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Psychiatry and Primary Care

Recent epidemiologic studies have found that most patients with mental illness are seen exclusively in primary care medicine. These patients often present with medically unexplained somatic symptoms and utilize at least twice as many health care visits as controls. There has been an exponential growth in studies in this interface between primary care and psychiatry in the last 10 years. This special section, edited by **Wayne J. Katon**, M.D., will publish informative research articles that address primary care-psychiatric issues.

Does the Study of Victimization Revictimize the Victims?

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Abstract: *Although the number of questionnaire surveys examining the sequelae of prior sexual and physical victimization has increased over the last decade, little attention has been given to understanding the impact of such studies on participants. As part of a larger study of long-term effects of prior sexual and physical victimization, 500 randomly selected women in an HMO received a comprehensive questionnaire including multiple symptomatic distress measures and several items inquiring into previous history of sexual, physical, and emotional abuse and neglect. They also completed a short rating scale asking about their reactions to completing the questionnaire. Despite the sensitive content, the women who participated generally found the experience to be a positive one. Only a small number of women were more upset than they had anticipated, but the vast majority felt they would have completed the survey even if they had known in advance how they would feel. The subset of women who did express distress was significantly different from the group that did not, with respect to other measures of symptomatic distress and trauma exposure. These data suggest that surveys that inquire into prior episodes of childhood victimization are generally well tolerated by women who participate, and that, although a small number may be disturbed by these investigations, in general, adverse reactions may be less common than previously anticipated.*

Introduction

The 1990s have witnessed a dramatic increase in the number of clinical investigations assessing emotional and medical correlates of sexual and physical victimization [1–7]. This growth has been accompanied by the development of increasingly sophisticated quantitative and qualitative assessment instruments with greater reliability and validity [8–12]. Because patients may have experienced multiple forms of victimization (i.e., both sexual and physical abuse) and may have experienced maltreatment over several episodes, newer investigative instruments have become longer and more complex, inquiring more comprehensively into the details of lifetime victimization experiences [13 and Krinsley et al., unpublished data].[1]

Beyond individual investigators' field experience, however, very little is known about the impact of victimization research on participants [14]. For instance, do questionnaires inquiring about prior episodes of exposure to trauma recreate distress in patients by again exposing them to their traumatic stimuli? Are respondents sufficiently aware of the potential distress they may experience so that truly free and informed consent for such inquiry is possible? Are trauma survivors able to accurately predict their level of anticipated dis-

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[1] Evaluation of Lifetime Stressors Questionnaire and Interview. Available from K. Krinsley, National Center for PTSD, Boston VAMC (116-B2), 150 South Huntington Avenue, Boston, MA 02130.

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tress? Can long-term coping strategies that are effective in managing a participant's adaptation to victimization be compromised by investigation?

Institutional review boards (IRBs), which are charged with the responsibility of balancing the rights and safety of research participants with the needs of scientific investigators [15], must answer these complex questions [16]. Surprisingly, there are few empirical studies to guide IRB members in deciding the risk-benefit ratios of particular protocols [17], and decisions are often influenced more by assumptions about the impact of research than the known facts, especially with respect to studies of violence and victimization [18]. Empirical evidence is needed to shape the ethics of research in a manner that simultaneously ensures that the well being of participants is preserved while allowing potentially useful clinical investigation into the etiology and treatment of long-term victimization sequelae [14].

As part of a larger study of long-term medical effects of early childhood and adult victimization, we included a scale designed to assess reactions to participation in the study. Three areas were of particular concern: 1) Do women feel that they obtain any benefit from participating in such an investigation? 2) Do the instruments create an unexpected degree of distress, and if so, do the women still feel it was a worthwhile experience? 3) If women could know in advance what the experience would be like, would they still participate?

To address these questions we included three items at the end of our questionnaire which inquired into the respondents' reaction to participation. Based on our previous experience with clinical and research interviews, we hypothesized that 1) as a group, the women who filled out the survey would generally find it to be a positive experience, that it would not be overly upsetting, and that most would still have agreed to participate even if they knew how they would feel beforehand; 2) compared with women with no victimization histories, those with such histories would report a higher degree of distress than anticipated after completing the survey, but that the absolute magnitude of the distress in that victimized group would be low, and that the majority of these women would report that they would have completed the survey nonetheless; 3) the intensity of unanticipated distress about completing the survey would correlate with severity of trauma exposure.

