



Distress and satisfaction with research participation: Impact on retention in longitudinal disaster research

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ABSTRACT

Previous studies of the impact of post-trauma research participation indicate that while the research experience may be emotional, it can still be valued by participants. This paper describes participant experiences of the Australian post-bushfire research study—Beyond Bushfires. It examines the relationships between distress during research participation, probable mental health conditions, and satisfaction with the research experience over time.

A range of strategies was incorporated into the study, including a distress and risk assessment and referral protocol, to minimise any risk of harm for people who had experienced the 2009 bushfires and their aftermath. Participants included 1056 respondents (Wave 1) interviewed via telephone and web-based survey between December 2011 through January 2013, and 736 (76.1%) of the participants were re-surveyed between July and November 2014 (Wave 2). Research impact was monitored through two questions about survey experience on each occasion. Reported distress at completing the survey was generally low, while overall satisfaction was relatively high. Participants' reported satisfaction was not associated with their reported level of distress as a result of the survey; and reported participation distress at Wave 1 did not predict whether a respondent would return to complete the survey at Wave 2. Fire-related Posttraumatic stress symptoms were associated with increased satisfaction and likelihood to return at Wave 2.

These findings suggest that for Beyond Bushfires survey respondents the perceived benefits outweighed the costs of participation over time.

1. Introduction

The edict of 'do no harm' is the ethical standard for research. This is particularly relevant in post trauma settings. It is well recognised that questioning an individual about their experience of traumatic events may precipitate some emotional reaction [1, 2]. Those with the greatest levels of trauma or mental illness are more likely to experience distress during the research process [2–8]. However, the likelihood of this distress persisting is small, with available research evidence suggesting that only a small minority of participants will experience participation distress, and this distress will be for the most part minimal and of short

duration [2,5,6,8–10]. Nevertheless, the possibility that some participants may experience some level of negative impact demonstrates the need for having mental health support available for participants [1,8].

Research has shown that experiencing distress as a result of participation in research does not affect participants' willingness to complete the study activity [2–6]. Experiencing participation distress is also not associated with how useful participants find the research experience, with the majority of research participants in post trauma studies reporting the experience as useful and/or positive [2,4–6,9–11].

There is still limited information however, about the ongoing impact of the post trauma research experience for participants and their

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engagement with the research over time [1,12]. Where studies have conducted follow up research activities, willingness to continue to participate reflected participants' trust in the researchers, the usefulness of the experience for themselves, and/or the perceived contribution of the research to the welfare of others [9,13].

There is also limited information available concerning the impact of asking certain 'sensitive' questions in the research setting. This can lead to the omission of pertinent questions (such as those relating to suicidality and self-harm) when assessing participants' health and wellbeing as researchers may feel there are not adequate supports in place for participants [18]. This highlights the need for both increased understanding of the impact of such questions on participants within the research context, and comprehensive risk assessment and referral protocols for research participants.

1.1. The Beyond Bushfires Study

In February 2009 severe bushfires occurred across the State of Victoria, Australia. The worst of the fires occurred on 7 February 2009, commonly referred to as 'Black Saturday'. The fires resulted in 173 fatalities, 3500 buildings being damaged or destroyed, and massive adverse impact on community infrastructures [14]. This paper describes participants' experiences of the Beyond Bushfires study, a mixed methods longitudinal study conducted from 2010 to 2016 (www.beyondbushfires.org.au). Strategies were implemented throughout the study to minimise potential negative impact on people who had experienced the disaster and its aftermath. This included: a community based participatory approach, obtaining informed consent before presenting the survey material about the bushfires; referral material for support services; a participant guided approach for qualitative interviews; checks embedded within the surveys to alert people to upcoming questions about disaster exposure; closed questions about trauma exposure; and mental health supports.

This paper reports on participants' self-reported levels of distress and satisfaction about participating in the longitudinal survey and their association with mental health, as well as the use of the distress assessment and referral protocol (outlined in Section 2.1.1). More specifically, this paper aims to investigate the relationship between participation distress and self reported symptoms of poor mental health, and how this may impact upon participant retention in a longitudinal study. Drawing from previous literature in this area the association between symptoms of mental illnesses and these outcomes will also be considered.

