



## Sexual Assault Victims Participating in Research: Causing Harm When Trying to Help?



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### ABSTRACT

For fear of causing unnecessary distress, ethical concerns have been raised in regard to asking vulnerable persons e.g. sexually traumatized victims to participate in scientific research studies. The current study investigates how victims of sexual assault perceived participating in scientific research in regard to victims' psychological and/or physiological distress and potential beneficial outcomes from participation (N = 51). Results from interviews with victims indicated that the majority of victims of sexual assault who had taken part in the study considered their participation in research a positive experience causing little short- or long-term psychological or physiological distress. In addition, over half of the respondents reported some benefits from participation.

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As focus has increased around the world on victims of sexual assault and the psychological and physiological consequences following sexual assault the amount of trauma-focused research on this population has also increased over the past two decades (Backes, 2013). This raises ethical questions regarding the potential risks for victims when participating in trauma-focused research. The question many lawyers, board members of ethical committees and mental health professionals are concerned with is whether researchers are in fact re-traumatizing those, they are trying to help. One of the main reasons for doing research on sexual assault is to shed light on issues that might lead to changes and improvements for survivors of sexual crimes. Mental health professionals have an ethical responsibility to conduct research that minimizes harm to victims and not seldom are they faced with questions from other mental health professionals (psychologists, nurses, psychiatrists) working with victims of sexual crimes who are concerned about research participation re-opening old wounds or actually re-traumatizing these victims. However, to the best of our knowledge, no one has yet investigated specific psychological and physiological distress symptoms over time following sexual trauma-focused research participation. Victims should be given an opportunity to articulate how research participation actually affects them when researchers and mental health professionals continue to ask them to participate in research – even if they feel justified in doing so for the greater cause of improving victims' lives in the wake of a sexual assault. The purpose of the current study is therefore to address an ethical concern in relation to collecting data among sexual assault victims investigating

specific psychological and physiological symptomatology over time that may occur or re-occur as a consequence of participating in research.

### *Victims of Interpersonal Trauma and Research Participation*

Within the past two decades a number of studies have shed light on such ethical concerns by investigating why victims of trauma agree to participate in research and what effect this participation has on them. Several reviews have looked at studies examining distress following participation in trauma-focused research in general (Bonde, Johannsen, Bramsen, & Elklit, 2012; Jorm, Kelly, & Morgan, 2007; Legerski & Bunnell, 2010; McClinton Appollis, Lund, de Vries, & Mathews, 2015). Combined, most studies conclude that only a minority of participants become distressed immediately after participation in trauma-focused research, and there is currently no solid evidence to suggest long-term adverse impact on research participants. However, the overall picture is far from clear since studies diverge on issues of methods, such as types of trauma, sampling strategies, definitions, and research designs (Fontes, 2004; Newman & Kaloupek, 2004). Hence, it makes sense to look at studies of more specific traumas.

Trauma-focused studies on assault victims (victims of domestic violence and other violent assaults) have looked at research participation and distress from participation in scientific research. In a study from Ruzek & Zaitzick (2000), they found that 25% of victims of violent assaults (and motor vehicle accidents) reported being more upset by research participation than they themselves had anticipated while only 6% reported regretting participation. In comparison, Johnson & Benight (2003) found the numbers to be 32% and 2% respectively for victims of domestic abuse.

However, it could be argued that victims of sexual assault constitute a more vulnerable group when participating in trauma-focused research since sexual trauma is typically considered a more sensitive

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topic compared to other types of trauma, due to the risk of evoking intense and painful emotions and memories (Draucker, 1999) as well as shame and guilt. Numerous studies have looked at the ethical concerns surrounding sexual assault victims' research participation.

Two studies have attempted to evaluate the impact of participation in childhood sexual trauma-focused research. In a study by Carlson et al. (2003) of 206 psychiatric in-patients a majority (70%) of participants rated relatively low levels of distress while 51% of participants found the experience relatively useful. In another trauma-focused health-survey including questions regarding childhood sexual abuse, Newman, Walker, & Gefland (1999) demonstrated that although individuals with a history of sexual maltreatment were more likely to underestimate their level of distress from research participation than individuals without a history of sexual maltreatment, no one wished to stop the interview when they were given an option to do so and the majority (98%,  $n = 168$ ) reported that they did not regret participating.

One study on both childhood and adult victims of sexual victimization ( $N = 330$ ), Walker, Newman, Koss, & Bernstein (1997) reported that 13% ( $n = 42$ ) of the participants experienced research participation as more upsetting than they had anticipated but only 1% ( $n = 4$ ) of these respondents reported that they would not have completed the survey if they had known in advance what participation would be like.

