Prevalence and predictors of distress associated with completion of an online survey assessing mental health and suicidality in the community

Philip J. Batterham[a], Alison L. Calear[a], Natacha Carragher[b], Matthew Sunderland[c]

[a] Centre for Mental Health Research, Research School of Population Health, The Australian National University, Canberra Australia

[b] Office of Medical Education, University of New South Wales, Sydney Australia

[c] NHMRC Centre of Research Excellence in Mental Health and Substance Use, University of New South Wales, Sydney Australia

Corresponding author: Philip Batterham
Centre for Mental Health Research
Research School of Population Health
63 Eggleston Road
The Australian National University
Acton ACT 2601 AUSTRALIA
Tel.: +61 2 61251031
Fax: +61 2 61250733
Email: philip.batterham@anu.edu.au

Word count: 1,560

Abstract

While there is evidence that mental health surveys do not typically increase distress, limited research has examined distress in online surveys. The study investigated whether completion of a 60-minute online community-based mental health survey (n=3620) was associated with reliable increases in psychological distress. 2.5% of respondents had a reliable increase in distress, compared to 5.0% with a reliable decrease, and decreased distress overall across the sample (Cohen's d = -0.22, $p<0.001$). Initial depression/anxiety symptoms were associated with increased distress, but suicidality was not. Online mental health surveys are associated with low prevalence of increased distress.

Key words: distress, survey, internet, suicide, mental health

1. Introduction

There is a considerable body of literature indicating that distress arising from participation in mental health research and suicide prevention research is rare, and that positive reactions are considerably more common (Jorm et al., 2007). Nevertheless, ethics committees and institutional review boards often remain resistant to the inclusion of "sensitive" questions regarding mental health symptoms and suicidality in survey-based research. The rise of internet-based survey research has raised additional queries around privacy, security, data quality and informed consent (Buchanan and Hvizdak, 2009), as well as concerns around duty of care to participants (British Psychological Society, 2007) and lack of researcher contact (Barchard and Williams, 2008). While measures can be taken to maximise the safety of online survey research (e.g., providing lists of service resources to all participants, providing contact details for researchers, fully describing the nature and sensitivity of the research in advance), there is a need for further evidence that the risk of inducing distress in participants is not magnified in the online setting.

To our knowledge, only one study has examined the effects of participating in online mental health research (Gibson et al., 2014). The study (n=103) found that of the small number of participants who reported feeling distressed during the survey, most found the distress to be manageable. Larger scale quantitative examination of whether community-based online surveys are associated with increased distress is warranted. The current study aimed to examine whether distress increased in a sample of 3,620 adults following the completion of an anonymous community-based online mental health survey. Factors associated with increased distress were also identified.

2. Method

2.1 Participants and Procedure

Participants were recruited without incentives, using advertisements on the online social media platform *Facebook* in January-February 2016. Advertisements linked directly to the online survey and targeted Australian adults aged ≥18 years (see Batterham et al., 2016 for more details of the recruitment approach). Ethical approval was obtained (ANU Human Research Ethics Committee).

Prior to obtaining consent, a participant information sheet was provided, outlining survey involvement, noting that: participation was optional and anonymous, participants could exit the survey at any time, the survey contained sensitive mental health questions, and the survey took 40-60 minutes to complete. The sheet also included a list of local and national mental health resources, reiterated in the middle and end of the survey. From 7,174 individuals who clicked on the survey link, 5,220 (73%) commenced the survey and 3,620 (50%) completed the full survey. The survey included measures of psychological distress, specific mental disorders, suicidality, fatigue, sleep disturbance, help seeking, disclosure, demographics and personality.

2.2 Measures

Psychological distress was assessed using the Distress Thermometer, a single-item measure ranging from 0-10 that has been shown to be a valid and reliable indicator for current distress (Gessler et al., 2008; Donovan et al., 2014). The Distress Thermometer was administered twice: once at the beginning of the assessment and once at the end. Change scores were calculated.

A number of independent self-report variables were examined as predictors of increased distress. These included age group, gender, employment status, area of residence, language, education, suicidal ideation and attempts (Lindelow et al., 1997) and depression/anxiety symptoms (Patient Health Questionnaire-4, range 0-12; Kroenke et al., 2009).

2.3 Analysis

Changes in distress were assessed from pre- to post-survey and compared using a paired samples *t*-test. Reliable change was assessed as a four-point increase (or decrease) in the Distress Thermometer (DT) rating from pre- to post-survey, based on the Jacobson and Truax (1991) definition. Predictors of reliable increase in distress were evaluated using a multiple logistic regression model. Rates of dropout through the survey were described to further investigate possible distress responses.

