The Utility of the RRPQ in Assessing the Costs and Benefits of Participating in Trauma Research within the South African Context

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ABSTRACT

Across all disciplines, research needs to follow certain ethical guidelines in order to protect participants from harm. These principles include autonomy, beneficence and non-maleficence. Previously within trauma research, these principles have been adhered to by means of subjective assessments due to the absence of empirical data. This created difficulties in accurately identifying the possible costs and benefits of research participation in trauma studies. The Reactions to Research Participation Questionnaire (RRPQ) by Newman, Sinclair and Kaloupek (2001) is a recently developed empirically based questionnaire which requires participants to self-report their perceived costs and benefits of participating in trauma research. This study aims to use this measure for the first time within the South African context, in order to determine whether the factor structure of this questionnaire found in other studies, is applicable to the South African context. Data were collected in two phases. Phase 1 involved using a structured questionnaire which surveyed child abuse experiences and the RRPQ which evaluated participants’ reaction to research participation. Phase 2 occurred as part of a two week follow up to assess short-term effects of Phase 1 participation. Results indicated that research participation was well tolerated with the majority of respondents reporting satisfaction with their participation (65%) and personal benefit as a result of participating (56%), as well as positive risk-benefit ratios (67%). A sizeable proportion of respondents (31%) found participation distressing; with 13% of respondents reporting distress at a two week follow up. Research findings provided no evidence that participation was experienced as re-traumatising. This study therefore has important implications for future research within the field of trauma, and for the possibility of redefining the ethical paradigm which has thus far dominated trauma related research.
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CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1. INTRODUCTION

Within the field of trauma research, there are few empirical studies which have been conducted on the impact of trauma research on respondents, due to the scarcity of objective measures for measuring the impact of trauma research, as well as the strict ethical code that has been implemented for the protection of participants. In the past, trauma research has primarily been conducted using subjective measures which were biased by common decision-making errors and an over reliance on case examples. This has resulted in ethical concerns which have stringently been aimed at protecting participants from foreseeable harm that might arise due to participation and consequent re-traumatisation.

However, recent literature indicates that objective measures that have been implemented in some trauma related research studies (see Newman & Kaloupek, 2004; and Newman, Willard, Sinclair and Kaloupek 2001) have provided results which contradict prior assumptions about the nature and extent of distress experienced by respondents. These research studies indicate that distress is not experienced beyond minimal risk; that distress does not equate to regret; and that respondents perceive equipoise between the risk and benefits associated with their participation. As a result, ethical guidelines surrounding trauma research need to be redefined in order to incorporate these new objective findings.

1.2. RATIONALE

Across all disciplines, research needs to follow certain ethical guidelines in order to protect participants from harm. Within the field of psychology, these include the principles of beneficence, non-malificence and autonomy. Previously within trauma research, these principles have been adhered to by means of subjective assessments and judgements due to the absence of empirical data. However these subjective evaluations of the risks and
benefits involved in research are not empirically based or scientific in nature, which makes it difficult to correctly identify the possible risks and benefits crucial for conducting ethical research, especially within the field of trauma or disaster research. The Reactions to Research Participation Questionnaire (RRPQ) developed by Newman, Willard, Sinclair and Kaloupek (2001) is a recently developed empirically based questionnaire which asks participants to self-report the perceived costs and benefits of participating in trauma research. This study will use this measure for the first time within the South African context, in order to determine whether the factor structure of this questionnaire, found in other studies, is applicable to a culturally diverse South Africa. Results of this study can open the doors for future research on scientifically based methods which can help identify the costs and benefits perceived by respondents in trauma research. This study represents a move toward a more empirical approach to trauma research and the ethics involved.

1.3. AIMS OF THE STUDY

The aim of this research study is not only to respond to the need for more research on trauma related areas, but its primary focus is to establish whether the extent and nature of recent empirical findings based on objective measures such as the RRPQ is applicable and relevant to the South African context. This issue will be addressed in order to determine the validity and reliability of the tool in our diverse context.