2. Method

2.1. Participants and procedure

The Beyond Bushfires study was approved by the University of Melbourne Human Research Ethics Committee. It focused on adults residing in 25 communities in 10 locations within the state of Victoria. These communities were selected to capture diversity in bushfire impact ranging from high impact (operationalised as extensive property loss and fatalities), medium-impact (significant property damage with few or no fatalities), to low-impact (no fatalities and limited or no damage to property). The Social Research Company, an ISO accredited organisation,¹ was commissioned to conduct quantitative data collection, using well established and sensitive recruitment and data collection procedures.

For Wave 1 recruitment, census data from 2006 indicated a total adult population of 7693 in the selected communities (including 702

adults in the two pilot communities) and the Victorian Electoral Commission (VEC) supplied contact details of both current residents and those who had relocated since the bushfires (N = 7467 adults). A letter and reply-paid envelope was sent to these individuals to invite them to participate in the study, and additional activities to raise community awareness of the project were also undertaken, including through news and social media, mailbox drops, and area-based phone calls to those eligible. A total of 1056 people (16%) ultimately completed the survey including 416 males and 640 females, ranging in age from 18 to 87 with a mean age of 56.19 years (SD = 13.33) at the time of the first survey.

Wave 1 survey data collection was undertaken from December 2011 through to January 2013, 3–4 years post disaster. Participants provided informed consent, and surveys were either self-completed via an online questionnaire or administered via Computer Assisted Telephone Interview (CATI), depending on participant preference. Of the 1056 participants who took part in the Wave 1 survey, 966 agreed to be recontacted for the second phase of data collection which commenced 15 July through to 7 November 2014. Attempts were made to contact participants by phone, letter, or email depending on their expressed preference at the original Wave 1 data collection. Of those who agreed to be recontacted, 736 (76%) were retained at follow-up. This sample comprised 282 males and 450 females, ranging in age from 21 to 89 with a mean age of 58.37 years (SD = 12.84) at the time of the second survey. Survey questions at Wave 1 covered sociodemographics, disaster exposure, life circumstances since the disaster, mental and physical health, wellbeing, community factors, and social connections. Wave 2 data collection followed the same format as Wave 1, with bushfire exposure questions replaced with additional items added inquiring about additional trauma events that may have occurred in the period since the Wave 1 survey, and seeking more details about some of the key factors influencing outcomes.

2.1.1. Distress and risk assessment and referral protocol

A mental health support check was embedded within the survey as part of the strategies implemented throughout the study to minimise any potential negative impact on people who had experienced the disaster and its aftermath. This check was part of a distress and risk assessment and referral protocol built into the survey at both Wave 1 and Wave 2. This protocol was activated if responses to specific survey questions, nominated as 'triggers' for the protocol, indicated the respondent was experiencing extreme distress and/or considering self-harm as a result of the research process. This automatically activated an appropriate 'counselling prompt' follow up question to appear in the online survey or to be read by the interviewer administering the CATI. In these cases, participants were offered the option of: being given the contact details for mental health support services; mental health support services being contacted on their behalf; or being referred to a government funded suicide prevention program provided by Lifeline, a national crisis support service.

2.2. Measures

The survey measures included in the analyses for this paper are described below:

2.2.1. Psychological distress

Probable mental illness was assessed using the Kessler 6 (K6), an index of non-specific psychological distress, measuring self-reported symptoms of anxiety/mood disorders over the preceding month. Scores on this scale (scored 1–5 on each of the 6 items; $\alpha = .90$) can be categorised into a measure of degree of severity of mental illness: with scores of 0–7 classified as no mental illness, scores of 8–12 as mild-moderate mental illness, and 13–24 as probably severe mental illness (SMI) [15].

¹ The Social Research Centre has quality accreditation according to the ISO 20252–Market, Opinion and Social Research Standard (an internationally recognised Quality Management System).

2.2.2. Posttraumatic stress disorder (PTSD)

Posttraumatic stress disorder (PTSD) symptoms were assessed using a 4-item version of the Posttraumatic Stress Disorder Checklist (PCL) [16]. This short form of the PTSD checklist assesses four symptoms that provide a high degree of information relative to the other items in the full 17 item measure. These are re-experiencing, concentration, avoidance, and hyper arousal. These items are measured over the preceding four weeks on a 5-point Likert-type scale ($\alpha = .82$). Scores greater than or equal to 7 indicated a probable diagnosis of PTSD that is comparable to that of the full version of the PCL, which assesses each of the 17 diagnostic symptoms outlined in the DSM-IV (the current edition at the time; American Psychiatric Association, 1994 [16,17]). PTSD was assessed in two ways: (a) regarding responses that were specific to the Black Saturday fires and (b) in response to traumatic events generally.