Methods

Setting

The study took place in 1995 among the members of Group Health Cooperative (GHC), a large HMO serving 450,000 individuals in Seattle WA. The sample was constructed by GHC's Center for Health Studies which sponsors medical research within the HMO. We selected all women aged 18–45 who were currently English-speaking GHC consumers, assigned a random number to each case, sorted the cases, and selected the first 500, thus giving each woman an equal opportunity for selection. Each was mailed a questionnaire as part of a larger study of long-term medical sequelae of childhood victimization. The center was responsible for mailing the questionnaire, tracking the responses, and sending second and third request letters to those participants who had not yet returned the questionnaire.

The 22-page questionnaire included portions of previously validated instruments whenever possible. The victimization portion of the questionnaire included selected categorical questions about the presence or absence of childhood abuse and assault adapted from two previously used instruments: the Childhood Maltreatment Interview [19] and the Sexual Experiences Survey [20]. The texts of these questions can be found in the Appendix. We reviewed potential questions from several existing instruments and chose these because they appeared to have the best face validity, the most clearly operationalized definitions, and they had been used in several previous studies. Our experience with these questions showed that they also had good convergent and discriminant validity with other measures of maltreatment. Minor modifications were made to the items, and each was elaborated into three ordinal categories (e.g., adult physical abuse: 0 = none, 1 = just once, 2 = more than once).

Our dimensional measure of trauma severity was a 34-item short form of the Childhood Trauma Questionnaire (CTQ) that was developed for use in this study [8]. The CTQ is a self-administered questionnaire that inquires about childhood maltreatment in five areas: emotional, physical, and sexual abuse, and emotional and physical neglect. Respondents complete a series of five-point Likert-type scales, and then the items are summed to produce severity scores for each subscale. Previous studies have supported the reliability and validity of trauma histories obtained using the CTQ, including their stability over time [8], convergent and dis-

criminant validity with structured trauma interviews [21 and Walker et al., unpublished data] and corroboration using independent data [22]. Although an initial factor analysis of the CTQ items produced a four-factor solution in which physical and emotional abuse items were loaded on a single factor [8], a replication study produced separate physical and emotional factors and was preferred for its face validity [22]. For this study, a short form of the CTQ was created by selecting items with the highest factor loadings in the studies described above. Analysis of item performance for the modified scale (i.e., item-factor correlations, internal consistency reliabilities) across five separate validation samples (N = 979) indicated that the CTQ short form retained the sound psychometric properties of the original version (D. Bernstein, unpublished data).

Several other dimensional measures of distressing physical and psychological symptoms were included in the questionnaire. The Post Traumatic Stress Disorder Checklist (PCL) [23] is a 17-item checklist based on the DSM-IV diagnostic criteria for PTSD. Each of the 17 symptoms is rated on a 4-point scale, ranging from not at all (1) to often (4). The PCL has good sensitivity (0.82) and specificity (0.83) relative to a cutoff score of 50 for a population of veterans, and has shown strong, positive correlations with several other standard measures of PTSD severity. The PCL can also be scored in direct correspondence to DSM-IV decision rules.

We also included items from the neuroticism (NEO) scale of the personality inventory [24]. Neuroticism is a general personality trait in which patients experience anger, disgust, sadness, anxiety, and a variety of other negative emotions. High levels of neuroticism are associated with poor coping and maladaptive responses to stress. The 12 items can be rated 1–5 and are summed up into a combined neuroticism score. The NEO is a widely used personality measure with excellent psychometric properties.

The three items we used to study the reaction to the questionnaire were selected from a novel instrument to assess potential benefits, psychological distress, and risk-benefit ratios in trauma research [27] (unpublished data)[2] and are listed in Table 1. Specifically, the constructs measured by these three questions are called "benefit, expected upset, and regret."

The final version of the questionnaire was reviewed by the Group Health Human Subjects Committee and approved to be sent as a confidential survey. Participants reviewed a consent form which stated that the return of the completed survey constituted an agreement of consent to participate.

Statistical Analysis

Data were entered into SPSS for Windows Version 6.0 and were cleaned and verified against the questionnaire. We first determined the demographic characteristics of the sample and computed the frequency counts for each of the reaction questions. We then computed Kendall tau-b correlation coefficients for correlations with interval variables and Spearman coefficients for correlations with ordinal variables for comparisons among each of the reaction questions and other distress measures within the questionnaire. Correlations with each of the three reaction questions were Bonferroni corrected, using a per comparison critical alpha = 0.006 (experiment-wide alpha = 0.05/8 comparisons per item).

