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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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DECLARATION

Submitted in partial fulfillment of the requirements for the degree of Masters in Psychology, in the Graduate Programme in Social Sciences, University of KwaZulu-Natal, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. I confirm that an external editor was not used. It is being submitted for the degree of Masters in Psychology in the Faculty of Humanities, Development and Social Sciences, University of KwaZulu-Natal, South Africa. None of the present work has been submitted previously for any degree or examination in any other university.

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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.

Contents

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

World Trade Centre, 3 out of 100 individuals were excluded due to their critical traumatic state which prevented them from participating; with another study finding decisional incapacity to be highest among hospitalised psychiatric inpatients where 13% of participants were excluded on the basis of poor mental or medical capacity (Newman & Kaloupek, 2009). On this basis, many IRBs and ethical committees do not grant approval to research studies which target traumatised individuals as they want to protect these individuals from unnecessary harm.

Many trauma researchers would, however, challenge these assumptions with the general consensus within trauma research being that decisional capacity is not impaired as a result of exposure to trauma and that there is a relative absence of decisional incapacity for this group (Newman & Kaloupek, 2009). Additionally there is no evidence that experience with trauma impairs an individual's ability to make an informed decision to participate in a study (Newman & Kaloupek, 2004). The above consensus fosters and acknowledges the principle of autonomy because if research studies completely exclude traumatised individuals from participating, not only does it violate their right to autonomy, which states that they should be given the right to choose whether to participate or not; but by rigidly adhering to these guidelines with the intention of protecting vulnerable, traumatised individuals, we may run the risk of further stigmatising traumatised individuals by discriminating against them (Newman, Risch & Kassam-Adams, 2006).

Simmerling (2006) argues that the current ethical paradigm, which considers people with experiences of trauma as vulnerable or with diminished autonomy and requiring more protection from risks and coercion, is actually disrespecting of these trauma survivors rather than protective of them. In her study using survivors of sexual assault, Simmerling (2006) states that the preconceived idea of trauma survivors held by IRBs and ethical committees, disrespects them in ways related to the trauma or violence they have already experienced. Considering them as vulnerable, diminished and less able to choose freely suggests that the traumatic experience "has had the effect of necessarily, intrinsically, and permanently reducing them as people", which may exacerbate any symptoms they may be experienced

(Simmerling, 2006). Simmerling suggests that talking to trauma survivors about their experiences may in fact be more beneficial and therapeutic than risky and/or harmful.

2.3.2. Informed Consent and Mandatory Reporting

Researchers have questioned whether people with a history of exposure to trauma are able to accurately predict the degree of distress they will feel when asked to answer intimate questions about their experiences of trauma; or to disclose personal information regarding their thoughts, feelings and experiences of a traumatic event (Grifin, Resick, Waldrop & Mechanic, 2003). Failure to accurately anticipate levels of distress associated with the memory of trauma thus results in the inability to provide informed consent as defined by ethical principles because participants are not effectively fully informed prior to consent (Grifin, Resick, Waldrop & Mechanic, 2003 and Newman, Risch & Kassam-Adams, 2006). Research studies which aim to evaluate this concern have been limited, but one study assessed informed consent among female sexual assault survivors in crisis. These women were contacted 72 hours after receiving medical care. They were provided with informed consent forms which requested them to participate in the study. Although they agreed to participate at the time, when they were contacted 10-39 months later, 14 out of 15 women in the sample did not remember providing consent. However, an equal number of participants stated that they would be willing to participate in future studies of the same nature (Grifin, Resick, Waldrop & Mechanic, 2003). It should be noted, however, that just because information was not encoded into the long term memory of these participants, this does not mean that consent was not provided at the time.

Authors of other studies have also provided guidelines on informed consent procedures in order to ensure that important and critical research within the field of trauma can be conducted. Newman and Kaloupek (2009) suggest that detailed information be provided in informed consent documents which can assist participants to weigh the personal costs and benefits of the research experience, as well as guidelines on how to manage emotional reactions should they occur. However the authors also suggest that this information be

given sensitively so as not cause undue anxiety or expectations of an unpleasant experience which can reduce beneficence. Newman and Kaloupek (2009) also suggest the need for more research on how informed consent procedures affect participants' experience of research.

When working with children who have experienced some form of developmental trauma (for example sexual, physical or emotional abuse) concerns around the principle of confidentiality and informed consent arise (Mudaly & Goddard, 2009). This is mainly due to mandatory reporting which postulates that if the researcher becomes aware during the process of research of ongoing abuse which the child may be subjected to, then he/she is ethically obligated to report it. However, reporting knowledge of abuse, which supports the principles of autonomy and beneficence; would mean violating confidentiality, anonymity and fidelity between the researcher and the participant which are also important ethical considerations (Newman, Risch & Kassam-Adams, 2006; Mudaly & Goddard, 2009). In order to arrive at a compromise, researchers such as Newman (n.d.) have suggested outlining the limits of confidentiality in the informed consent procedures so that if mandatory reporting applies, participants do not feel betrayed by the researcher.

However, within the field of trauma, there are concerns that a highly detailed warning about duty to report in informed consent will eliminate from the sample the very people the researcher hopes to study (either by them self-selecting not to participate or by changing their responses when they do); and whether the child and family will suffer more if the suspected abuse is reported or not (Newman, n.d.). A lack of empirical studies on the effects of disclosure of mandated reporting in informed consent leaves many researchers without guidelines on how to navigate this field of ethical dilemmas (Newman, n.d.).

2.3.3. Vulnerable Populations

Some researchers like Mudaly and Goddard (2009) and Collings (2011) have attempted to provide insight on how to deal with vulnerable populations such as children when

performing trauma related research. Mudaly and Goddard (2009) consider the rights of children's welfare and their right to be heard which appear to be in conflict with each other. Collings (2011) study of child rape survivors stressed that children have a right to be heard and to be given a voice. These rights are reflected in the requirements of the United Nations Convention on the Rights of the Child which emphasize that children be provided the opportunity to express their opinions and views on matters which affect them. However, exercising these rights contradict ethical principles which aim to protect children from possible secondary victimisation or re-traumatisation. On the one hand, children need to be protected from possible harm, exploitation and vulnerability which may arise from research participation. Therefore, there is a tension between the view of children as dependent on adult protection and incapable of taking responsibility for their decisions and the view that does not see them as people with civil and ethical rights like the right to participate in decisions which directly affect their lives (Lansdown, 1994 cited in Mudaly & Goddard, 2009). Children's right to protection and welfare therefore appear to contradict their right to self-determination and autonomy.

Collings (2011) has explored the phenomena of secondary victimisation in child populations, which postulates that children who have been sexually abused usually experience secondary victimisation from community service providers. These include the medico-legal examinations, legal proceedings and criminal justice systems which are seen to mimic the nature and dynamic of the traumatised experience, making children vulnerable to possible re-traumatisation. Research within the area indicates that 26% of children experience secondary victimisation. However Collings (2011) points out that these findings need to be treated with caution due to the limited research studies available on the subject. Additionally, these statistics often do not reflect the views of children but rather of the helping professionals responsible for the care of traumatised children such as caretakers and social workers. The tendency to uncritically generalise findings obtained from research on adult rape survivors to child survivors of sexual abuse is also seen as a contributing factor to the notion of prevalent secondary victimisation (Collings, 2011). Furthermore as is the case with trauma research studies, there is little empirical evidence relating to the impact of participating in research on traumatised children who have been sexually abused.

In order to minimise possible secondary victimisation or re-traumatisation, and in order to adhere to ethical guidelines and prescriptions, Collings (2011) has suggested possible safeguards which need to built into research designs in order to minimise any risk to children and their welfare, and to provide some benefit to child participants thereby maintaining equipoise of risk and benefit. These safeguards include: Informed parental consent; an option of having a caretaker present; children's assent based on age appropriate information; prior trauma focused therapy; an offer of immediate comfort or containment should distress be experienced; and comprehensive counselling intervention and post-interview debriefing. Mudaly and Goddard (2009) have similar suggestions for safeguarding children's welfare in research study designs; adding that researchers should consistently check with the child in order to ascertain their level of comfort during the interview process. These measures should be implemented as they can provide direct benefit to the child participants, allowing their voices to be heard and giving them the opportunity to voice their opinions in coherent, meaningful and reliable ways (Collings, 2011). By using such measures it is possible to satisfy ethical principles such as the protection of children's welfare, as well as providing a beneficial experience involving the realisation of their need to be heard.

2.3.4. Minimal Risk

Minimal risk is generally defined as: the probability and magnitude of harm or discomfort anticipated in the research not being greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. This means that minimal risk applies if the research does not induce distress that is not normally experienced on a daily basis or in the course of exposure to regular physical or psychological examination.