2.2.3. Depression

Probable major depression was assessed using the Patient Health Questionnaire (PHQ-9) [18], which assesses how many days in the preceding two weeks a respondent experienced each of the nine symptoms ($\alpha = .92$). Probable major depression was recorded if five of the nine PHQ symptoms had been present for a majority of days in the preceding two weeks. The ninth item on the PHQ-9 assessed whether an individual had experienced 'Thoughts that [they] would be better off dead or hurting [themselves] in some way' in the last two weeks (scored *yes/no*). Affirmative responses to this item served as one of the two distress and risk assessment and referral protocol triggers embedded in the survey.

2.2.4. Survey participation and experience

Amongst those participants contacted via phone, reasons for not participating in the survey were recorded as open text responses and subsequently coded, categorised and ranked according to frequency. All survey respondents were asked to complete two additional questions at the conclusion of the survey to assess the level of distress and satisfaction they experienced in completing that phase (Wave 1 or Wave 2) of the data collection. These questions were [1] 'How distressing did you find the survey', and [2] 'We are interested to know whether or not you are glad that you participated in this survey'. Responses were measured on 11 point scales from 0 = *not at all* to 10 = *extremely*. Responses of 6 or higher to the question 'How distressing did you find the survey?' served as one of the distress assessment protocol triggers, indicating a markedly high level of participation distress. Another of the triggers was a yes response to a survey question about whether in the last 2 weeks they had been bothered by: "Thoughts that you would be better off dead or of hurting yourself in some way", indicating they may benefit from referral to mental health support services.

2.3. Data analysis

The relation between participation distress and satisfaction was examined cross-sectionally and longitudinally using a range of analyses. All analysis was conducted in IBM SPSS Statistics 24. Missing data were modest (0–3.7%), and Little's MCAR test showed that data were missing completely at random (MCAR), ($\chi^2(94) = 109.90, p = .126$), indicating that data were not missing as a function of any other variable on the analysis. Considering data were MCAR and for the majority of variables missing data were under 1% ($M = .75\%$), analysis proceeded without the imputation of missing data.

Relations between reported distress and satisfaction at each time point were examined using Spearman's rho and independent samples *t*-tests, while paired *t*-test were used to assess each variable over time. The relation between concurrent SMI and participant reported distress and satisfaction was analysed at both time points using Kruskal-Wallis tests. Independent samples *t*-tests were used to assess the relation between distress and satisfaction, and concurrent fire-related PTSD symptoms and probable major depression.

Logistic regression was used to examine whether a range of factors at Wave 1 would predict the probability of an individual returning to complete the survey at Wave 2. Participant survey experience (participation distress and satisfaction) and measures of mental health (continuous scores of probable PTSD and depression, and SMI) at Wave 1 were included as predictors in this model. A second variation of this model was also conducted, to examine whether activation of the distress assessment trigger question about self-harm and suicidal ideation at Wave 1 was related to the likelihood of a participant returning to complete the survey at Wave 2. In order to do this the variable for depression within the model was replaced by this item, asking whether the participant was 'bothered in the last 2 weeks by thoughts that you would be better off dead or hurting yourself in some way'.

A subsequent regression was conducted to examine which variables would significantly predict participation distress at the second wave of data collection. Variables included in this model were participant survey experience at Wave 1 to examine whether participation experiences were consistent longitudinally, and mental health reported at Wave 2 to examine the impact of concurrent mental health on survey participation distress. To address concerns reported in other literature on the possible detrimental effect of inquiring about self-harm or suicidal ideation, a second variation of this model was conducted, with the variable for depression replaced with the self-harm or suicidal ideation indicator. Where probable PTSD is examined here it refers to fire-related PTSD. Sociodemographic variables (gender, age, and education) were included as controls in both models.

3. Results

3.1. Participant characteristics and retention

Ninety participants (8.5%) at Wave 1 refused to be recontacted for further research. Where reasons were provided, the most common reason was that they had 'moved on' from the bushfires (reported by eleven people), closely followed by a general lack of interest in participating (ten people), or the named person was deceased (eight people). Five participants reported that the thought of doing the survey was too distressing.

