enquiries into biographical data and data about their physicians or referring agencies contributed most to the dropout.

Seventy-eight respondents were interviewed, of whom 49 (63%) were excluded. Main reasons for exclusion were incest ( $n = 20$ ) and being in concurrent treatment ( $n = 9$ ). All in all, of those not excluded from the study by the researchers ( $n = 106$ ), only 23% ( $n = 24$ ) started the baseline-control period. Of those, one withdrew after the baseline-control period, and four dropped out during the treatment phase. All participants completed the posttest.

The mean age of the participants was 20 years (range 14-25,  $SD = 3.5$ ). One participant was younger than 16, four were between 16 and 18 years and 19 were between 18 and 25. An average of 5 years had passed ( $SD = 4$ ) since the occurrence of the traumatic events.

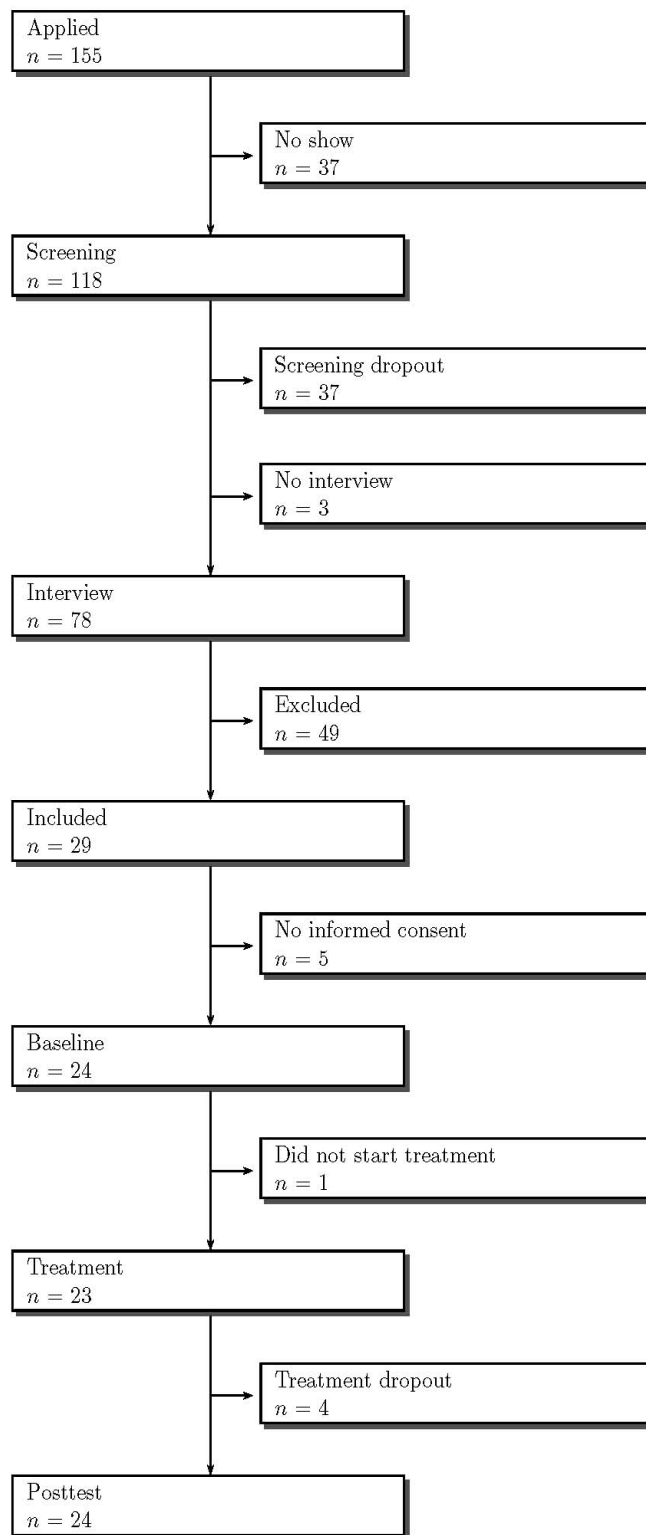


Figure 2. Flow of Participants in the Controlled Trial.

### ***Reduction of traumatic stress, depression, impairment and increase of empowerment***

Figure 3 shows initial decrease in traumatic stress after the screening. From then to the end of the control period (C4) there is no further reduction of traumatic stress. C4 is the dividing point. It is the end of the baseline-control period and the beginning of treatment. After T1, when the treatment has started, the graph shows a steady further decrease in traumatic stress. At screening, the average score was well above the cut-off score for PTSD, at final posttest the IES-score was clearly below the cut-off score.