Within trauma research there are many issues and concerns around minimal risk, which involves anticipating the risks and benefits participants may experience during the research procedure. However, accurately anticipating such risks is complicated by factors such as

individual differences and an absence of research (Newman, Risch & Kassam-Adams, 2006). Newman and Kaloupek (2009) state that:

> "It is often unknown how the degree of emotional upset experienced during a research protocol compares to the magnitude of distress participants confront during their daily lives. Further, it is unknown whether any upset reflects acute intensification of existing symptoms or emotional responses that are characteristic of the individuals."
> [598]

The above citation expresses the uncertainty/ambiguity experienced by researchers regarding how they should determine whether minimal risk applies to participants in trauma research. One way in which researchers have attempted to differentiate between minimal risk and emotional upset caused by research participation is by using post-participation questionnaires (Newman & Kaloupek, 2009). Other researchers have postulated that if the level of emotional distress experienced during research is manageable and typical for the respondent, then this may be an expression of emotional engagement which can be associated with perceived positive benefits, rather than a de facto indicator of harm (Newman & Kaloupek, 2009; and Newman and Kalpupek, 2004). Other researchers have found that respondents who complete survey questions on their traumatic experiences, may experience distress during the research procedure but do not remain upset at completion – which is consistent with formal definitions of minimal risk as defined above (Ezekiel et al, 2008; Newman & Kaloupek, 2009). Research on the long-term effects of participation in trauma research and how this affects emotional engagement post participation and therefore minimal risk, is limited with a few studies. Legerski and Bunnel (2010) cite the following studies which have attempted to assess possible long-term effects on trauma research respondents.

In a study conducted by Galea et al (2005, cited in Lergeski & Bunnel, 2010), 5 774 New Yorkers were asked about their experiences regarding the 9/11 terrorist attacks. The found that only 12.9% felt some distress during participation and only 1% were still upset at the

end of the interview. Furthermore only 0.3% of respondents requested assistance from a counsellor which was one of the services offered as part of the study. In another study by Martin et al (1999), negative feelings associated with interviews about childhood sexual abuse decreased from 8% during the study to 2% after a 6 month follow up. This time-related diffusion of emotion regarding experiences of distress in trauma research, suggests that experiences of distress have few long-term negative effects. In fact, negative affect and emotion can be seen to decrease over time, with affect positive appraisals increasing over time (see Lergerski and Bunnel, 2010; and Newman, Risch & Kassam-Adams, 2006). Newman, Walker and Gefland (1999) conducted a study which re-contacted a community sample 48 hours after participation and found that the majority of participants reported benefit from participation with none reporting regret about participation. Therefore, available studies would suggest participants do not experience elevated or unusual upset during research procedures; but in fact that they have positive beneficial experiences of their research participation which can be effectively balanced with the possible costs of distress, and thereby maintaining equipoise. These studies also indicate that minimal risk is present in trauma related research studies, as none of the participants experienced emotional upset or distress that was more intense or unusual than is normal or ordinarily experienced by them. In order to validate these assumptions however, more research studies need to be conducted within this critical area.

2.4. EVALUATING THE IMPACT OF TRAUMA RESEARCH

Trauma has always been an important, critical area of interest to social scientists who have been deprived of furthering their understanding of the field, due to stringent ethical guidelines which have aimed to protect respondents. Recently however, there have been studies which aim to revolutionise the way trauma research is perceived and evaluated. Elana Newman and her colleagues have been at the forefront of this change and have made some interesting arguments about the way we have perceived trauma within research.

Newman, Risch and Kassam-Adams (2006) and Newman and Kaloupek (2004) state that IRBs and ethical committees often resort to common sense approaches which are vulnerable to common decision-making errors such as under utilisation of base rate information, risk estimates which have been based on a few outcomes rather than risk probability, and the tendency to over rely on case examples to inform important decisions. Newman, Risch and Kassam-Adams (2006) further state that common sense, clinical judgement, imagined personal substitution and multidisciplinary consultation which have previously been the foundation upon which ethical decisions have been made, are essentially based on biased opinions and untested assumptions with no empirical reliability or validity. They further argue that the ability to operate scientifically in the midst of personal values, politics and strong emotion (which may be heightened in trauma research) may compromise scientific objectivity and lead to errors in ethical judgements. As a result, we may be restricting research on trauma, based on wrong assumptions and decisions. Therefore, investigators should not be deterred from conducting meaningful and beneficial studies due to uninformed decisions or prejudice but should proactively fill the urgent need for a valid, scientifically and empirically based approach to conducting trauma research which can provide us with reliable data upon which to base our future ethical decisions (Newman & Kaloupek, 2004).

Another argument for conducting trauma research comes from Lergerski and Bunnel (2010), who have found that experiences of emotional distress is not unique to trauma research. In a study by Newman et al (2001, cited in Lergerski and Bunnel, 2010) which examined the health, cognition and lung-cardiovascular function of respondents, researchers reported hearing 57% of their participants cry. In another study which interviewed women on their mental and physical health, 20% of participants experienced negative emotional distress (Lergerski & Bunnel, 2010). Thus, it appears that even in studies which do not focus on trauma, emotional distress is nevertheless still experienced by a small subset of the participants, which suggests that this cost is not unique to trauma related research (Lergerski & Bunnel, 2010).

Kilpatrick (2004) states that as members of a research community we should also consider the ethics of **not** conducting important research such as trauma and disaster related research. Kilpatrick (2004) postulates that research is needed on populations which have experienced trauma in order to determine which victims are most likely to experience symptoms of PTSD after a traumatic event, what can be done to prevent this, the types of interventions that are needed, and the kind of mental and physical services which will be most effective in helping individuals. Therefore, there needs to be a balance between our responsibility towards participants and our responsibility towards society (Newman, Risch & Kassam-Adams, 2006); meaning that the participants have to be protected during research but this should not create a regulatory environment that stifles important research (Kilpatrick, 2004). However, in order to maintain equilibrium of these responsibilities, there is no requirement that research be totally risk free - it is acceptable if researchers have endeavoured to address the risks and that there are great potential benefits (Kilpatrick, 2004) – i.e. that there is minimal risk or a maintained sense of equipoise between risk and benefit.

It is also important to acknowledge that our previous conceptions of the risk involved in trauma research have been based on our own common sense assumptions and not on empirical fact. Therefore by continuously restricting trauma related research based on these biased and misjudged opinions, we have been depriving a critical area of research, the results of which can benefit society. Kilpatric (2004) eloquently addresses this by saying:

> "Everyone is entitled to their own opinions, but they are not entitled to their own facts [...]Therefore it is incumbent upon all of us to base our decisions about research and protection of research participants on facts – not opinions. Our opinions may tell us that this type of research is inherently risky, but the facts say otherwise. Risks to participants are generally not great, and these can be managed by thoughtful researchers. The facts also tell us that additional research is needed to answer many important questions, so lets get on with it."
>
> [362]

The “facts” which Kilpatrick refers to, have been primarily gathered by the innovation of an objective research measure, the facets of which will now be discussed.

2.4.1. Concluding Comments

The review of the literature has thus far provided a broad over view of the current debates around trauma research. The reader should now have a good sense of what ethical concerns there are for trauma research as well as the ethical dilemmas that many trauma researchers are faced with.

The need for a more objective approach to evaluating trauma research and the consequent move away from subjective methods to understand participants’ experiences in trauma research should also be understood.

2.5. THE REACTIONS TO RESEARCH PARTICIPATION QUESTIONNAIRE (RRPQ)

The literature so far has paved the way for the introduction of the RRPQ and subsequent studies which are the first to be empirically based within the field of trauma research. These studies have objectively evaluated individuals’ perceived costs and benefits of participating in trauma research and have produced results which have important implications for future research studies.

The RRPQ, its development, factor structure, psychometric assessments and other factors will be discussed followed by a review of studies which have made use of this innovative and revolutionising tool.

2.5.1. Reason for Development

The Reactions to Research Participation Questionnaire (RRPQ) was developed by Newman, Willard, Sinclair and Kaloupek (2001) in response to the need for an empirical measure which can assess the reactions of participants who engage in trauma research. Previously, this area has been founded on subjective assumptions in the absence of scientific and objective data, which has resulted in rigorous ethical restrictions on trauma related research and consequently a limited number of studies within this field. Additionally without an empirical tool it is not possible for researchers to deduce which individuals are at greater risk for participation and also what these risks might be. As a result trauma research appears to have been trapped in a cycle of relative inactivity due to strict ethical requirements.