Those participants retained at Wave 2 ($n = 736$) and those lost to follow-up ($n = 321$) differed on several sociodemographic and experiential variables. Participants retained at the second wave of data collection were generally older (53.46 ± 12.86 vs 51.33 ± 14.28 ; $t(554.32) = -2.29, p = .022$), more likely to possess a tertiary education (38.7% vs 27.7%; OR: 1.66, 95%CI: 1.25–2.21, $p < .001$), rated their satisfaction at Wave 1 participation higher ($t(398.22) = -2.68, p < .001$), and had experienced more property loss as a result of the fires ($t(1051) = -5.76, p < .001$). Respondents retained in the study were not found to differ from those lost to follow up on gender, mental health (probable fire related or general PTSD, psychological distress) or the other fire exposure variables (loss of a loved one and fear for life as a result of the fires).

3.2. Activation of distress and risk assessment protocol

The distress and risk assessment and referral protocol was activated seven times during Wave 1 data collection (.7% of participants). On six of these occasions, the respondent stated that they were either 'Not at all likely' or 'Not very likely' to act on thoughts of self-harm expressed during the survey. In the last instance, the respondent indicated that they were 'Moderately likely' to act on thoughts of self-harm, and were subsequently referred to Lifeline, who followed up with the respondent and placed them on their eight week program of daily contact with a qualified counsellor.

The protocol was triggered nine times during Wave 2 data collection (1.2% of participants). Three respondents said they did not need additional support, two took the contact details of mental health services,

and four accepted the offer for a mental health service to be contacted on their behalf.

3.3. Distress and satisfaction

Generally, respondents positively evaluated their experience of participating in the survey. Overall distress resulting from survey participation was low at both Wave 1 ($N = 999$, $M = 2.58$, $SD = 2.35$) and Wave 2 ($N = 730$, $M = 2.52$, $SD = 2.29$; on a scale from 0: 'not at all' to 10: 'extremely'), and respondents generally reported that they were glad they had taken part in the survey (T1: $N = 968$, $M = 8.29$, $SD = 2.35$; T2: $N = 708$, $M = 8.05$, $SD = 2.46$). How distressing participants found the survey was shown not to be significantly different at Wave 2 ($M = 2.50$, $SD = 2.28$) compared to Wave 1 ($M = 2.50$, $SD = 2.33$), $t(725) = -.05$, $p = .96$. However, on average participants were found to be less satisfied that they participated in the second wave of data collection compared to Wave 1 levels (T1: $M = 8.50$, $SD = 2.22$; T2: $M = 8.08$, $SD = 2.44$), $t(688) = 4.43$, $p < .001$, $d = .17$.

At Wave 1 ($N = 1001$), a weak negative correlation was observed between how distressing participants found the survey and how glad they were that they participated, $r_s(965) = -.111$, $p < .001$. However, amongst those individuals who reported higher levels of participation distress (scores of 6 and above) ($N = 96$), no correlation was observed, $r_s(93) = .147$, $p = .155$. Therefore it appears that the negative correlation between distress and satisfaction is confined to individuals with lower levels of distress (scores of between 0 and 5, $N = 970$), $r_s(870) = -.148$, $p < .001$. At follow-up no significant correlation was found between how distressing participants found the survey and how glad they were that they participated, $r_s(702) = -.014$, $p = .711$.

These findings were supported when the participation distress item was re-coded to reflect its role in the survey as a trigger for the distress assessment protocol questions. There was no significant relation between activating this trigger within the survey and reported satisfaction with survey participation at either Wave 1 (high distress: $N = 95$, $M = 8.26$, $SD = 2.52$; low distress: $N = 872$, $M = 8.30$, $SD = 2.33$; $t(965) = .14$, $p = .89$) or Wave 2 (high distress: $N = 66$, $M = 2.09$, $SD = 1.94$; low distress: $N = 638$, $M = 8.04$, $SD = 2.51$; $t(702) = -.18$, $p = .88$).

3.4. Mental health and survey evaluation

The evaluation variables—participation distress and satisfaction—were compared across mental illness (SMI) groups (no mental illness, mild/moderate mental illness, and probable mental illness), fire-related PTSD status (probable PTSD vs. no PTSD), and major depression status (probable depression vs. no depression). The findings are presented in Table 1. On average, participation distress was higher for those with probable major depression, fire related PTSD symptoms, and higher levels of probable mental illness at both time points. Those with probable mental illness or major depression and those without did not differ significantly in satisfaction at survey participation at either time point. However, a notable finding was that those with probable PTSD also reported being significantly more satisfied that they participated than their counterparts without PTSD. This was observed at both time points.