Next we compared women with and without histories of childhood or adult victimization with respect to their degree of benefit, expected upset, and regret. Based on categorical questions about the presence or absence of abuse we divided women into four mutually exclusive groups: 1) no lifetime occurrences of any sexual or physical abuse; 2) childhood sexual or physical abuse only; 3) adult sexual or physical assault only; 4) both childhood and adult abuse and assault. Because sexual and physical assault can vary in intensity and reaction, we limited ourselves to more severe forms of victimization. Sexual assault was defined in the questionnaire as any form of penetration that was either involuntary or before the age of 16. Physical assault was defined as intentional infliction of physical injury before age 16 that resulted in a visit to a medical care provider. These groups were compared using one-way analysis of variance (ANOVA). Although the data on some of the dependent measures were moderately skewed, ANOVA produces results that are quite robust to modest violations of the normality assumption [25]. When a nonparametric Kruskal-Wallis test was performed on these same data for purposes of comparison, results were virtually identical.

We further identified characteristics of women

[2] Reactions to Research Participation Questionnaire. Available from E. Newman, University of Tulsa, Department of Psychology-Lorton Hall 308, 600 South College Ave., Tulsa, OK 74104.

Table 1. Frequency counts for questionnaire items concerning reactions from completing the survey $N = 330$

	Strongly disagree (no)	Disagree	Neutral	Agree	Strongly agree (yes)
1. I gained something positive from filling out this survey.	18 (5.5)	24 (7.3)	200 (61.2)	69 (21.1)	16 (4.9)
2. Completing this survey upset me more than I expected.	160 (48.9)	71 (21.7)	53 (16.2)	34 (10.4)	8 (2.4)
3. Had I known in advance what completing this survey would be like for me, I still would have agreed.	9 (2.8)	8 (2.4)	62 (19.0)	104 (31.8)	144 (44.0)

Numbers in parentheses indicate %.

who indicated that they were more *upset* by the survey than they had expected (those who chose 4 or 5 on question #2), or who might not have consented had they known in advance how they would react (those who chose 1 or 2 on question #3) and were *regretful*. We then compared the women with and without upset and regret with respect to the other distress measures in the survey, as well as the prevalence of various forms of victimization.

Results

Of the 500 surveys initially mailed, 330 or 66.0% were returned. The women had a mean ± SD age of 35.6 ± 7.5 years. Half had completed college, the median income was approximately $40,000, and 47% were married. The demographic characteristics of the sample were similar to those found in the population of 18–45-year-old women served in the HMO. Comparison with the 170 (34.0%) women who did not return the questionnaire could only be made with respect to age and location of residence (as indicated by zip code), but there were no significant differences on either variable.

Table 1 shows the frequency counts for the three questions. More than 25% of the women felt that they gained something positive from completing the questionnaire, and only 13% felt they did not. When asked whether they would still complete the survey even if they knew in advance how they felt, 76% said they would, with 5% saying they would not.

Despite the sensitive nature of the items in the questionnaire, only 13% of the respondents felt that the experience was more upsetting than they had anticipated. To further understand the characteristics of women who may have found the survey unpleasant we computed correlations with several other distress variables in the survey. Item #2 of the scale (expected upset) was significantly correlated with several other measures of distress in the questionnaire, whereas the other items were not. After Bonferroni correction for multiple comparisons, item #2 was significantly correlated with the CTQ total score ($r = 0.30$), sexual abuse ($r = 0.21$), emotional abuse ($r = 0.29$), physical neglect ($r = 0.18$), and emotional neglect ($r = 0.27$) subscale scores, as well as the PCL total score ($r = 0.28$) ($df = 325$, $p < 0.001$ for all correlations). The correlation of the CTQ total score and the PCL total score with item #2 remained significant after controlling for scores on the NEO (partial correlations, $r = 0.28$, $p < 0.001$ and $r = 0.20$, $p < 0.001$, respectively), suggesting that correlations with item #2 were attributable to reported trauma and trauma-related symptoms and not to general distress (i.e., neuroticism).

Responses to the three questions about participation were compared next using mutually exclusive, lifetime categories of victimization, illustrated in Table 2. Women were classified as having no lifetime abuse (no abuse), either child physical or sexual abuse, but no adult assault (child only), adult sexual or physical assault without prior childhood history (adult only), or previous sexual and physical abuse before and after age 16 (both times). The Table shows the one-way ANOVA findings across the four groups. The groups differed significantly in their responses to items #2 and #3, with the main differences between the abused and nonabused groups.