2.5.2. Process of Development

The RRPQ was developed by initially listing the ethical constructs discussed in social science literature and thereafter creating a pool of items which aimed to measure the constructs illustrated in Table I.

Item content was then reviewed for representativeness of the constructs and wording and applicability to different research protocols. Using an iterative process, the authors generated a total of 60 items, which were later revised for a final total of 23 items to be included in the measure (Newman, Willard, Sinclair & Kaloupek, 2001).

In Newman, Willard, Sinclair & Kaloupek's (2001) study, a total of 613 sample participants were recruited from classes at a small Midwestern university and a large, public West Coast University in the United States of America, using a stratified random sampling technique. This sample was then split into two subsamples for an exploratory factor analysis and thereafter a confirmatory factor analysis. Comparisons provided in their study indicate that

the two samples did not differ significantly with regard to gender, religion, marital status or sexual orientation.

Table 1: Ethical constructs and associated definitions in relation to research participation

ETHICAL TERM	DEFINITION
Cost/Risk	Experienced negative consequences (e.g. intrusion, physical damage, privacy invasion, inconvenience)
Benefit	Experienced positive reactions (e.g. emotions, responses to treatment, kinship)
Cost-benefit ratios	Analysis of the benefits relative to the costs experienced
Adequacy of consent	Accurate information is provided in an understandable and clear manner, a priori regarding procedures, potential adverse consequences, and positive consequences
Adequacy in recruitment	1. Lack of concern regarding how participant was identified and approached (including suspicion, fear etc) 2. Perception of choice or absence of perceived or actual coercion with respect to recruitment
Faith in confidentiality	Confidence that information provided by the respondent will not be shared with by research staff nor presented in a way to identify the individual
Perceptions of the study	Concern that the study is safe and that others are not harmed by participation
Perceptions of science	Research team is competent and professional and the team and project appears well designed and controlled
Perception of the research teams' respect for the individual, including cultural sensitivity	Research team communicates respect for both the autonomy and vulnerability of the individual, and is sensitive to issues of culture and ethnicity

[adapted from Newman, Willard, Sinclair & Kaloupek, 2001]

The exploratory factor analysis was used to identify the underlying latent constructs accounting for covariation among scale items. Three criteria were also used to decide on the appropriate number of factors to retain. These were: the eigenvalue of the factor was greater than 1.00; the scree plot of the eigenvalues supported retaining the factors; and the

factor was substantively interpretable (Newman, Willard, Sinclair & Kaloupek, 2001). The authors also focused on the interpretability of the pattern and magnitude of the factor loadings to determine which items to retain, and eliminated items with low or ambiguous patterns of loadings on rotated factors. Full sample communalities were also estimated and items below .40 were omitted from all further analyses (Newman, Willard, Sinclair & Kaloupek, 2001). Criteria used for deciding whether to include items in the interpretation were that the item should have a factor loading of .40 or greater; the item should not have high loadings on multiple factors; and the item should be among the highest loading items on a factor (Newman, Willard, Sinclair & Kaloupek, 2001).

The confirmatory factor analysis focused on the covariance matrix of 18 items which retained from the exploratory factor analysis. The maximum likelihood model estimation from LISREL 8.12A was used to test the model that emerged from the exploratory factor analyses (Newman, Willard, Sinclair & Kaloupek, 2001). The model fit was evaluated on the basis of four criteria: the ratio of model chi square to degrees of freedom; the Root Mean Square Error Approximation (RMSEA); the Standardised Root Mean Sqaure Residual (S-RMR); and the Comparitive Fit Index (CFI) (Newman, Willard, Sinclair & Kaloupek, 2001). Common rules of thumb for adequate model fit were used such as chi square ratios under 5:1; RMSEA values below .08 and CFI values of .90 or above.

The exploratory factor analysis yielded 5 significant factors and this was replicated in the confirmatory factor analysis. Each of these factors and their relevant items will be now be described.

2.5.3. Description of Measure

The RRPQ is a short assessment tool which comes in the form of a questionnaire with 23 items. The items are rated on a Likert Scale ranging from 1 (strongly agree) to 5 (strongly disagree). Negatively worded items are reverse scored so that a higher score indicates more favourable reactions to participation. The maximum total one can get on the RRPQ is 125

and the minimum score is 23 (Schwerdtfeger, 2009). The measure is usually administered last as it aims to measure participant's experience of the research process.

An initial 60 items were used in the exploratory and confirmatory factor analysis. Based on the results obtained from these statistical procedures (see Newman, Willard, Sinclair & Kaloupek, 2001) through the process of elimination based on factor loadings and relevance, the RRPQ was revised with a final total of 23 items. These items measured five different dimensions and are related to the definitions of the ethical constructs provided previously: **Personal Benefit** and **Perceived Drawbacks**, which addresses the ethical principles of benefit and cost-risk ratio respectively; **Emotional Reactions**, which suggests that emotional and cognitive reactions are separable experiences; **Participation**, which is related to overall satisfaction with research procedures; and **Global Evaluation** relating to faith in confidentiality, scientific quality of the study, and the researcher's respect for and towards the individual (Newman, Willard, Sinclair & Kaloupek, 2001). As can be seen, the final dimensions are still representative of the ethical constructs initially listed.

Here are the 23 items of the RRPQ in relation to the factors/dimensions they measure with the numerical order of appearance provided:

A. Participation Factor

14. I was glad to be asked to participate
15. I like the idea that I contributed to science
17. I felt I could stop participating at any time
21. Participation was a choice I freely made

This factor explores respondent's emotions and perceptions about their participation in order to determine the extent to which they feel forced or obliged to participate; or whether it was an activity which they enjoyed or felt proud to be a part of.

B. Personal Benefits Factor

1. I gained something positive from participating
4. I gained insight about my experiences through research participation
7. I found participating in this study meaningful
13. I found participating beneficial to me

This factor provides respondents with the opportunity to state whether they found participation beneficial for themselves. This factor allows respondents to indicate any possible personal benefit related to their experience of participation.

C. Emotional Reactions Factor

3. The research raised emotional issues for me that I had not expected
5. The research made me think about things I didn't want to think about
10. I experienced intense emotions during the research session and/or parts of the study
16. I was emotional during the research session

This factor centres on any emotional distress which may have been experienced during participation. Researchers have reverse scored items in this factor in order to have responses which indicate emotional distress and also to assess those which indicate little or no emotional distress.

D. Perceived Drawbacks Factor

2. Knowing what I know now, I would participate in this study if given the opportunity
6. I found the questions too personal
18. I found participating boring
19. The study procedures took too long
20. Participating in this study was inconvenient for me
22. Had I known in advance what participating would be like, I still would have agreed to participate.

This factor allows respondents to express any regret they may have experienced during participation and also to provide feedback on whether they would participate in similar studies in the future.

E. Global Evaluations Factor

8. I believe this study's results will be useful to others
9. I trust that my replies will be kept private
11. I think this research is for a good cause
12. I was treated with respect and dignity
23. I understood the consent form

This factor requests respondents to provide their opinions on how beneficial their participation may be to others. This factor is also able to determine if respondents have firm faith in research procedures, trusting the process; or whether they do not feel safe or comfortable with the process.

Items 3, 5, 6, 10, 16, 18, 19 and 20 are reverse scored.

2.5.4. Administration of RRPQ

The RRPQ is easy to administer and can be efficiently attached to a wide variety of study designs and samples which aim to focus on trauma or any other area, without adding to participant burden (Newman, Willard, Sinclair & Kaloupek, 2001). By allowing for such easy administration and applicability, the questionnaire is an empirical method that can be used to gather objective data that can quantify participants' perceptions of the costs and benefits of research participation and general research procedures. Therefore, by attaching such a questionnaire to research studies, data on respondents' perceptions can be easily gathered

across a wide range of contexts, samples and fields of research, which can efficiently build on and add to the present limited studies on trauma.

Being the first empirical measure to objectively measure participant's responses, the RRPQ has revolutionised trauma research. As it is a new measure, there are few studies which have used it, but those that have, have found surprising results relating to participants' perceptions of the costs and benefits of participating in trauma research. Results of some of the studies which have used the RRPQ have found for the first time the following objective, quantifiable results relating to risks, costs and benefits.

2.5.5. Costs of Research

The RRPQ has found that the most prominent cost of participation in trauma research is the extent of emotional distress experienced by participants. This concept is also related to the ethical principles of beneficence and non-maleficence. Asking individuals to recount their intimate experiences of trauma in great detail, raises concerns that making individuals re-live these encounters puts them at risk of being 're-traumatised', which violates both the principles of beneficence and non-maleficence (Legerski & Bunnel, 2010 and Newman, Risch & Kassam-Adams, 2006). IRBs are especially apprehensive about the prospect of re-traumatising individuals through research practices, and it is for this reason that research on trauma has been so scarce and limited, despite the urgency within the field to understand trauma related experiences.