3. Results

The sample was disproportionately female (81%), with elevated rates of psychopathology including depression/anxiety symptoms (PHQ-4: *M*=4.0, *SD*=3.5) and high prevalence of suicidal ideation (37%) and attempts (4%) in the past year. Age was distributed evenly across adulthood: 32% aged 18-35, 35% aged 36-55 and 33% aged >55. Representation from metropolitan (52%), regional (36%) and rural/remote (12%) areas was consistent with the Australian population. Most of the sample was employed (61%), although 12% were unemployed and 29% were not currently in the labour force. Participants had a mean of 15.4 (*SD*=2.3) years of education, and 8% reported speaking a language other than English at home.

Among participants who completed the survey (N=3620), mean DT scores were 3.1 (SD=2.8) at pre-test and 2.7 (SD=2.7) at post-test, an overall significant decline of 0.4 points (t=12.6, df=3619, p<0.001; Cohen's d=-0.22). Reliable change was observed in 270 (7.5%) of the participants: 91 (2.5%) had reliable increase in distress and 180 (5.0%) had a reliable decrease. In sensitivity analyses to account for floor/ceiling effects, 728 (13.5%) had any increase and 1427 (26.5%) had any decrease in distress scores (>0 points change).

Factors associated with reliably increased distress are shown in Table 1. No demographic factors were associated with reliably increased distress, with the exception of less education. Initial distress and depression/anxiety symptoms were associated with increased distress. Specifically, lower initial distress was associated with greater odds of reliably increased distress, which is likely to reflect the definition for reliable increase – participants with initial scores >6 could not meet the definition of reliable increase. In contrast, participants reporting higher initial depression/anxiety symptoms had higher odds of a reliable increase in distress. Nevertheless, even participants with severe PHQ-4 scores (≥9) had a mean DT decrease of 0.09 points. Suicidal ideation or attempt in the past year had no association with increased distress.

Withdrawal of participants from the survey was also examined as a potential indicator of distress. Of the consenting participants (N=5220), respondents who completed the initial distress item but later withdrew from the survey (N=1600) had significantly higher distress scores at pre-test (M=3.4, SD=2.9) than survey completers (M=3.1, SD=2.8) (t=3.4, df=5218, p=0.001; Cohen's d=0.10). However, the majority of participants who withdrew completed little of the survey, with 1475 (92%) completing less than half of the survey. Fifty-one (3%) withdrew during the most sensitive section of the survey (at the mid-point) covering suicidal

thoughts and behaviours and risk factors associated with suicide. By comparison, the previous section on personality and sleep had 189 (12%) withdrawals; the subsequent section on worry and attention deficit had 35 (2%) withdrawals.

4. Discussion

This study found that reliable increases in distress were rare (2.5% of the sample) following a lengthy community-based survey on mental health and suicidality. Reliable decreases in distress were twice as prevalent as increases. In the overall sample, average distress levels decreased significantly across the administration of the survey. The prevalence of increased distress was very similar to that observed in other observational studies conducted using traditional recruitment approaches (typically 3-12%; Jorm et al., 2007). The findings consequently suggest that anonymous online surveys are not inherently more risky than more traditional forms of survey administration.

Accounting for initial distress levels, depression and anxiety symptoms were associated with 43% greater odds of increased distress per unit increase on the PHQ-4. This finding suggests that individuals with depression or anxiety symptoms may be more likely to report elevated distress in response to repeated questions about mental health symptoms. Interestingly though, the presence of recent suicidality was not associated with increasing distress in response to the survey. This finding is consistent with trials indicating that suicidality does not typically increase in response to being questioned about suicidal thoughts or behaviours (Gould et al., 2005). Each year of education was associated with a 12% reduction in the odds of increased distress. This finding may represent a bidirectional effect, as depression and anxiety impair educational attainment (Breslau et al., 2008), while reduced educational attainment may reduce effective coping behaviours (Taylor and Stanton, 2007). Alternatively,

less educated individuals may have found the questionnaire more cognitively taxing, leading to less reduction in distress.

This is the first study to examine distress in response to a comprehensive, community-based online survey. Nevertheless, there are several limitations to these findings. First, there was no control group. Individuals asked to respond to a neutral survey may have similar prevalence of increased distress. A controlled study would be required to compare the low prevalence of increased distress observed here to other types of online surveys. Long-term follow-up would also be beneficial to test persistence of change. Second, a proportion of individuals who withdrew from the survey may have been experiencing increased distress. The examination of drop-out rates in the most sensitive section of the survey suggested that distress may not have played a significant factor in drop-out, and most respondents withdrew early in the survey. Nevertheless, future research should examine reasons for withdrawal. Third, the sample was not representative of the general population, particularly in terms of gender and psychopathology. Finally, the DT is an ultra-brief screener for distress, used to minimise response burden.