There were 42 (12.8%) women who reported unexpected upset and 17 (5.2%) who reported regret. Only 4 (1.2%) who reported unexpected upset disagreed that they would still complete the survey even if they had known in advance what participation would be like. Table 3 shows differences be-

Table 2. Differences in satisfaction, upset, and regret in women who did and did not report previous victimization

	No abuse $N = 158$	Child only $N = 49$	Adult only $N = 63$	Both times $N = 60$	F (df = 3326)	p
1. I gained something positive from filling out this survey.	3.03	3.16	3.21	3.27	1.51	n.s.
2. Completing this survey upset me more than I expected.	1.68	2.00	2.10	2.48	8.23	$<0.001^{a,b}$
3. Had I known in advance what completing this survey would be like for me, I still would have agreed.	3.97	4.33	4.16	4.30	2.64	$<0.05^{c,d}$

One-way Anova.

[a] Difference between no abuse group and adult abuse group < 0.05.

[b] Difference between no abuse group and both group < 0.05.

[c] Difference between no abuse group and child abuse group < 0.05.

[d] Difference between no abuse group and both group < 0.05.

Table 3. Comparison of women with and without upset and regret with respect to the other distress measures

	Upset ($N = 42$) (mean ± SD)	Not upset ($N = 288$) (mean ± SD)	t	df	p
NEO	35.2 ± 8.1	31.6 ± 9.3	2.43	310	<0.02
PCL	35.9 ± 12.1	28.0 ± 11.1	4.10	309	<0.001
CTQ	10.8 ± 4.2	8.0 ± 2.9	3.72	297	<.001
	Regretful ($N = 17$)	Not regretful ($N = 313$)	t	df	p
NEO	33.9 ± 8.7	31.9 ± 9.3	0.83	310	n.s.
PCL	26.5 ± 8.6	29.1 ± 11.6	−0.88	309	n.s.
CTQ	8.9 ± 3.9	8.3 ± 3.2	0.68	297	n.s.

tween women who expressed unexpected upset (choosing 4 or 5 on question #2) or regret (choosing 1 or 2 on question #3). Women who were unexpectedly upset about the survey reported significantly higher distress scores on the NEO, the PCL, and the CTQ. The women who reported regret showed no significant differences on these three measures.

Discussion

This study found that most women who completed a questionnaire including sensitive items about early childhood and adult forms of victimization generally found the experience to be a positive one. Only a small number of women were more upset than they had expected and the vast majority felt that they would have completed the survey even if they had known in advance how they would feel. The minority of women who expressed either distress were significantly different from those who did not with respect to other measures of symptomatic distress including a measurement of NEO and symptoms consistent with the diagnosis of PCL. In addition, those who expressed distress reported a significantly higher degree of exposure to traumatic events during childhood.

Care should be taken in generalizing the results of this study. This was a secondary analysis of a data set collected for another purpose (the study of long-term effects of early childhood victimization). Though the women who returned questionnaires closely resemble the general population from which they were drawn with respect to demographics, we do not know if there were other factors such as reactions to the survey itself that resulted in differential return rates for the questionnaire [26]. This

could result in biases in either direction (i.e., that women who were upset by the survey did not return it, thus resulting in an underestimation of the negative effects of the questionnaire; or that women who were less upset failed to return the questionnaire due to its lack of salience for them, thus overestimating the degree of distress). The prevalence rates for each form of maltreatment (unpublished data, EA Walker), however, were similar to other previously published population estimates, suggesting that the group of women who returned questionnaires is representative of the larger HMO population from which it was drawn.

Another limitation is that it is not known whether equivalent results would have been obtained during the research protocol if the scale were used with an interview instead of a questionnaire. Interviews, which require the interpretation of overt and subtle interpersonal cues and involve direct disclosure of information to another person, may represent a variety of new risks and challenges for a trauma survivor engaged in research. Our methodology must be tested in these settings as well. It is reassuring, however, that early findings from the interview phase of our study (currently in progress, $N = 25$) using the same scale show that a similar distribution of responses is reported both immediately after an intensive trauma-focused interview and at a later follow-up assessment 48–72 hours after interview. This suggests that both interview and questionnaire forms of reaction assessment may be comparable and that there appears to be short-term stability of self-assessment.