3.5. Predictors of participation distress and follow-up retention

3.5.1. Distress

The logistic regression model was statistically significant, $\chi^2(8) = 102.43$, $p < .001$, and explained an estimated 29.2% (Nagelkerke R²) of the variance in participation distress at follow-up. Variables were assessed for multicollinearity, with VIF scores within the permissible range, 1.03–1.85. Odds ratios for both predictive models are displayed in Table 2. After adjusting for gender, age, and education the likelihood

of an individual reporting high participation distress at follow-up was significantly predicted by participation distress in Wave 1 (OR = 1.38, 95%CI = 1.24–1.53, $p < .001$) and probable fire-related PTSD at Wave 2 (OR = 1.12, 95%CI = 1.01–1.24, $p = .03$). How satisfied a participant was that they participated in the survey at Wave 1 did not predict their reported distress at follow-up (OR = 1.05, 95%CI = .91–1.21, $p = .50$). SMI and probable depression at Wave 2 were also both found to have no significant relation with participation distress (OR = 1.58, 95%CI = .82–3.04, $p = .17$, and OR = 1.02, 95%CI = .95–1.10, $p = .59$, respectively). As was observed with depression, the reporting of self-harm or suicidal ideation was not found to be associated with participation distress (OR = 1.97, 95%CI = .80–4.84, $p = .14$).

3.5.2. Retention

The logistic regression model was statistically significant, $\chi^2(8) = 43.70$, $p < .001$. The model explained 6.5% (Nagelkerke R²) of the variance in participant retention. Variables were assessed for multicollinearity, with VIF scores within the permissible range, 1.03–2.66. Adjusting for gender, age, and education, reported distress experienced as a result of the Wave 1 survey was not found to predict retention (OR = .99, 95%CI = .92–1.07, $p = .80$). However, how satisfied participants were at Wave 1 was a significant predictor of the likelihood of a participant returning to complete the Wave 2 survey (OR = 1.12, 95%CI = 1.05–1.19, $p < .001$). Interestingly, severity of probable fire-related PTSD at Wave 2 predicted an increased likelihood of participants returning to complete the survey at Wave 2 (OR = 1.10, 95%CI = 1.03–1.18, $p = .005$), while SMI and probable depression were not found to significantly predict retention (OR = .77, 95%CI = .53–1.12, $p = .17$, and OR = .99, 95%CI = .95–1.03, $p = .53$, respectively). Adjusting for the other variables in the regression, the reporting of self-harm or suicidal ideation was not found to be associated with participant retention (OR = .96, 95%CI = .51–1.8, $p = .89$).

4. Discussion

A suite of strategies was included in the Beyond Bushfires study as part of an ethical imperative to minimise potential harm, to increase potential participants' decisional capacity and to assess the impact of the research experience [1,12]. The results add to earlier findings about participation in post trauma research by demonstrating their relevance in the aftermath of a natural disaster and provide increased understanding about how participation distress and mental illness impact on study retention and ongoing participant research experience.

Some research participants demonstrated their capacity to exercise their rights by opting out of wave 2 for various reasons including lack of interest and concern it would be too distressing. This is consistent with previous research into sensitive topics, which reported that participants weighed the costs and benefits of research participation, and declined involvement when participation was anticipated to be too distressing [11]. Failure to recognise this level of participant control, and its differentiation from the lack of control inherent in most trauma situations, can lead to exaggeration of research risks [9].

On average, participants reported that their distress as a result of participating in the survey was low. However, a minority of respondents did report that they found participation in the survey considerably distressing. This is in line with findings from previous research with participants who have experienced traumatic events [9]. More generally, approximately 5% of Australian residents completing a mental health survey reported feeling distressed during the interview [7], suggesting that such emotional distress in response to research is not unique to trauma-related studies. The majority of the survey respondents found the research experience positive at both Wave 1 and Wave 2, regardless of their level of participation distress. Consistent with previous research in this field, signs of mental illness were associated with high levels of participation distress but were not found to

Table 1
Participation distress and satisfaction for those with and without probable SMI, major depression, and fire related PTSD.