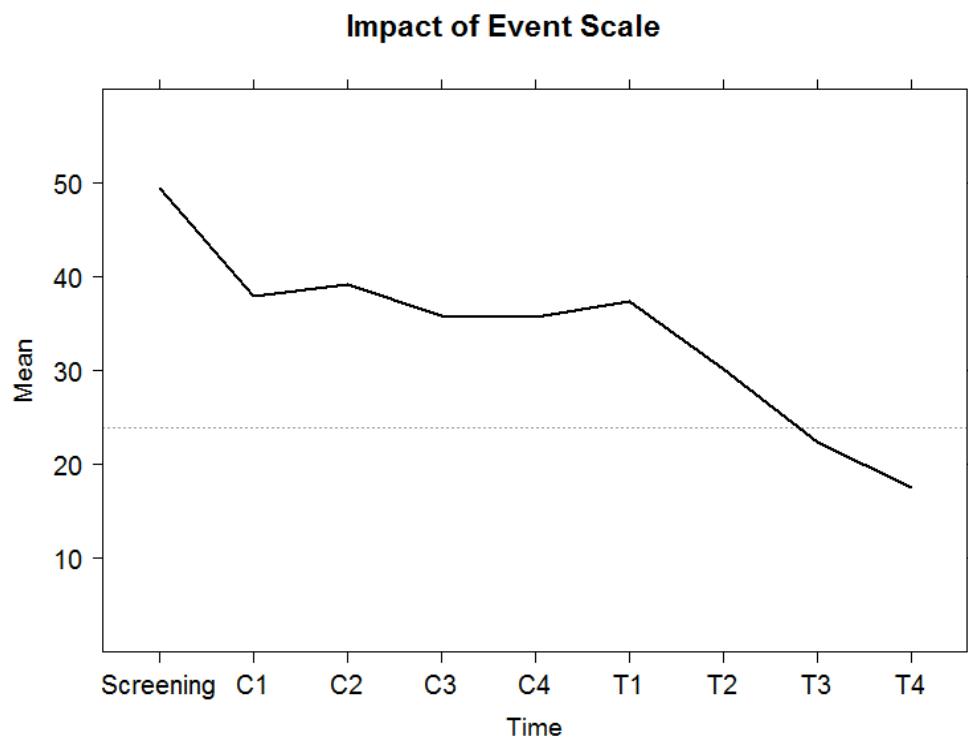


Figure 3. Averages ( $n = 24$ ) of repeated assessments of symptoms of posttraumatic stress, as measured by the Impact of Event Scale during the Screening, the baseline-control period (C1-C4), and during the Treatment (T1-T4) ( $n = 24$ ). The dotted line provides the IES cut-off score for PTSD (24).

Figure 4 shows the mean scores of impairment and empowerment after each module. The graph demonstrates a small reduction in impairment during the baseline period. During the first treatment episode (exposure) the feeling of impairment increases slightly, turning to a steady and dramatic drop till the end of treatment.