To our knowledge, despite these limitations, the strength of this study is that this is the first time the reaction of participants to victimization research has been objectively studied. This information is potentially valuable to researchers and IRB members who must carefully balance the scientific requirements of clinical researchers and privacy needs of patients. Overall it appears that the inquiry into sensitive areas such as previous victimization, though not without some consequence, may be less traumatic than many have supposed. The presence of some negative reaction is clinically reasonable in that it would be expected that not all women should face such investigation with equanimity. The small number of women who did report distress and regret suggests that the questions (which have good face validity) are sensitive enough to pick up this distress. It is important to note, however, that in addition to the assessment of traumatic experiences, the questionnaire also included questions about marital satisfaction, abortions, birth control, and sexually transmitted diseases. It is not clear that all of the expressed distress was the result of reactions to the trauma questions. Future research to examine the specificity and intensity of the discomfort will be important in this methodology. As such data accrues, researchers can anticipate potential specific problems and design methods and policies (e.g., follow-up services, specific informed consent forms, screening policies) to facilitate positive outcomes for all research participants.

From the perspective of informed consent, it appears that most women correctly anticipated their reactions to the survey. Only 42 (13%) of the 327 women were more upset than they had anticipated, but of that group of 42 women, only 4 (1.2% of the entire returned sample) felt that they regretted participation. Thus, even though this minority experienced some discomfort with the instrument, more than 90% of those who experienced distress did not regret participation and felt that they had gotten something positive out of the experience. This suggests that evaluating subjective distress alone is not sufficient to judge the impact of a sensitive questionnaire as most women appear to be willing to experience some distress and still perceive benefit from participation. It is impossible to know how many of the women who did not return surveys would have been distressed by the experience; however, it is reassuring to know that the vast majority of those who chose to participate appear to have given fully informed consent, despite the presence of very sensitive questions.

One possible interpretation of our findings is that women who expected to be upset (and were) and those who did not expect to be upset (and were not) answered the perceived distress question the same way. However, the main goal of this reaction assessment is not the measurement of distress in and of itself, but the adequacy of informed consent and the person's ability to anticipate his or her own risk for harm. In this way it becomes meaningful to those charged with the responsibility of protecting individuals from unnecessary exposure to possibly traumatic experiences in the conduct of research. It appears that for the majority of participants in this sample, current informed consent procedures are adequate and that most trauma survivors are capable of anticipating their threshold for psychological risk.

It is interesting that the minority of women who were more upset than they had anticipated also had

higher PCL, NEO, and CTQ scores. Although it is likely that the distress identified by item #2 is related to the questionnaire items about prior traumatic experiences, it is also possible that this distress partially arises from a more general, chronic distress unrelated to the victimization. By controlling for the effects of the NEO score, however, it appears that general distress adds very little to the correlation between self-reported distress and measures of trauma exposure and symptoms, suggesting that item #2 reflects a more specific assessment of trauma-related distress, although the absolute intensity of the distress is not specified. Most importantly, however, the great majority of women who reported distress did not express regret, indicating that their distress was within tolerable limits.

The methodology of this study suggests a way to further investigate the risks and benefits of studying trauma so that viable and safe protocols may be implemented [7]. Evaluations of the social, psychological, and economic costs of participation can routinely be incorporated into ongoing studies, yielding empirical data that help investigators develop realistic estimates of the risks and benefits of victimization research. Individuals need to be protected from unnecessary revisitations of painful experiences to which they may have successfully adapted, but it is equally important to recognize the long-term benefits to all trauma survivors of empirical research that articulates the components of effective strategies for coping with trauma. As the future needs of victims and researchers are carefully weighed by researchers and IRB members, the balance of privacy, compassion, and scientific inquiry should be increasingly based on the solid methodologic ground provided by empirical data.

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APPENDIX

Questions Used in the Categorical Assessment of Maltreatment

Before age 16 did a parent (or any adult in charge of you) ever do something harmful (e.g., hit, kicked, or punched you) that gave you injuries requiring a trip to a doctor or hospital?

Before age 16 did anyone *who was NOT about the same age and social status* touch your breasts or genitals or ask you to touch theirs when you did not want to?

Before age 16 did any man ever use force to put his penis into your vagina, mouth or anus, either when you did not want to, or when you had gotten high or drunk?

Before age 16 did any man ever force you to endure other sexual things such as putting his mouth on your genitals or putting fingers or objects inside of your vagina or anus?

After you were 16 years old did any man ever use force to put his penis into your vagina, either when you did not want to, or when you had gotten high or drunk?

After you were 16 years old did any man ever try to do sexual things like oral sex, anal sex, or put fingers or objects inside of you, either when you did not want to, or when you had gotten high or drunk?