However trauma researchers state that the term is misleading because there is an important difference between the direct experience of a traumatic event; and asking individuals to voluntarily consider their experiences in a safe and controlled environment, which allows them the control to end their participation at any time (Newman, Risch & Kassam-Adams, 2006 and Newman & Kaloupek, 2004). Some researchers also state that misunderstanding the term significantly underestimates the nature of the traumatic experience and the

"intense fear, helplessness and horror" associated with it (Legerski & Bunnel, 2010 and Newman & Kaloupek, 2004).

With regard to the prevalence of emotional distress, trauma researchers using the RRPQ have found that there is a small subset within the population, ranging from 2.5% to 25%, who experience marked or unexpected upset during research participation (Newman, Risch & Kassam-Adams, 2006 and Newman & Kaloupek, 2004). For example, Kassam-Adams and Newman (2003) found that 5% of parents and 5% of children felt sad or upset during research. In another study on the analysis of individual item responses of the RRPQ using a sample of college students Newman, Willard et al (2001, (cited in Newman & Kaloupek, 2004) found that 9% experienced intense emotions, 3% felt out of control and 1.8% felt that there condition was worsening. The experience of such emotional distress is another reason why IRBs are so apprehensive of approving trauma research.

However, the majority of empirical studies have found that experiencing high levels of distress does not imply regret over participation, with most research participants neither experiencing regret nor negatively evaluating their overall experience (Lergerski & Bunnel, 2010). For example, a study which assessed the experiences of survivors of violent victimisation reported that they did not experience distress, with 92% of participants stating that trauma related questions needed to be asked (Lergerski & Bunnel, 2010). Newman, Walker and Gefland (1999) conducted a study on women regarding sensitive issues and found that although a small subset of the sample with a history of maltreatment experienced some unanticipated distress, the majority of participants did not regret participation and even perceived it as beneficial. Another study by Walker et al (1997) cited in Legerski & Bunnel (2010) examined women's reactions to their experiences of sexual, physical and emotional abuse and neglect, and found that, again, although a small number of participants experienced unexpected distress; the vast majority felt that they would have completed the survey even if they had known how they would feel once they had started. Lergerski and Bunnel (2010) summarise the research on distress and regret in trauma research by stating succinctly that "*distress* from participation does not equate *regret* of participation". This statement means that even when participants do experience emotional

distress during trauma research, they would choose to participate again if given the opportunity. Therefore, the participants' own judgement of the costs and benefits of participation favours the ethical principle of beneficence (Newman, Risch & Kassam-Adams, 2006).

It is important however, to establish the type of factors which make a small subset of the population vulnerable to experiencing distress, so as to not involve them in research studies which may be extremely risky or distressing for them. Although some characteristics have been identified by various research studies, these vary across different contexts. Newman and Kaloupek (2004) cite research by various authors which postulate that current or past trauma experiences makes participants vulnerable to experiencing unanticipated or marked distress post participation. In another study by Newman, Walker and Gefland (1999), respondents with higher levels of PTSD endorsed greater unexpected distress than those with lower PTSD symptomatology. Similarly those with PTSD also had greater difficulty describing their traumatic experiences than those without PTSD (Griffin, Resick, Waldrop & Mechanic, 2003). Contrastingly however, a study on a college sample found that participants who are likely to develop PTSD rated their experience as significantly less emotionally distressing than those who were formally diagnosed with PTSD (Newman and Kaloupek, 2004).

Other factors such as younger and older age, a history of exposure to trauma, social vulnerability, current depression, greater physical injury and severity have also been shown to increase participant distress during participation in trauma research (Newman and Kaloupek, 2004). However, due to the limited number of studies, it is unclear how much these predictors vary in relation to sample characteristics, measurement methods and other procedural features (Newman and Kaloupek, 2004). This once again highlights the need for more research within the trauma field.

2.5.6. Benefits of Research

The concerns and apprehensions of IRBs and ethical committees which surround trauma research should be soothed by the available research, as a result of the implementation of the RRPQ, which postulates that many respondents view and rate their participation as beneficial. Women with exposure to interpersonal violence find participation highly interesting and trauma survivors experience the (otherwise limited/scarce) opportunity: to share their story, increase their access to resources, gain insights into their experiences, and create the potential to help others by increasing scientific knowledge – all of which are perceived as personally beneficial (Newman, Risch & Kassam-Adams, 2006). Other benefits include a helpful review of life events, increasing self-awareness, reducing self-perceptions of blame and feelings of relief, positive self-esteem and pride in helping others (Newman & Kaloupek, 2009). Other respondents find the process of research engagement therapeutic, they find it easier to talk about their experiences with the interviewer than their friends or spouses (Newman, Risch & Kassam-Adams, 2006). Ruzek and Zatzick (cited in Newman, Risch & Kassam-Adams, 2006 and Newman & Kaloupek, 2004) found that 95% of acutely injured adults reported that benefits outweighed the costs of participation and 98% endorsed no regret for participation. Positive appraisal of research participation also applies to 74% of parents who have had acutely injured children as well as to 77% of their children. The authors also found that 50% of parents and children reported positive self-esteem post participation, with 50% of children feeling good about helping others and 90% of parents experiencing the same emotion. Furthermore, 95% endorsed the item indicating that benefits outweighed costs of participation and 98% indicated they had no regrets over participation. Newman, Risch & Kassam-Adams (2006) also reviewed the content analysis of open-ended responses in four studies and found that participants find it beneficial to consider their experiences, including the difficult ones, and that research allows them this opportunity. Participation has also been found to encourage respondents to rethink and analyse their situation which can lead to new insights and be helpful to the participants or survivors of trauma. Positive, beneficial experiences in trauma research also appear to increase over time with some studies indicating that after a 2 week follow up, 83% of their participants reported feeling better than they did immediately after participation and with

57% reporting that they felt better than they did prior to their initial participation (Runeson & Beskow, 1991 cited in Lergerski & Bunnel, 2010).

Considering that equipoise between the costs and benefits of research is being met, it is possible to deduce from the above review of the literature that trauma related research can legitimately be conducted as it allows for the opportunity for both costs and benefits to be experienced during participation in relative balance to each other. However, in order to keep the balance or equipoise of costs and risks, trauma researchers need to err on the side of caution as this is a sensitive field which needs to be handled delicately and thoroughly.

2.5.7. Adaptations of the RRPQ

Due to the reliable and valid results that the RRPQ has produced, such as those mentioned above, researchers have taken advantage of this innovative empirical measure and created many adaptations for different samples and contexts, all with good results (see Schwerdtfeger, 2009; Chu, DePrince & Weinzier, 2008; DePrince & Chu, 2008; Newman & Kaloupek, 2004 and Newman, Risch & Kassam-Adams, 2006). By applying the RRPQ to children (Chu, DePrince & Weinzier, 2008) and assessing the methodological differences in reactions to research (DePrince & Chu, 2008) researchers are attempting to expand on trauma research and fill the gap and need for more research within this critical field. By doing this, we can increase our knowledge and understanding of people's experiences with trauma and hopefully plan interventions to prevent future experiences. The innovation of the RRPQ thus provides a way of answering many of the questions we have on trauma; whilst at the same time comforting the concerns of IRBs and ethical committees with the empirical evidence it provides.

2.6. APPLICATION OF THE RRPQ TO THE SOUTH AFRICAN CONTEXT

Now that the RRPQ has been fully described, it is important to emphasize to the reader why there is a need for such a tool within the field of trauma research in the South Africa context.

South Africa is known in some areas of the world, for the repeated violence and crime which its citizens experience. Rape, murder and assault and break-ins are not uncommon to any South African. In addition, statistics appear to support the perception of South Africa as a country that experiences a lot of violence. For example, a 1996 study indicated that in a period of 5 years at least 70% of the urban population in South Africa were victimised at least once (Hamber & Lewis, 1997). South African Police Service (SAPS) figures indicate that in 1996 there was also a total of 25 782 reported murders, 28 516 attempted murders and 12 860 car hijackings. In terms of sexual violence, there were a total of 50 481 rapes. South African children are not exempt from violence. In 1996, 20 333 crimes of a sexual nature were reported to the Child Protection Units, while there were 8 626 reported assaults of children (Hamber & Lewis, 1997). More recent statistics support the above. For the 2005/2006 reporting year statistics show 302 000 reported rapes, 1 075 reports of murder of children, 20 879 reports of assault and 4 725 reports of indecent assault against children – these statistics exclude those violent behaviours that weren't reported, making the actual figures much higher (Burton, 2007).