		Distress		Satisfaction	
		Wave 1	Wave 2	Wave 1	Wave 2
No mental illness^a	M ± SD	2.11 ± 1.98	2.13 ± 1.91	8.28 ± 2.34	7.99 ± 2.47
(1)	(Median)	(1)	(1)	(9)	(8)
Mild/moderate mental illness^a	M ± SD	3.39 ± 2.79	4.54 ± 2.88	8.31 ± 2.33	8.18 ± 2.41
(2)	(Median)	(2)	(4)	(9)	(8)
Probable mental illness^a	M ± SD	5.05 ± 2.83	5.25 ± 2.94	8.38 ± 2.45	8.58 ± 2.37
(3)	(Median)	(6)	(6)	(9)	(9)
		1 < 2**	1 < 2**	n/a	n/a
		1 < 3**			
		2 < 3**	1 < 3**		
No major depression^b	M ± SD	2.29 ± 2.14	2.31 ± 2.09	8.28 ± 2.33	8.02 ± 2.47
Probable major depression^b	M ± SD	4.41 ± 3.03	4.77 ± 3.09	8.43 ± 2.48	8.30 ± 2.35
Mean difference (95% BCI)		- 2.11 ⁺	- 2.45 ⁺	- .16	- .28
		(- 2.72 to - 1.55)	(- 3.29 to - 1.63)	(- .65 to .37)	(- .89 to .41)
No fire related PTSD^b	M ± SD	2.20 ± 2.06	2.26 ± 2.08	8.21 ± 2.37	7.96 ± 2.50
Probable fire related PTSD^b	M ± SD	4.97 ± 2.94	5.19 ± 2.73	8.90 ± 2.11	8.95 ± 1.85
Mean difference (95% BCI)		- 2.77 ⁺	- 2.93 ⁺	- .69 ⁺	- 1.00 ⁺
		(- 3.36 to - 2.21)	(- 3.60 to - 2.13)	(- 1.11 to - .24)	(- 1.52 to - .50)

^a Kruskal-Wallis H test.

^b Bootstrapped independent samples t-test, BCI = Bootstrapped CI.

* p < .05.

** p < .001.

Table 2
Odds Ratios for Logistic regressions predicting participant retention and distress at Wave 2.

	Distress (Wave 2) O.R. (95% CI)	Retention O.R. (95% CI)
Gender	1.34 (.70–2.59)	1.07 (.79–1.45)
Tertiary Education	1.09 (.60–1.99)	1.89** (1.36–2.61)
Age	1.02 (1.00–1.05)	1.01 ⁺ (1.00–1.02)
Survey Distress (Wave 1)	1.38** (1.24–1.53)	.99 (.92–1.07)
Survey Satisfaction (Wave 1)	1.05 (.91–1.21)	1.12** (1.05–1.19)
PTSD (fire related)	1.12 ⁺ (1.01–1.24)	1.10 ⁺ (1.03–1.18)
SMI	1.58 (.82–3.04)	.77 (.53–1.12)
Depression ^a	1.02 (.95–1.10)	.987 (.95–1.03)
Self-harm ^a	1.97 (.80–4.84)	.96 (.51–1.80)

* p < .05.

** p < .001.

^a Self-harm indicator substituted for depression.

diminish satisfaction about participating [2,4–6,9,11]. This is an important finding which, situated within the existing literature, suggests that research can be a positive experience for those suffering from symptoms of mental illness, and that those who experience distress as a result of participation may still view the experience favourably. This contradicts a tendency in some sectors to regard mentally ill participants as vulnerable and therefore unable or unfit to participate in research. Indeed, these findings support conclusions from a review of 46 studies into the relation between psychiatric research and participant distress, which found that while a minority of participants may experience distress (particularly in studies addressing traumatic experiences), the available evidence suggests that there are unlikely to be longer term negative impacts of participation [8]. Furthermore, as observed in the present study, satisfaction and positive reactions to research participation were reported by the majority of participants, and

showed limited or no association to participation distress [8].