In conclusion, the current study found that an online mental health survey, delivered anonymously to the general population, was associated with low prevalence of increased distress. The findings suggest that online surveys are not inherently more distressing than other types of surveys. Researchers conducting online surveys should consider including elements in their study designs to minimise distress and increase the likelihood that distressed respondents receive appropriate support (e.g., providing participants with a list of support agencies that they may contact, and encouraging withdrawal). Nonetheless, twice as many participants had reliably decreased distress compared to those with reliably increased distress.

Acknowledgements

PJB, ALC and MS are supported by NHMRC Fellowships 1083311, 1122544 and 1053237 respectively, and the study was funded by NHMRC Project Grant 1043952. The authors would like to thank Dr Jacqui Brewer, Dr Sonia McCallum, and Ms Angeline Tjhin for their assistance in data collection, and Ms Jennie Walker for assistance in preparing the manuscript.

Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

References

Barchard, K.A., Williams, J., 2008. Practical advice for conducting ethical online experiments and questionnaires for United States psychologists. Behav. Res. Methods 40, 1111-1128.

Batterham, P.J., Sunderland, M., Carragher, N., Calear, A.L., Mackinnon, A.J., Slade, T., 2016. The Distress Questionnaire-5: Population screener for psychological distress was more accurate than the K6/K10. J. Clin. Epidemiol. 71, 35-42.

Breslau, J., Lane, M., Sampson, N., Kessler, R.C., 2008. Mental disorders and subsequent educational attainment in a US national sample. J. Psychiatr. Res. 42, 708-716.

British Psychological Society, 2007. Report of the working party on conducting research on the Internet: guidelines for ethical practice in psychological research online. British Psychological Society Leicester.

Buchanan, E.A., Hvizdak, E.E., 2009. Online survey tools: Ethical and methodological concerns of human research ethics committees. J. Empir. Res. Hum. Res. Ethics 4, 37-48.

Donovan, K.A., Grassi, L., McGinty, H.L., Jacobsen, P.B., 2014. Validation of the distress thermometer worldwide: state of the science. Psycho-Oncology 23, 241-250.

Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A., Jones, L., 2008. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. Psycho-Oncology 17, 538-547.

Gibson, S., Boden, Z.V., Benson, O., Brand, S.L., 2014. The impact of participating in suicide research online. Suicide Life Threat. Behav. 44, 372-383.

Gould, M.S., Marrocco, F.A., Kleinman, M., Thomas, J.G., Mostkoff, K., Cote, J., Davies, M., 2005. Evaluating iatrogenic risk of youth suicide screening programs: a randomized controlled trial. JAMA 293, 1635-1643.

Jacobson, N.S., Truax, P., 1991. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. J. Consult. Clin. Psychol. 59, 12.

Jorm, A.F., Kelly, C.M., Morgan, A.J., 2007. Participant distress in psychiatric research: a systematic review. Psychol. Med. 37, 917-926.

Kroenke, K., Spitzer, R.L., Williams, J.B., Löwe, B., 2009. An ultra-brief screening scale for anxiety and depression: the PHQ–4. Psychosomatics 50, 613-621.

Lindelow, M., Hardy, R., Rodgers, B., 1997. Development of a scale to measure symptoms of anxiety and depression in the general UK population: the psychiatric symptom frequency scale. J. Epidemiol. Community Health 51, 549-557.

Taylor, S.E., Stanton, A.L., 2007. Coping resources, coping processes, and mental health. Annu. Rev. Clin. Psychol. 3, 377-401.

Table 1: Logistic regression examining predictors of reliably increased distress (N=3620)

	OR	χ^2	*df*	*P*
Age group		0.403	2	0.817
18-35	0.906	0.092	1	0.762
36-55	1.088	0.070	1	0.792
56+ (reference)	1.000			
Gender				
Female	1.312	0.707	1	0.401
Male (reference)	1.000			
Employment status		2.324	3	0.508
Full time	0.803	0.423	1	0.515
Part time/casual	0.793	0.584	1	0.445
Unemployed	1.280	0.512	1	0.474
Not in labour force (reference)	1.000			
Location		1.570	2	0.456
Metropolitan	0.689	1.155	1	0.283
Regional	0.645	1.501	1	0.221
Rural/remote (reference)	1.000			
Non-English vs English only (reference)	1.387	0.599	1	0.439
Years of education	0.878	6.235	1	**0.013**
Suicidal ideation vs no ideation (reference)	1.128	0.206	1	0.650
Suicide attempt vs no attempt (reference)	1.562	1.034	1	0.309
Initial distress thermometer score	0.544	77.278	1	**<0.001**
PHQ-4 depression/anxiety score	1.431	78.640	1	**<0.001**
(Constant)	0.138	5.171	1	0.023

Notes: PHQ-4: Patient Health Questionnaire-4; **bold** values indicate $p < 0.05$