The number of violent acts experienced by South African individuals means that at some point in their lives, many South Africans have witnessed a violent traumatic act or were a victim of one. The psychological impact of experiencing traumas such as interpersonal violence has not been adequately researched within the South African context, due to the ethical concerns about re-traumatising trauma survivors.

Based on the empirical evidence obtained from the research on the RRPQ, researchers now have valid arguments for conducting trauma research, as it has been shown to be beneficial to the majority of participants. However, in order to determine whether these results which have been gained using American samples, applies to our diverse context, it is imperative for South African researchers to evaluate and validate the RRPQ in South African samples. Conducting such research will not only provide the opportunity to assess whether trauma experiences are universally experienced, regardless of context; but we can also use this research to further understand people's experiences of trauma and expand on the field of trauma related research within South Africa as well as in other countries.

CHAPTER THREE: METHODOLOGY

This section will provide the reader with details of the research methodology.

3.1. RESEARCH QUESTIONS

This study aimed to provide answers to the following research questions:

1. ***Does the factor structure of the RRPQ apply to the South African context?***

This study performed a confirmatory factor analysis on a sample of university students in South Africa, in order to determine whether the factor structure of the RRPQ found in Newman, Willard, Sinclair and Kaloupek's (2001) study was applicable to the South African context. Using a measure that would for the first time empirically measure response to trauma related research participation was seen as a significant area of study that needed to be explored.

2. ***How valid is the use of RRPQ within the South African context?***

This study aimed to establish whether the RRPQ could be used as a valid and reliable empirical measure of participant's response to trauma related research.

3. ***What are the perceived costs and benefits of participating in trauma focused research?***

Given the controversial debate surrounding trauma research, this study aimed to determine *empirically* if there were perceived costs and/or benefits to participation.

4. ***What is the duration of distress experienced by respondents?***

There is also a debate surrounding the extent and duration of distress that may be experienced by participants of trauma related research. This study aimed to determine whether levels of distress (if experienced) were still present at two week follow up.

3.2. TYPE OF DESIGN

This study was a quantitative study which enabled the researcher to analyse all of the variables involved. Using a quantitative design also facilitated the collection of data from a large sample, permitting generalisations to the population from which the sample was drawn.

The study had a test-retest component and therefore comprised two phases. In the first phase, respondents were asked to complete the Developmental Trauma Inventory, and thereafter, the RRPQ. The second phase took place two weeks later and was used to assess the duration of distress experienced by respondents.

This study used data from an electronic database, which consisted of responses from questionnaires which had already been administered. This study therefore made use of secondary data.

3.3. SAMPLE

This study made use of a non-probability, purposive sampling technique.

The study used secondary data, which were available from an electronic database. The study used data from a study which targeted volunteering male and female undergraduate and postgraduate students. Respondents included 323 undergraduate students attending the University of KwaZulu Natal during 2010, within the faculties of Humanities, Law and Engineering. The mean age of respondents was 20.14 years (range: 18-28 years). Consistent with university enrolment figures, respondents were predominantly female (70.9%) and predominantly black African (87%).

Table 2: Descriptive Statistics for Study including Means, Alphas and t-scores

Characteristics	Phase 1 (n = 323)	Phase 2 (n = 119)	Group Differences	
Respondent				
Age	20.14 (1.82)	20.08 (2.01)	$t(440) = -0.26$	$p = .795$
% female	70.90	81.51	$\chi^2(1) = 4.53$	$p = .033$
% ethnic minority	87.00	86.43	$\chi^2(1) = 0.08$	$p = .933$
Abuse exposure				
% Sexual	50.46	53.80	$\chi^2(1) = 0.26$	$p = .609$
% Physical	54.18	55.46	$\chi^2(1) = 0.18$	$p = .895$
% Emotional	29.41	25.21	$\chi^2(1) = 0.56$	$p = .453$
% Neglect	14.55	14.29	$\chi^2(1) = 0.01$	$p = .983$
Pretest trauma				
DTS severity	36.41 (21.90)	36.03 (22.83)	$t(440) = 0.16$	$p = .873$
SIDES-SR severity	4.47 (3.60)	4.48 (3.52)	$t(440) = -0.04$	$p = .972$
Phase 1 reactions				
RRPQ: Satisfaction	33.74 (5.56)	34.05 (5.72)	$t(440) = -0.51$	$p = .609$
RRPQ: Benefit	19.42 (3.78)	19.95 (3.50)	$t(440) = -1.33$	$p = .184$
RRPQ: Distress	17.15 (4.21)	17.32 (3.98)	$t(440) = -0.39$	$p = .972$

3.4. INSTRUMENTS

Data were collected using two measures: the Developmental Trauma Inventory (DTI) and the Reactions to Research Participation Questionnaire (RRPQ).

The DTI (Collings, Valjee & Penning, 2011) is a 36 item, retrospective, self-administered screen for interpersonal childhood trauma experiences developed specifically for the South African context. Preliminary validation of the DTI indicates that the DTI probe items constitute 10 internally consistent factors: emotional abuse, community assault, domestic assault, poverty, witnessing community violence, witnessing domestic violence, indecent assault, domestic neglect, rape, and domestic injury (Collings, Valjee & Penning, 2011). Scale scores defined by these factors have also been shown to be significantly correlated with scores on clinical measure of PTSD and/or complex PTSD.

The RRPQ was developed by Newman, Willard, Sinclair and Kaloupek (2001). This measure aims to assess the reactions of participants who engage in trauma research along five different dimensions. These dimensions were identified by Newman and her colleagues using an exploratory factor analysis and a confirmatory factor analysis on a sample of college students in the United States.

The RRPQ is a short assessment tool that has 23 items in the form of a questionnaire. The items are rated on a Likert Scale ranging from 1 (strongly agree) to 5 (strongly disagree). Negatively worded items are reverse scored so that a higher score indicates more favourable reactions to participation. The maximum total that can be achieved on the RRPQ is 125 and the minimum score is 23 (Schwerdtfeger, 2009).

The RRPQ is composed of the following 5 different dimensions or factors:

- → **Personal Benefit** addresses perceived benefits
- → **Perceived Drawbacks** which assesses cost-risk ratios
- → **Emotional Reactions** measures emotional and cognitive experiences
- → **Participation** is related to overall satisfaction with research procedure
- → **Global Evaluation** relates to faith in confidentiality, scientific quality of the study and respect for and towards the individual

(Newman, Willard, Sinclair & Kaloupek, 2001).

An example of the items from each subscale can be found below:
Personal Satisfaction: *I like the idea that I contributed to science*
Personal Benefits: *I found participation personally meaningful*
Emotional Reactions: *The research raised emotional issues for me which I had not expected*
Perceived Drawbacks: *The study procedures took too long*
Global Evaluation: *I was treated with respect and dignity*

The RRPQ has good reliability and validity. In her study on the methodological differences in trauma research using a sample of pregnant women, Schwerdtfeger (2009) reported an

alpha score of the full scale being .82 and from the subscales an alpha score ranging from .66 to .84. In DePrince and Chu's study (2008) using a sample of ethnically diverse community participants and undergraduate students, alpha scores were also very high, with the subscale alphas ranging from .72 to .87. Kassam-Adams and Newman (2002) also found good internal consistency in their study using a child and parent version of the RRPQ (RRPQ-C and RRPQ-P). In the RRPQ-C, Cronbach alphas were .62 in Study 1 and .69 in Study 2 indicating respectable internal consistency. Similarly, for the RRPQ-P alpha scores were found to be .78 in Study 1 and .80 in Study 2.

3.5. PROCEDURE

3.5.1. Phase 1

Phase 1 of the research involved a confirmatory factor analysis in order to establish the relevance of the RRPQ to the South African context and to determine whether the factor structure for the RRPQ could be replicated in a South African sample.

During Phase 1 of the research, respondents were recruited through posters placed on University notice boards and on the university intra-web which invited interested students who wanted to participate in "a study on the impact of childhood trauma" to present themselves at a designated lecture venue at a particular time. Three hundred and forty-two students indicated an interest in participating in the research, with each of these students being provided with a pack containing an information sheet, an informed consent documentation form, and a study questionnaire.

The sequence of items in the questionnaire was demographic information first, followed by trauma measures, then an assessment of developmental trauma experiences (DTI), and finally the reactions to research participation questionnaire (RRPQ).

At the end of the questionnaire respondents were asked if they would be prepared to participate in a similar study in 2 weeks time, with respondents who were interested in doing so being asked to provide a unique alpha-numeric code (4 letters of the alphabet followed by any 2 numbers) which was used to anonymously match Phase 1 and Phase 2 questionnaires.