Identifying the perceived costs and benefits of research as determined by traumatised participants is also an area that will be explored within this study in relation to the current ethical principles which govern research related to trauma.

Identifying the duration of distress experienced by participants in trauma research will also be explored using a study comprising two phases in order to identify whether distress or emotional upset experienced during trauma related research is present at a two week follow up.
1.4. **STUDY DESIGN**

This study is a quantitative study which made use of secondary data, as data were obtained from an electronic database. The study employed a sample of South African university students in order to determine whether perceived costs and benefits of participating in trauma research could be empirically measured by an objective tool such as the RRPQ. The study consists of two phases: The first phase employed statistical measures to determine the validity of the RRPQ measure in a South African sample. A factor analysis was also performed in order to determine the factors that emerged from the data and the extent to which these related to the original factor structure identified by Newman and her colleagues. The perceived costs and benefits of research participation were also identified in this phase. The second phase, which took place two weeks later, was designed to determine whether levels of distress (if experienced) were still present after a period of two weeks.

1.5. **RESEARCH HYPOTHESIS**

This research study hypothesizes that the factors of the RRPQ found in international studies will be relevant and applicable to the South African context, with the RRPQ being implemented as a valid and reliable objective tool for trauma research. Furthermore, results of this study are expected to be in line with previous objective studies on trauma which postulate that participation is beneficial to respondents and that equipoise is met. Regarding the duration of distress, it is expected that distress will be transient in nature without any persistent distress present in the majority of respondents.

1.6. **STRUCTURE OF THESIS**

A brief background to the study has been provided, together with the rational, aims, study design and hypothesis which allow the reader to gain a general sense of what the thesis is about.
In the following chapters, a review of literature will be provided in order to help the reader engage with studies on trauma research that are currently available. This review allows the reader to become familiar with the ethical principles involved in research and enables them to become aware of the ethical dilemmas that arise within the field of trauma research. The bulk of available research focuses on the Reactions to Research Participation Questionnaire (RRPQ) and the perceived costs and benefits that have been objectively identified using this measure. Finally the application of this measure is discussed.

The methodology section provides the reader with an in-depth description of the research questions addressed by the thesis, the sample selected, the procedure of the study as well as the instrument used and possible ethical issues that may be relevant to the study.

The results of the study are then presented under the data analysis section and the implications of these results are discussed.

The discussion first addresses the results and their relevance to the research questions outlined in the methodology section. Thereafter, the results are discussed in relation to past research studies explored in the literature review. Finally the implications of the study findings are discussed.
CHAPTER TWO: LITERATURE REVIEW

2.1. INTRODUCTION

The literature review is structured to provide a general understanding of literature surrounding trauma research. Firstly, the core ethical principles of research are provided which are important for understanding the rights given to respondents, and the rights which are expected to be valued and considered by researchers before collecting data from participants. Secondly, the ethical principles which become a cause for concern for trauma researchers are discussed in relation to how they have been informed by previous research which has been based on subjective measures that have assumed that trauma research violates the basic ethical rights of respondents. The newly developed measure, the RRPQ, is thereafter discussed as the first empirically based measure that can be used to objectively identify risk, benefit and perceived distress of respondents participating in trauma research. Finally the implications of this measure for use within the South African context are discussed.

2.2. THE CORE ETHICAL PRINCIPLES OF RESEARCH

Across all disciplines, research on human subjects need to follow certain ethical guidelines in order to protect participants from potential harm or stress. Within the field of psychology, these include the core principles of autonomy, beneficence and non-maleficence and their related concepts. A description of these concepts will now be presented.