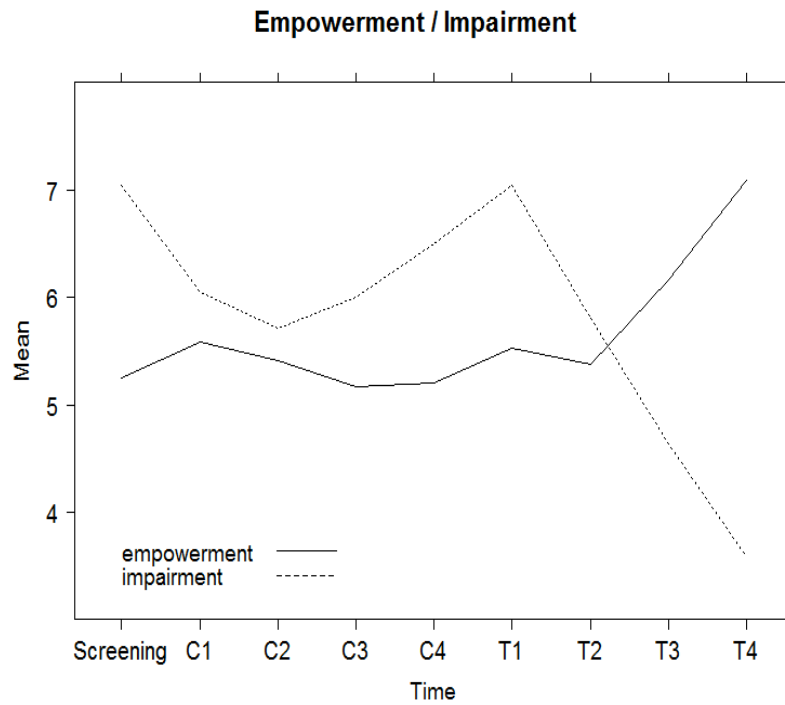


Figure 4. Repeated measurements of empowerment and impairment, assessed during the screening, the baseline-control period (C1-C4), and during the treatment (T1-T4).

The graph in Figure 4 shows a complementary trend in empowerment: a small increase after the screening, followed by a gradual but small decline until the end of the control period. During treatment, there is a steady rise in empowerment after the module that focused on the somatic trauma-related complaints.

Table 2 shows the averages of the participants on the outcome measures at screening, at post-control/pre-treatment (C4) and at the end of treatment (T4). The participants who had dropped out from treatment had completed the posttest and were included in this table.

Table 2. Means and Standard Deviations ( $n = 24$ ) of Trauma Symptoms, Depression, Impairment and Empowerment as measured at Screening, at the end of the Baseline-Control Period (C4), and Post-Treatment (T4)

Measure <sup>a</sup>	Screening		End of Baseline		Posttest	
	M	SD	M	SD	M	SD
Trauma (IES)	49.5	9.1	35.7	15.2	17.5	15.4
Depression (SCL90)	43.7	13.3	41.8	12.0	29.3	11.6
Impairment	7.0	1.4	6.5	1.1	3.6	1.7
Empowerment	5.2	1.7	5.2	1.6	7.1	1.6

<sup>a</sup> IES: Impact of Event Scale; SCL-90: Symptom Check List 90. Higher scores represent less favorable conditions, except for the Empowerment measure, for which higher scores represent better conditions.

Table 3 summarizes the difference scores in the baseline period and the treatment period, and provides tests of significance of the differences between the changes in these periods. The net effect size can be calculated by subtracting the effect size of the control period from the treatment period.

Table 3. Changes during Treatment versus Changes during the Baseline-Control Period: Means, Standard Deviations, Effect sizes, and Paired *t*-tests of the Differential Improvements.

Measure <sup>a</sup>	Baseline (Screening-C4)			Treatment (C4-T4)			Test of difference	
	M	SD	<i>d</i>	M	SD	<i>d</i>	$t_{df=23}$	<i>p</i>
Trauma (IES)	13.8	12.4	1.5	18.2	11.6	2.0	1.1	.28
Depression (SCL90)	2.0	10.0	.1	11.8	9.3	.9	3.3	.01
Impairment	.5	1.7	.4	2.9	2.0	2.0	3.7	<.001
Empowerment	.0	1.8	.0	1.9	1.9	1.1	3.2	.01

<sup>a</sup> Differences represent favorable outcomes, i.e. higher scores represent more improvements.

There are several striking results in Table 3. Most noticeable are the very large effect sizes for decrease of impairment and increase of empowerment after treatment, while there was no or only small improvement during the control period. Also, there was a large net effect size for depression. However, the net



effect sizes on trauma symptoms were only moderate ( $d = .5$ ). As the results in the table show, this was caused by the large reduction in IES-scores in the control period, which originated from the screening. The screening included many questions that required the participants to focus on their trauma and on their present situations. This might have resulted in some sort of unintended exposure. Combined with the psycho-education and the awareness of the upcoming treatment, this might have reduced their traumatic stress symptoms as expressed in the IES. This ad-hoc explanation is supported by Figure 3. The drop in IES right after the screening is very steep, but after this there is no further decrease in the IES-scores during the baseline-control. When treatment starts, the decrease resumes, and persists during the whole treatment period.

In exploratory analyses, we again compared the change in trauma symptoms during the baseline-control period with the change during treatment, but we did it in a different way. In these analyses, we calculated the IES scores at the start of the baseline-control at C1 (the first measure of the baseline-control). This resulted in a significant difference between treatment and baseline-control of  $p < .001$ , and a net effect on the IES of the treatment period of  $d = 1.8$ .