Questionnaires were completed anonymously (i.e. no uniquely identifying information being requested in the questionnaire) away from the lecture theatre, with respondents being given a 24 hour period to submit completed questionnaires to a central collection point. A total of 331 completed questionnaires (96.8%) together with signed consent forms were returned. In eight cases, returned questionnaires were regarded as unusable (due to missing data), providing a final total of 323 usable returns (94.4%).

Respondents who indicated that they were interested in participating in Phase 2 were informed when and where they needed to present themselves to obtain a follow-up questionnaire.

3.5.2. Phase 2

The aim of phase two was to determine the duration of distress experienced by respondents as a result of their participation, and whether distress experienced during phase 1 was still evident at the end of a 2 week follow up.

Of the 323 participants from Phase 1, 119 (36.8%) returned for Phase 2 and submitted usable questionnaires Although females were more likely than their male counterparts to return for the second phase, there were no significant differences between Phase 1 and Phase 2 respondents with regard to age, ethnicity, child abuse exposure, pretest measures of trauma, or reactions to participation (see table 2, p42). The sequence of items on the questionnaire was adapted for Phase 2, with demographic information being presented first,

followed by the RRPQ, completed with reference to current feelings regarding Phase 1 participation.

3.6. ETHICAL ISSUES

Being a research study which aimed to study traumatised individuals, there were many ethical issues that became a cause for concern, the most predominant being re-traumatisation which has already been discussed in the literature.

In order to acknowledge the fact that there might be a minority of participants who would become distressed during the research process, we placed contact details regarding where a distressed participant could seek help.

For this particular study, however, we attempted to prevent distress or duress of any kind. In the informed consent, we provided numerous contact details of all the researchers involved should there be any distress experienced by participants. Participants were also provided with the contact details of the student counselling centre which offers free counselling. Participants were also told to discontinue participation at any time, should they feel the need to do so.

In order to maintain the ethical standard of this research, it was also submitted to and approved by the ethics committee of the University of KwaZulu Natal in order to ensure that ethical standards were being met.

CHAPTER FOUR: RESULTS

This chapter of the thesis contains a description of the data analysis procedures that were used in the study. The results of the study are also presented, including results for the first and second phase of the research study.

4.1. DATA ANALYSIS

Descriptive statistics such as the mean, standard deviation and variance were used in order to describe the data and provide us with an overall picture of the results. They also provided the foundation for more advanced data analysis. Cronbach Alphas were also conducted in order to test the reliability and internal consistency of the various scales and subscales for this particular sample.

The nature of this research was to test whether the factor structure of the RRPQ found in studies conducted by Newman (2001) applied to the South African context. Following a similar study design by Newman, Willard, Sinclair and Kaloupek (2001), a confirmatory factor analysis was conducted in order to establish if the factor structure found in other studies was applicable to the South African context. A test-retest design was implemented in order to determine the duration of distress experienced by respondents as a result of their participation.

4.2. RESULTS

4.2.1. Phase 1

Confirmatory factor analysis of the RRPQ (see table 3) in the present sample, which employed principal components analysis and oblique factor rotation using the VARIMAX

procedure, yielded three factors which met the study criteria for retention (i.e., an eigenvalue greater than 1, the scree plot of eigenvalues supporting retention, a factor loading of at least .40, and the meaningfulness of identified factors).

The first of these factors (α = .892), which corresponds to the Participation factor identified by Newman et al., (2001), contained items such as "I was treated with respect and dignity by the researchers" and "I understood the information sheet given to me at the start of the study". The second factor (α = .813), which corresponds to the Personal Benefits factor identified by Newman and her associates, contained items such as "I found participating in this study personally meaningful" and "I gained something positive from participating". Finally, the third factor (α = .780), which corresponds to the Emotional Reactions factor identified by Newman and her colleagues, contained items such as "The research made me think about things I didn't want to think about" and "I experienced intense emotions while answering questions in this study".

For purposes of analysis, mean item scores of 4 or higher (agree/strongly agree) on RRPQ subscales (Satisfaction, Personal Benefit, Emotional Reactions) were used to define the presence of participation related satisfaction, benefit, and distress (respectively).

Satisfaction. Mean item scores for respondent satisfaction were high (*M* = 4.22, *SD* = 0.70), with 209 respondents (64.71%) reporting satisfaction with their participation.

Benefit. Mean item scores for perceived benefit were relatively high (*M* = 3.88, *SD* = 0.76), with 181 respondents (56.04%) reporting that they had obtained personal benefit through their participation. In addition, 251 respondents (77.71%) agreed or strongly agreed with item 2 on the RRPQ ("Knowing what I know now, I would participate in the study again if asked to do so.").

Distress. Mean item scores for distress fell above the neutral midpoint (*M* = 3.43, *SD* = 0.84) with 100 respondents (30.96%) reporting that they had found their participation to be distressing.

The above 3 factors were found to be relevant to the South African sample and deemed as similar to the three of five factors found by Newman. Satisfaction incorporates the participation and global evaluations factor found by Newman; the Benefit factor incorporates the personal benefit factor; and the Distress factor incorporates the emotional reactions factor. However, the perceived drawbacks factor, which assesses cost-risk ratios and allows respondents to state any negative experiences of participation, did not emerge as a factor in the South African sample.

The three factors that were found in the present study indicate that the factor structure found in the study conducted by Newman, Willard, Sinclair and Kaloupek (2001) was not present in the South African sample, as the study's confirmatory factor analysis only yielded 3 factors as opposed to the 5 originally found in Newman's study. However the items corresponding to factors found in the South African sample are similar to three of the central factors found in Newman's study.

4.2.2. Phase 2

The second phase of the research comprised a follow-up assessment (2 weeks, n=119) designed to assess the short-term impact of research participation.

Distress. A McNemar test for the significance of change indicated that there was a significant improvement in distress levels over the 2 week period, $\chi^2(1) = 17.05$, p,.001. Of the 35 respondents (29.41%) who experienced phase 1 participation as distressing, only 16 (13.45%) reported persistent distress at follow up.

Table 3: Relevant factors found on the RRPQ using South African sample

Factor	Satisfaction	Benefit	Distress
12. I was treated with respect and dignity by the researchers	.83		
13. I understood the information sheet given to me at the start of the study	.75		
14. My decision to participate in the research was made freely	.74		
16. I was glad to be asked to participate	.69		
11. I think this research is for a good cause	.68		
15. I found that participating was helpful or beneficial to me	.56		
22. If I had known in advance what participating would be like, I would still have agreed to participate	.68		
17. I like the idea that I contributed to science	.65		
7. I found participating in this study personally meaningful		.75	
1. I gained something positive from participating		.73	
8. I believe this study's results will be meaningful to others		.66	
2. Knowing what I know now, I would participate in the study again if asked to do so		.62	
4. I gained insight about my experiences through participating in the research		.55	
5. The research made me think about things I didn't want to think about			.80
10. I experienced intense emotions while answering questions in this study			.81
3. The research raised emotional issues for me that I had not expected			.68
18. I was emotional during the research Session			.68
6. I found the questions too personal			57
% Variance	20.79	14.38	13.97
Eigenvalue	7.64	2.23	1.69

CHAPTER FIVE: DISCUSSION

This chapter discusses the results of the study in two ways. Firstly the reader gains an understanding of how the four primary research questions were answered using the results obtained from the study. Thereafter the manner in which the study findings relate to previous research findings will be discussed, as well as how these findings have implications for future research studies on trauma and on the ethical principles which guide them.

5.1. DISCUSSION OF RESULTS

The first aim of the study was to establish whether the factor structure of the RRPQ found in Newman, Willard, Sinclair & Kaloupek's (2001) study was applicable to the South African context. The study's confirmatory factor analysis yielded 3 factors as opposed to the 5 originally found in Newman's study. However, the items corresponding to factors found in the South African sample are similar to three of the five central factors found in Newman's study: The *Satisfaction* factor in the present study contained items relating to Newman's participation factor and the global evaluations factor. The *Benefit* factor had items which related to the personal benefits factor by Newman. And the *Distress* factor in the present study related to items found in Newman's emotional reactions factor. The perceived drawbacks factor was not found to be a significant factor.

These results have important implications for trauma research for two reasons. Firstly the fact that both studies yielded similar factors suggest that there is a possibility of a universal experience of engagement within trauma related research and trauma research participation. However, further research is indicated in order to establish the extent of this claim. Secondly, the difference in the number of factors found in this study suggests that different contexts may attribute significance to different factors. The Americans samples used by Newman have different contextual behaviours expected than that of the South African sample which could have affected their response to the RRPQ. For example, the perceived drawbacks factor which provided the opportunity for respondents to indicate they

were bored with the research procedures or found the procedures too long, was not found to be significant in the South African sample. The reason for this result could be that perhaps there is a South African cultural propensity to be polite when responding to questionnaires, or maybe due to the history of submission to political authority, individuals find it difficult to assert their true feelings regarding procedures. This contrasts with American cultural propensity to be assertive and outspoken about their feelings in the face of authority. However, this is an assumption which will have to be further researched.