2.2.1. Autonomy

The principle of autonomy involves the recognition of both the independence and capabilities of the individual, which allows for individuals to enact their own decisions and choices. It also acknowledges the need to protect individuals with diminished autonomy (Kaloupek & Newman, 2009).
2.2.2. **Informed Consent**

Autonomy strongly relates to the principle of informed consent. Informed consent refers to the individual’s ability to reflect on provided information and then make an informed decision using their autonomous ability. A person can provide informed consent to participate in a study provided that they are competent and are capable of making such a decision; that they understand the information (i.e. they comprehend the risks, benefits and procedure), and are able to rationally evaluate this information, including limits to confidentiality and anonymity in the study; and that they consent to participate voluntarily and are not coerced in any way (Ezekiel, Grady, Crouch, Lie, Miller & Wendler, 2008; Newman, Walker & Gefland, 1999). The above explanation indicates that respondents need to possess decision-making capacity which refers to the ability to understand factual information and the implications of it (Newman & Kaloupek, 2009). Consideration of these factors are meant to protect people from being exploited and manipulated by scientific researchers; as by asking participants for informed consent researchers provide them with the opportunity to decide for themselves whether participation will be in their best interests and whether it involves risks they are not willing to take.

2.2.3. **Confidentiality**

Confidentiality is another important ethical principle which stipulates that there should be some form of fidelity and trust between the researcher and the participant. Confidentiality is meant to guarantee some form of anonymity to the participants so that they will be comfortable providing private and sensitive information knowing that they will not be identified by the information they provide.

2.2.4. **Beneficence and Non-Maleficence**
The principle of Non-maleficence is usually translated as ‘do no harm’ as it aims to minimise prospective harm and injury to participants. Complementing this principle is the principle of beneficence which essentially aims to maximise potential benefits of the research, which are weighed against the possible costs and risks of the research to the individual (Newman & Kaloupek, 2009). There are subtle differences between costs and risks, with costs defined as transient discomfort experienced and risk identified as lasting psychological or physical harm (Newman & Kaloupek, 2009).

2.2.5. **Minimal Risk**

Minimal Risk is also an ethical principle which needs to be adhered to, with the requirement being that “the probability and magnitude of harm or discomfort anticipated in research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examination or tests” (Ezekiel et al, 2008).

2.2.6. **Equipoise**

Equipoise refers to the need for a balance between the risks and benefits involved in research in order for it to be conducted. Potential risks or costs of the research need to be relatively balanced by the potential benefits in order for equipoise to be present and for research to be acceptably conducted.

2.2.7. **Concluding Comments**

Ethical committees, such as Institutional Review Boards (IRBs), are set up to ensure that research studies adhere to the above ethical guidelines. The reason for this is the obvious need to protect participants from probable and potential harm they might be exposed to during research participation. Consequently, research studies which pose high risk or stress to participants with low benefits are deemed unethical and unsuitable to be conducted.
One field of research which has been neglected due to the possible risk it might pose to participants; is the field of trauma research. Although this is an important area of research, with few research studies available, and consequently many areas for exploration, research is still scarce in the field. The reason for this is due to the general assumption that this sensitive area of research is more likely to pose possible danger and harm to participants, as they have been exposed to or have experienced some kind of trauma, which makes them more vulnerable to the risks associated with participating in research. These ethical concerns will now be discussed.

### 2.3. ETHICAL CONCERNS WITHIN TRAUMA RESEARCH

The aim of trauma research is to increase understanding in order to prevent traumatic events and their dire consequences and to intervene and alleviate these consequences (Newman, Risch & Kassam-Adams, 2006). However these aims are not given many opportunities to be realised, due to the many ethical issues and concerns regarding the sensitive nature of the research and the vulnerability of participants. Ethical principles and ethical dilemmas which manifest within the field of trauma research will be discussed to provide the reader with an understanding of the various concerns ethical committees are faced with.

#### 2.3.1. Autonomy and Decisional Capacity

Ethical principles such as autonomy and decision-making capacity become a concern when researchers question the competency of traumatised individuals to provide informed consent and exercise their decisional capacity, due to diminished autonomy and vulnerability which places them at risk of coercion. A few studies have reported exclusions of participants by health professionals due to concerns about their decisional capacity and the effects the research may have on them (Newman & Kaloupek, 2009). In a study on the