### ***Client satisfaction***

As shown in Table 4, the participants expressed general satisfaction with the treatment and the therapists. Although 22% of the participants did miss face-to-face contact, they were highly satisfied with their therapists, and 88% stated that they would recommend the treatment to others. In general, they evaluated the treatment favorably, in particular the exposure part of the writing. The psycho-education module concerning bodily symptoms received the lowest rating. This is striking, since this module was specially designed for this population.

Table 4. Client Satisfaction with Treatment and Therapists ( $n = 23$ ).

<b>Aspect</b>	<b><i>M</i></b>	<b><i>SD</i></b>
<i>Satisfaction with Treatment (1-10)<sup>a</sup></i>		
Overall	7.9	1.3
Writing / Exposure phase	8.1	1.3
Body phase	6.7	2.1
Cognitive reappraisal phase	7.3	2.5
Taking leave / Social Sharing phase	6.8	2.9
<i>Satisfaction with Therapist (1-10)<sup>a</sup></i>	8.6	1.0
	<b><i>n</i></b>	<b><i>%</i></b>
<i>Missed face-to-face contact</i>	5	22 %
<i>Internet therapy is a good method</i>	20	83 %
<i>Would recommend the treatment to others</i>	21	88 %

<sup>a</sup> Higher scores represent better evaluations.

### ***Discussion study 2 : Positive outcome and limitations***

In the controlled study, the effect sizes were calculated on intention-to-treat basis. The posttests that were completed by the dropouts were included in the tests. In both studies, the decrease of impairment and depression and increase in empowerment were high. The tests between improvements in the baseline period and the treatment period were highly significant and showed high effect sizes. Furthermore, the control period included repeated measures, which rendered the control period similar to an attention placebo condition.

Unexpectedly, the screening was associated with a sharp decrease in trauma symptoms (IES) during the beginning of the baseline-control period, resulting in a lower than expected between control-treatment effect on this measure. The exploratory analyses clearly demonstrates that the large improvement in the control period was nearly entirely due to this effect of the screening.

The design permitted the evaluation of the effects from pre-baseline (screening) to post-treatment (T4), which revealed significant improvement ( $p < .001$ ) and large effect sizes in all four measures. The effect on the trauma symptoms was very large ( $d = 3.5$ ). Taking these results into account, it is

worth considering to incorporate the screening and baseline period into the treatment itself. In future randomized trials, the effects of treatment with or without this baseline period may be studied.

In most experimental studies of the treatment of trauma, the measures of effects are expressed in terms of a decrease in trauma symptoms. The present study confirms that treatment effect may also be expressed in the increase in empowerment. This finding supports the suggestion to focus on the reduction of illness behavior and on the increase of self-esteem and empowerment as well [33-34].

There were limitations in the present study. First, only one male participated in the study. The underrepresentation of males may be due to the greater incidence of sexual abuse among women. However, a greater fear of disclosure in male victims may also discourage them from seeking treatment [35-36]. We will have to find ways to encourage victimized male adolescents to seek evidence-based help. A second limitation is the absence (at the time of writing this report) of a follow-up. The follow-up measures will be ascertained one year after the posttest. We shall then report on the maintenance of the treatment effects. We chose not to wait with the present publication given the importance of easily accessible treatment for this particular population. In addition, the present study raised urgent ethical questions that we will address in the following session of the discussion.

### ***Final Discussion: Large pre-treatment dropout: ethical dilemma's***

In the pilot study, about 90% of the applicants withdrew before treatment. In the second study, several measures were taken to reduce the pre-treatment dropout: a) The design of the controlled study was organized as an evaluation of treatment instead of an experimental randomized study. In this design, parental consent was obligatory only for applicants up to 16 years instead of 18 years. b) The upper age level for participation in the study was increased from 18 to 25 years. Thus, the population of potential participants who did not require parental consent was enlarged. c) Participants were offered the

alternative of a structured interview by chat if they were reticent to answer questions on the telephone. Most of the participants did not make use of this possibility. However, none of those who had chosen the chat option withdrew from the study.

All in all, the measures we took were not quite successful. In our second study, the pre-treatment withdrawal still amounted to 77%, which is still unacceptable given the objective of providing easily accessible help.

Only one client who required parental consent (age < 16) participated. Most participants were older than 18. We have no biographic data of those who withdrew before or during the screening. Accordingly, we cannot be entirely sure about the role which age and subsequent requirement of parental consent played in withdrawal of the study. But we do know that most withdrawal took place at the moment the biographic questions came in view. This suggests that the consent of parents is not the only cause of withdrawal. The fear of giving up anonymity turns out to be an important factor, even for those who are older and do not need parental consent.

