LETTER TO THE EDITOR

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Reply: benefits of screening cancer patients for distress still not demonstrated

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Sir,

We would like to thank Dr Coyne (2013) for providing the opportunity to further clarify the findings of our extensive evaluation programme of screening for distress interventions. As anyone who has conducted large-scale randomised clinical intervention trials would know, this type of evaluation research is difficult, expensive and time-consuming, yet incredibly important, as randomised, controlled trials are the one methodology that helps us to answer the key questions that Dr Coyne continues to raise: does screening for distress actually improve patient outcomes?

To directly respond to several of Coyne's comments:

(1) The term 'Viable' is meant to convey that the intervention is feasible, which we (Carlson *et al*, 2010) and others (Shimizu *et al*, 2004; Ito *et al*, 2011) have repeatedly demonstrated.

(2) 'Does screening improve patient outcomes relative to the results achieved in routine care without screening?' and 'screening for distress would be judged efficacious if it were shown to improve patient outcomes beyond what would be achieved in routine care'. As stated in the paper, we cannot answer, nor did we attempt to answer, this question from the design of this trial, as there was no randomised usual care comparison group. This trial answered a different question: is screening followed by personalised triage better for patients than screening followed by computerised triage?

The rationale for this research question and subsequent study design decisions was that we already knew from our previous work that:

- screening was better than no screening (Carlson *et al*, 2010),
- connecting with resources was key (Carlson *et al*, 2010),
- patients who needed support did not always self-refer to resources (Waller *et al*, 2011),
- without screening, problems did not always resolve on their own over 1 year (Carlson *et al*, 2013).

While Coyne may disagree with the first premise (which we will leave him to), we maintain our position and are now focusing on evaluating different forms of service delivery to see if it is possible to provide screening followed by triage in a simpler and cheaper format—via computer. Given that there were no group differences on rates of change in anxiety, depression, distress, pain and fatigue between groups, it does appear that a computerised screening programme with automated referrals may be a good alternative to programmes that, as pointed out by Coyne, can be costly.

(3) 'It is worth examining whether Carlson *et al* (2010) yielded results so compelling that to offer routine care condition without screening would be 'somewhat unethical''. Coyne raised this concern previously in a letter following publication of this paper (Palmer *et al*, 2011), and at that time we reiterated the results indicating that after 3 months 'The percentage of patients over the distress cutoff was significantly lower in the triage group, at 36%, compared to 46% and 48.7% in full screening and minimal screening, respectively' (p. 4888) (Carlson *et al*, 2011). Although Coyne may continue to debate this point, we personally find the evidence from our own research and other studies that have been conducted (see Carlson *et al*, 2012 for a review), convincing enough to support the value of screening for distress programmes. Hence, the current trial was designed with this premise in mind and in an attempt to find low cost yet effective means to surmount some of the difficulties Coyne mentions.

(4) 'Simply providing patients with an opportunity for a minimal discussion with information and encouragement to seek services, regardless of the level of distress, might provide the benefits sought by implementing screening'. That is the condition we offered in our previous paper, called 'minimal screening', which while we acknowledge likely has benefits in and of itself, was inferior to full screening and full screening followed by individualised triage in improving distress 3 months later, as noted above.

(5) 'Despite having the resources and focused attention of a funded clinical trial, these investigators lost a substantial proportion of their patients initially screened to follow-up.' We did lose about 1/3 of the patients to follow-up, which we believe was a consequence of the trial design. We contacted the patients at 3, 6 and 12 months post diagnosis by e-mail or phone, not for screening purposes, but rather for follow-up assessment of trial

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outcomes. Recommendations for clinical implementation of screening for distress call for routine screening in the clinic, at critical care points. Hence, the drop-outs from this study do not reflect at all upon the feasibility of implementing clinic-based screening programmes, rather on the usual attrition seen in clinical trials over an extended period of time.

(6) 'Furthermore, only a minority of distressed patients in either condition accessed services, with no group differences in outcome associated with group assignment, but those who accessed services improved more.' This is the second large study in which we have seen that patients who accessed services improved more over time; hence, our take-home message has come to be that screening alone is not enough—it must be effective in connecting patients with appropriate services. The fact that personalised triage was so much more effective in connecting patients with resources in this trial supports the recommendation for this screening format, particularly for 'at-risk' populations.

(7) 'Screening for distress should not be implemented without demonstration that it actually improves patient outcomes over routine care and that benefits exceed costs at patient and system levels'. We agree with this statement and challenge Dr Coyne to use his analytical skills and obvious interest in this area to help add to the evidence base, rather than detract from the evidence that currently does exist. No one study is going to answer these questions; a body of research is certainly needed to help incrementally advance our understanding of the benefits, potential drawbacks and alternatives to screening for distress in oncology populations. That is exactly what we are attempting to do within our research programme, and invite Dr Coyne and his team to join in the effort.

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