Finally, two studies of adult victims of sexual assault have investigated the impact of research participation. Griffin, Resick, Waldrop, & Mechanic (2003) indicated that despite a very extensive psychological and physiological assessment following a sexual assault, a majority (62%,  $n = 105$ ) of participants rated the experience (filling out a paper and pencil questionnaire) as not distressing. Most victims found their research participation both positive and interesting. In a study of 1056 college women's reactions to sexual assault research participation (Edwards, Kearns, Calhoun, & Gidycz, 2009), 3% of the participants reported some form of sexual victimization and negative emotional reactions but 27% of these also reported personal benefits to participating in the research. And although 85% reported that personal costs outweighed the personal benefits, 79% reported that they still would have participated in the study if they had known in advance what it would be like.

#### *Benefits From Research Participation*

A number of studies have also looked specifically at potential benefits from participating in sexual trauma-focused research for both victims of childhood sexual abuse and adult survivors of rape: In the above-mentioned study by Carlson et al. (2003) 51% of participants found research participation useful in some way (e.g. lead to new insights, felt like a relief, remembering positive aspects of life) and in the study by Newman et al. (1999) 74% of participants reported benefits 48 hours after research participation ("I gained something positive from filling out this survey") while 86% of participants reported benefits from research participation at 3–12 months follow-up. A qualitative study of 92 adult rape survivors participating in in-depth interviews Campbell, Adams, Wasco, Ahrens, & Sefl (2010) found that the majority of participants reported participation helpful and a supportive and insightful experience. Only 4% found the experience an unmitigated negative experience. In a study investigating the reasons adult rape survivors participate in research interviews, Campbell & Adams (2009) found that most commonly it was to help other victims (38%) followed by a way to help themselves and their own recovery (34%).

In sum, between 70% and 80% of respondents are not highly distressed by participating in sexual and physical assault trauma-focused research (Campbell et al., 2010) and a majority of participants who do experience strong emotional reactions to participating in trauma-focused research do not regret their participation in research (Newman & Kaloupek, 2004) or view their experiences negatively (Cook, Swartout, Goodnight, Hipp, & Bellis, 2014). In addition, existing

research indicates that between 27% and 96% of victims of sexual assault report some form of benefit from participating in sexual trauma-focused research (Campbell et al., 2010; Carlson et al., 2003; Edwards et al., 2009; Newman et al., 1999).

#### *Current Study*

Based on the above studies, what seems to be known, is that only a minority of victims become distressed immediately after research participation, and that there currently seems to be a lack of studies regarding long-term effects. To date, to the best of our knowledge, no study has investigated both specific psychological and physiological distress symptoms over time as well as potential beneficial outcomes from participating in research. In order to generate more detailed knowledge regarding potential harmful practices in the area of sexual trauma-focused research the current study set out to explore the experiences of a sample of Danish victims of sexual assault participating in research by posing specific questions regarding revictimization and potential benefits. The current study investigated the following three research questions: (i) Does answering a set of research questionnaires regarding an experienced sexual assault cause specific psychological and/or physiological distress symptoms? (ii) Do these distress symptoms persist over time? And (iii) does participating in a research project have any potential beneficial outcomes for the victims?

## **METHODS**

### *Setting*

In 1999, Denmark established its first regional center for victims of rape and sexual assault (Center for Rape victims in Aarhus - CRV) serving male and female victims of rape and sexual assault from 12 years of age and up. The Danish CRV covers a catchment area in the western region of the country of approximately 1.3 million residents, offering specially trained nurses, medical treatment if needed, forensic examination, counseling by licensed psychologists, and facilities for police questioning if requested, all in one central location in the emergency room in conjunction with the university hospital. Services are free of charge and available 24 hours, 7 days a week (for more details see Bramsen, Elklit, & Nielsen, 2009). All victims who contact the CRV are automatically enrolled in the ongoing data collection taking place at the CRV. Following verbal consent all victims receives three self-report questionnaire packages (T1 = within the first month post-assault, T2 = 3 months post-assault, T3 = 6 months post-assault) as part of an ongoing research and clinical follow-up strategy to improve quality of treatment at the CRV.

### *Participants and Procedure*

The present study was based on sexual assault victims' experiences of participation in the ongoing data collection taking place at the Danish CRV as described above. The sample for the present study consisted of victims who received services at the CRV from October 2011 to January 2012. All T3 questionnaire packages that were sent out from the Danish CVR in this period also included an introductory letter about the present study, including information on study rationale, study procedure and voluntary participation. Victims were contacted for a telephone survey within 2 weeks after receiving the T3 questionnaire package. Sixty-three female victims were included in the telephone survey. Fifty-three women participated in this study and 10 women declined participation. Among the 10 women who declined participation, three declined because of "discomfort", four reported "not feeling like it/not having the time", and three had "other reasons" for declining. An additional two women were excluded from the final sample due to too many missing responses. Hence, the final sample consisted of 51 female victims of sexual assault and this sample represents the dataset for the current study.

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