There are several options to consider to combat pre-treatment withdrawal.

- It may simply be necessary to accept the high pre-treatment withdrawal among the age group under 16. The parental consent that they need is prescribed by law, and with good reason (notwithstanding the unwanted implications it has in the present context).
- It may be possible to enhance the feeling of anonymity in the participants above 16 years. Perceived anonymity could be enhanced by posing fewer biographic questions. So far, the questions concerned age, gender, name, address, e-mail address, telephone number, name of parents, name of physician, and insurance details. We could confine ourselves to the information that is necessary to provide treatment in the present situation: age, name, e-mail address, insurance details.
- Alternatively, retaining the original biographical questions, we could allow participants to skip certain questions. However, this could have undesirable consequences. For example, withholding insurance details would result in the participants having to pay the treatment themselves.

- Changing the format from therapy to self-help. To fully solve the anonymity problem a completely automated self-help program might be the best option. Much of the content of the present protocol could be used in such a program. Yet, this might still leave unsolved some legal and responsibility problems. Furthermore, there is growing evidence that the effects of pure self-help are less robust than the effects of self-help with considerable guidance or online treatment [37-39].

None of the options above seem to be fully satisfactory. Notably, the following issues may arise.

- Is it ethical to withhold a promising treatment from the most vulnerable group (age < 16)?
- Is it responsible to forgo biographical information that is essential in the case of a personal crisis of the client? What is the responsibility of the care provider in that case? Obviously, the moral aspects seem to be the most compelling, but financial consequences might come up if claims of neglect are brought up against the care provider. Legal questions may present themselves in countries such as the Netherlands where care providers are obliged to obtain and register the 'Citizen Service Number' of all clients.
- Internet treatment like the one described here is fully integrated in the Dutch healthcare system and financed by the Dutch insurances. In what way can insurance companies pay for treatments, if the recipient is anonymous? And given anonymity, how can the incorporation of treatment packages such as the present one be guaranteed in the health system?
- How will research suffer given the absence of the biographic information that is required to improve treatments, e.g., to conduct long-term follow-up, dropout analyses, and analyses of moderators of treatment effect? This is a fundamental question that relates to the previous point. Serious research is necessary to establish a working relation with public and insurances.
- The internet format provides more feeling of anonymity than face-to-face treatment. Is it not preferable to capitalize on this aspect by stressing the fact that clients may follow treatment from their homes without having to face therapists, instead of giving up the data that are necessary to conduct therapy and research in the best possible manner?

As indicated above, we do not have ready answers to all these questions.

However we do tend towards the following course of action:

- Let us continue to find ways to reduce the pre-treatment dropout even if the gains are small. This may be achieved by adopting the following rules:
  - Provide information on the homepage about the necessity of gathering certain biographic data. The most effective phrasing and timing of this information is an important issue which will require careful consideration. This may be addressed in future pilot studies.
  - During the screening, the biographic questions should be preceded by clear explanation of why each question is asked, and why the answer is optional or obligatory.
  - Use the chat option as default for structured interviews, instead of the telephone option.
- Let us invest in pre-emptive automated self-help programs for specific vulnerable populations. These programs may also prepare clients for treatments which cannot be conducted in full anonymity.
- It may be possible to grant dispensation to youngsters below 16 years should they have good reasons not to inform their parents of their desire to seek treatment. Such dispensation could be made conditional on the disclosure to specially trained general practitioners. Consent of one of these should then be sufficient to initiate the screening and ultimately start the online treatment. This would require a change in the law which mental health institutions, political and governmental institutions would have to pursue together.
- Create awareness of this issue among the political and legal agencies and of the urgent need to address it.
- In the meantime: let us continue to provide online treatment to vulnerable groups even if the pre-treatment dropout is high. We consider it our moral obligation to do so. In addition, continuing to provide this treatment allows us to study, and improve the treatment protocols.

## **Acknowledgements**

I am very much indebted to the Rutgers-Nisso-Group who initiated this project, to the Scientific Guidance Committee, to the treatment coordinators of Interapy, the therapists, the clients, the graduate students who carried out some of the analyses, to Conor Dolan for the inspection of the manuscript in the final version, and last, but surely not least, to Jeroen Ruwaard for his considerable help in the analyses of this study.

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