The second aim of the study was to determine whether RRPQ was a valid and reliable measure of participant's responses to trauma related research. Results indicated that the RRPQ was a valid and reliable measure of assessment (see Table 3).

Identifying the perceived costs and benefits of respondent's participation in trauma related research was a third aim of the study. Findings of Phase 1 of this research study were found to be consistent with previous studies (see Newman, Risch & Kassam-Adams, 2006; Newman & Kaloupek, 2009; Lergerski & Bunnel, 2010) indicating that engagement in trauma related research is well tolerated. The majority of respondents (approximately 65%) reported satisfaction with their participation, with 56% reporting that they had experienced personal benefit through their participation, and 69% indicating that they did not experience participation and engagement with the research material as distressing. With regard to risk-benefit ratios, 67% of respondents reported positive risk-benefit ratios and 78% indicated that they would be prepared to participate in similar studies on trauma should they be asked to do so in the future.

These results are consistent with past research studies on trauma participation involving the RRPQ as an empirical measure (see Schwerdtfeger, 2009; Chu, DePrince & Weinzier, 2008; DePrince & Chu, 2008; Newman & Kaloupek, 2004; Newman, Risch & Kassam-Adams, 2006). Reasons for positive engagement are possibly due to respondents finding participation interesting, and using the opportunity to share their story and gain insight into their own experiences and also actualising their potential to help others increase their scientific knowledge. These facets of engagement have been found to be facilitating factors for

positive engagement in other studies as well, and can be considered as beneficial experiences (Newman, Risch & Kassam-Adams, 2006). Gaining a helpful view of life events, increasing self-awareness and reducing self-perceptions of blame by fostering pride in oneself by helping others and attaining feelings of relief could also be factors which could have influenced beneficent and non-maleficent experiences of participation. However more empirical research needs to be done to determine objectively what feelings of benefit are experienced.

With regard to the perceived cost of participation, the most prominent perceived cost was the experience of distress, with about 31% of participants finding their participation in trauma research to be distressing. This is higher than statistics found in past research studies which have suggested that there are a small subset of the population, between 2.5% to 25% who are more likely to experience distress during participation in trauma related research (Newman, Risch & Kassam-Adams, 2006). However, the higher figure in the present study could be due to the accepted fact that child abuse, as measured by the DTI, may be more distressing than other forms of trauma experiences.

However, distress of participation was not necessarily linked to regret over participation with results indicating that many participants endorsed items such as “Knowing what I know now, I would participate in the study again if asked to do so” and “If I had known in advance what participating would be like, I would still have agreed to participate.” This finding is consistent with international studies which have found that most participants neither experienced regret nor did they negatively evaluate their overall experience, indicating that “*distress* from participation does not equate *regret* of participation” (Lergerski & Bunnel, 2010). As a result it is suggested that even after having experienced emotional upset or distress during participation, most respondents would repeat their participatory experiences if given the opportunity.

The final aim of the study was to identify the duration of distress experienced by respondents and to establish whether experienced distress was still present at a two week follow up. Findings from Phases 2 of the study are not consistent with the view that

research-induced distress is either: (a) stable following study participation (cf., Newman et al., 2006), or (b) short-lived/transient in nature. In fact, findings for Phase 2 respondents fell somewhat between these two extremes, with 54% of respondents who had experienced Phase 1 as distressing reporting that they were no longer distressed at 2-week follow-up, and 46% reporting persistent distress. With respect to the total sample for Phase 2, this translates into the following outcomes: no initial distress (71%), transient distress (16%), and persistent distress (13%).

5.2. IMPLICATIONS OF RESULTS

The results of the above study will now be discussed in relation to the implications they have for ethical principles and the current paradigm of ethics which governs research.

In the past research on trauma has been restricted by ethical committees and IRBs due to the fear that trauma related research would re-traumatise participants as described in the literature. Basic ethical principles such as those of autonomy, beneficence and non-maleficence were seen to be violated in trauma research for this reason. However in light of the results of the present study and previous studies, it appears as though the reasons for preventing trauma research have been based on misjudged experiences of participants' engagement with trauma related research due to subjective assumptions that were biased and inaccurate. As a result, the ethical foundation of research needs to be considered based on the new objective and empirical research which has emerged.

5.2.1. Autonomy and Decisional Capacity

The principle of autonomy which involves the recognition of both the independence and capabilities of the individual, and which allows for individuals to enact their own decisions and choices, is still present and adhered to within trauma research. The present research study reveals that individuals who have participated in trauma research do not express

regret over their participation, nor do they feel as if they have been exploited or taken advantage of. In fact, results of the RRPQ indicate that 56% of respondents obtained personal benefit from engagement in the study. Past research has expressed concern that engagement in trauma research places individuals at risk for coercion due to vulnerability and diminished autonomy and decisional capacity, which is perceived to arise from their traumatising experiences. However decisional capacity for informed consent does not appear to be impaired, with no evidence available to indicate that experience with trauma impairs an individual's ability to provide informed consent (Newman & Kaloupek, 2004).

Other trauma researchers also agree that the general consensus for impaired decisional capacity does not apply to traumatised populations, as there is a relative absence of decisional incapacity for this group. Individuals have only been previously excluded on the basis of poor mental or medical capacity in studies such as the one on the World Trade centre which excluded 3 out of 100 individuals on the basis of poor psychological wellbeing; and in another study which found decisional incapacity to be most high for hospitalised psychiatric inpatients, excluding 13% of respondents (Newman & Kaloupek, 2009).

Contrary to past research, engagement in trauma research can be seen as actually fostering autonomy, because not only do we provide respondents with the opportunity to decide whether they want to participate, adhering to their autonomous decisional capacity, but by doing so we also reduce the stigma associated with traumatised populations (Simmerling, 2006). This provides respect for these populations which can further foster their acceptance of their experience and prove beneficial to them in the future, as it is a way of exercising their basic right to be autonomous and to make informed decisions.

Recent research therefore objectively suggests that trauma research does not violate autonomy, nor does it diminish decisional capacity, but contrary to past opinion (Kilpatric 2004), it actually provides a platform for traumatised individuals to foster and exercise their basic autonomous rights. Consequently, it is important for ethical committees and IRBs to acknowledge the new research studies which advocate for trauma research to be conducted

and the implications it has for future studies on trauma. This will enable opportunities to further broaden the current scarce research on trauma.

5.2.2. Informed Consent

Informed consent refers to an individual's ability to reflect on provided information and then make an informed decision using their autonomous ability as described above. A person can provide informed consent only if: they are seen as mentally capable of making such a decision; they understand the information and the possible risks and benefits associated with the procedure; they are able to evaluate this information, the confidentiality and its possible limits; and are voluntarily participating without being coerced in any way (Ezekiel, Grady, Crouch, Lie, Miller & Wendler, 2008).

Previous research on trauma has suggested that traumatised individuals do not meet the requirements for informed consent as explained above, because they are not capable of accurately predicting the degree of distress they might feel when asked to answer intimate questions about their experiences of trauma; or to disclose personal information regarding their thoughts, feelings and beliefs about their experience in a traumatic event (Grifin, Resick, Waldrop & Mechanic, 2003; Newman, Risch & Kassam-Adams, 2006). As a result, engaging with trauma populations about their trauma experiences is seen to violate their rights to beneficence and non-maleficence.

However recent studies on trauma which have aimed to explore informed consent and its implications within trauma research have found that participants who have engaged in trauma studies are willing to participate in future studies of the same nature. This is seen in Grifin, Resick, Waldrop and Mechanic's study (2003) where 14 out of 15 women who were sexually assaulted agreed to participate in future studies and in the present study where 78% of respondents endorsed the item stating that they would participate in similar studies. Furthermore, it can also be seen that positive risk ratios, as reported by 67% of respondents in the present study, indicate that equipoise of perceived costs and benefits of trauma

research can be achieved, which indicates that participants with exposure to trauma are more than capable of deciding when to participate in trauma research.

Based on available studies it is apparent that trauma participants, who are given the opportunity to choose to participate in research studies on their trauma experiences, provide consent which is informed and which meets the criteria for justified and approved informed consent, in line with ethical principles. Consequently, trauma research would not appear to exploit individual's experiences of trauma or take advantage of their vulnerable state as suggested by subjective opinion. Rather it provides the opportunity for individuals to exercise their basic autonomy and allows them to decide in an informed way what will be most beneficial to them.