Generally, the participants were found to be less satisfied that they participated in the second wave of data collection compared to Wave 1. This may be because the issues were becoming less relevant for them as time passed. It was notable that participants with probable fire-related PTSD reported being significantly more satisfied they participated than those without fire-related PTSD. When controlling for a range of other factors those participants with more severe fire-related PTSD symptoms were also more likely to return to participate in the Wave 2 survey two years later. When viewed in light of the significantly higher levels of fire related property loss experienced by those who returned to complete the second survey, this finding suggests that those who experienced considerable loss and distress as a result of the fires, may find involvement in the research process particularly meaningful and positive. This complements existing literature which reports that trauma impacted participants can gain personal insights through the research process, and feel that through research participation, their own experiences and insights may in turn assist others [9,13].

Participation distress at Wave 1 was found to predict participation distress at Wave 2 but did not predict retention. Respondents were equally likely to participate at Wave 2 irrespective of their distress resulting from the Wave 1 survey, demonstrating that participants experiencing distress in the first instance will not be discouraged from returning to take part in subsequent research [1,3,12]. It suggests that “distress may be understood as an indicator of emotional involvement in the research project rather than an indicator of harm” [1](p367), and that the benefits of research participation are perceived by participants as outweighing the risks and/or costs [9].

There is reluctance amongst some researchers to address sensitive topics such as participant distress, self-harm and suicide ideation for fear of causing harm [18]. However, there is a growing body of research that indicates that (in the presence of appropriate ethical considerations and provision of participant support) this is not the case [19,20]. This study examined the impact of asking certain ‘sensitive’ questions in the research setting, with one item included to assess self-harm or suicidal tendencies. Findings indicated that those respondents who did report thoughts of self-harm or suicide did not report higher distress as a result of participation in the study, nor did it impact upon their return to complete a second survey several years later. These findings complement existing literature which indicates that inclusion of such questions does not increase suicidal ideation or distress and may in fact have

positive outcomes for participants experiencing these symptoms [8,20].

The findings of this paper confirmed the high levels of trauma in the study sample. This, along with the activation of the distress and risk assessment and referral protocol, demonstrates the importance of having clear strategies in place for provision of mental health support [1]. Given the two waves of data collection were conducted between 3 and 5 years after the original disaster event, it also highlights the extended period of trauma for some. Many people who are distressed by trauma events never seek help or only access services for a short time. For a small number of participants in this present study who activated the distress and risk assessment and referral protocol, their participation led directly to identifying their individual need for support and connecting them with relevant services. In a separate analysis for this study, it was identified that one-third of those with very severe distress did not consult any health or related professional in the previous month for mental health assistance [21]. Therefore, the inclusion of distress and risk assessment and referral protocols may make an important contribution by identifying the proportion of people within the target population who are experiencing distress after a prolonged period, and reinforcing the availability of local services.

There are several limitations to the current study that should be acknowledged. Participant experience was assessed through two items (distress and satisfaction) and due to its longitudinal design examined the role these played in participants' continued engagement with the research project. However, the study does not have data on participants' uptake of referrals to mental health support services, or whether any self harm attempts may have been made by participants following participation. Existing literature indicates that need for support services and suicidal behaviour does not increase following such participation [3,20]. Furthermore, participants of this study were not given the opportunity to provide open ended feedback on their experience, or explain their answers on the distress and satisfaction items. Instead, the inferences made in this paper are drawn from previous qualitative studies into participant experiences of research. Therefore, a more multifaceted approach to evaluating participant research experience could be considered in future research.

4.1. Conclusion

Conducting posttraumatic mental health research that maximizes its scientific validity, while remaining steadfast in its duty of care, requires advance knowledge of people's likely distress and satisfaction arising from research participation, and also being adequately prepared for extreme, albeit rare, scenarios of suicide and self-harm risk. This study provides increased understanding of the relationships between post trauma research participation, mental health, and the distress and satisfaction arising from participation in a telephone and web-based social survey in the aftermath of a natural disaster. It confirms previous trauma research findings demonstrating the benefits and minimal risks associated with research participation. This longitudinal study also shows that these positive research experiences are maintained over time, that probable fire related PTSD is associated with a more positive research participation experience, and retention is not related to levels of reported participation distress. While it is not possible to attribute the positive satisfaction responses to the strategies employed to minimise mental health impacts, we nevertheless advocate use of sensitive strategies and inclusion of a distress and risk assessment and referral protocol in research conducted in post disaster settings to ensure appropriate supports are in place for those experiencing symptoms of mental illness and high levels of distress.

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Declarations of conflicting interests

The Authors declare that there is no conflict of interest.

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