5.2.3. Beneficence and Non-Maleficence

Despite the urgency to expand and explore the areas of trauma research, one of the reasons for the limited research studies within the field of trauma is due to IRBs and ethical committees fearing the violation of individual's rights to beneficence and non-maleficence. As such, asking individuals to recount their intimate experiences of trauma in detail raises concerns that this would place participants at risk for possible 're-traumatisation' as has been discussed in the literature which may violate both the ethical principles of beneficence and non-maleficence.

However, by using the RRPQ to objectively measure individual's perception of the costs and benefits associated with their participation, which can be seen to be related to the principles of beneficence and non-maleficence; the present study found 30% of respondents who reported finding their participation distressing. Other research studies indicate that there is only a small subset of participants within the population ranging from 2.5% to 25% who experience marked or unexpected upset during participation (Newman, Risch & Kassam-Adams, 2006 and Newman & Kaloupek, 2004). In a study on children with severe injuries, Kassam-Adams and Newman (2003) found that 5% of parents and 5% of children felt sad

during research procedures. In another study on college students, 9% of respondents experienced intense emotions and 3% felt out of control (Newman, Willard et al 2001; cited in Newman and Kaloupek, 2004).

However, distress during participation does not necessarily equate regret over participation as in the present study 69% of respondents reported that they were not distressed and 78% of respondents indicated that they would be prepared to participate in similar studies in the future. In many other studies the majority of participants do not express regret or negatively evaluate their experience of participation (Legerski & Bunnel, 2010). This has been found to be true in studies which have assessed the experiences of survivors of victimisation, of women being asked about sensitive issues, and of women's reactions to their experiences of sexual, emotional and physical abuse and neglect (see Lergerski & Bunnel, 2010; Walker et al, 1997; and Newman, Walker & Gefland).

Based on these new research studies, it can be seen that research studies on trauma do not violate the beneficence of participants nor do they violate the principle of non-maleficence. Instead, respondents find their engagement in the research process satisfying and personally beneficial. In the present study, 65% reported personal satisfaction with their participation; and 56% indicated that they found their engagement with the study as personally beneficial. Two thirds of respondents (67%) also reported positive risk-benefit ratios regarding their participation and experience of engaging with trauma study. The present study also found that there was significant improvements in distress levels after a two week follow up, as of the 30% of respondents who experienced phase 1 as distressing only 14% reported persistent distress at follow up. This indicates that distress was likely to decrease over time as suggested by more recent studies on trauma.

Satisfaction in participating in trauma research has also been explored in studies where women with exposure to interpersonal violence and trauma have described their participation in trauma research as highly interesting, providing an opportunity to share their story, increasing their access to scarce resources, gaining insight into their experiences, and engendering satisfaction and pride that they are contributing to science which can help

others (Newman, Risch & Kassam-Adams, 2006). Other benefits experienced by participants such as increasing self-awareness, reviewing and reframing their life experiences, reducing self-perceptions of blame and increasing positive self-esteem were also present. In a study on parents with injured children, 95% of parents reported that benefits outweighed the costs of their participation and 98% endorsed no regret for participation (Newman and Kaloupek, 2004). Fifty percent of parents and children in one study rated positive self-esteem post participation, and 50% of children and 90% of their parents felt good about helping others (Newman & Kaloupke, 2004). Positive beneficial experiences were also seen to increase over time with 83% of respondents in one study feeling better at a two week follow up than they did prior to participation, and 57% reporting feeling better than before they participated (Runeson & Beskow, 1991 cited in Lergerski & Bunnel, 2010).

As can be seen from these study results, including the present findings, trauma research does not violate individuals' basic rights to beneficence or non-maleficence. Rather engagement with the research related to traumatic experiences provides them with the rare opportunity to engage with their traumatic experiences; which instead of re-traumatising them, actually produces beneficial experiences that are perceived as personally meaningful with unique personal and intimate benefits. This is further evidenced by the fact that the majority of individuals have reported no regret over their participation and positive risk ratios.

In light of these findings, it is possible to state that allowing individuals who have been traumatised to use their autonomous ability and decide to participate in trauma related research, actually enables them to exercise their right to beneficence and its associated right to non-maleficence due to perceived benefits that lie in their engagement with these studies. Contrary to the past perception regarding trauma research, these studies have produced clear results which could argue the fact that **excluding** the trauma population from participation in trauma studies could actually be violating their basic ethical rights to beneficence, non-maleficence and autonomy.

Based on research discussed in this thesis, it is important for ethical committees and IRBs to reframe their ethical principles to incorporate these new findings so that future research on trauma can be facilitated. Research within the field has been limited due to the ethical concerns which have restricted trauma studies out of fear for re-traumatisation. However the facts are that participation in trauma research has positive cost-benefit ratios and are perceived as beneficial by participants. Therefore, these need to be highlighted and acknowledged which would then hopefully result in a new ethical paradigm that facilitates further trauma research, and hopefully further expand this crucial field of research.

5.3. LIMITATIONS

Although this study is the first of its kind within the context of South Africa, it did have several limitations which may impact on the generalisability of research findings.

One of the limitations of the study was that the sample constituted students who attended a South African university. This sample was characterised by a tertiary level of education supposedly normal adaptive functioning which could have affected their emotional regulation and consequently their performance on the RRPQ. It is possible that had this study been administered and conducted on a different sample, for example a clinical sample, or an inpatient sample, different results may have emerged. It is therefore recommended that more research be done on this area of study to further validate the RRPQ for all populations.

The sample used in this study is also not representative of the South African population, the majority of whom do not have access to tertiary level education. Consequently the level of generalisability for this sample is limited.

Using the questionnaire as a method of obtaining data was a limitation as some students could have misunderstand the questions and consequently not answer them correctly. Using

a questionnaire also assumed that all the questions would mean the same thing for respondents as it did for the researcher, which may not always be case.

Another limitation involved in the use of a questionnaire was that of response sets or formats. This relates to incidents where people responded in a consistent way but which had no relevance to the concept being measured, such has known to occur in two forms: acquiescence and social desirability. The former relates to ‘yay-saying’ and ‘nay saying’, where respondents either agree or disagree with the questions and the latter is when respondents provide answers they think you want to hear.

CONCLUSION

The need to adhere to the core principles of research such as autonomy, beneficence and non-maleficence have been a central reason for the limited research that has been conducted on trauma related areas of interest. The primary reason for this has been due to the concerns of IRBs and ethical committees that conducting research on sensitive respondents might endanger them or possibly re-traumatise them. These concerns however have been based on subjective assessments and measures and biased opinions; which have been vulnerable to common decision making errors such as under utilisation of base rate information, risk estimates which have been based on a few outcomes rather than risk probability, common sense, clinical judgement and imagined personal substitutions. (Newman, Risch and Kassam-Adams, 2006). This unscientific basis for ethical decision making has led to a cyclical pattern which has further limited ethical research.

However, the use of the RRPQ on a South African sample as a valid empirical tool can change the manner in which trauma research has been conducted for two reasons. Firstly it is a revolutionary measure that has been validated in studies by Elana Newman and her colleagues in US based studies, and now for the first time, it has been established as a valid and reliable tool of empirical, objective measurement for use within the diverse South African context.

Secondly, the use of this scientific tool has also produced results which elicit conclusions very different to those drawn from subjective measures of trauma related participation. Empirical results indicate that the majority of respondents have personally beneficial experiences of engaging in trauma related research, finding the experience satisfying, personally meaningful and taking pride in being able to contribute to science. These feelings suggest that possibly traumatised participants do not feel re-traumatised by their experience of engaging in trauma research.

There is, however, a small subset of the sample who did experience distress. However this distress did not necessarily mean regret of participation for these respondents, with many individuals endorsing that in retrospect they would repeat their engagement in trauma research despite experiencing some feelings of distress.

Experiences of distress in the present study were also found to be relatively short lived with 16% reporting distress that was transient in nature, and only 13% of respondents reporting persistent distress. Furthermore, respondents were not found to be re-traumatised by their participation as was initially stated as a cause for concern by many researchers.

Findings based on the RRPQ would therefore appear to have major implications for the field of trauma research as well for the ethical paradigm which has thus far dominated research on trauma related subjects.

Ethical committees and IRBs, have in the past, strictly adhered to the ethical assumptions about trauma research for the sake of ensuring safety for traumatised respondents. Now that empirical research has indicated that these assumptions have been slightly misguided or misjudged, the door stands open for new ethical guidelines on trauma related research to be implemented.

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