

Unresolved problems with distress screening

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Sir,

The critique of Coyne, 2013 of the Carlson *et al*, 2012 paper and response by Carlson *et al*, 2013 raise important issues regarding screening patients for cancer-related distress that have concerned us for some time. Relevant to the debate are the following:

(1) The comment by Coyne, 2013 regarding declines in distress over time following cancer diagnosis and treatment is widely believed, but incorrect. Distress trajectories based on group mean values are problematic. The problem is, if in a study 50% of the sample score 10 out of 10 on a notional distress scale declining to 0 out of 10 over time, whereas the other 50% score 0 out of 10 increasing to 10 out of 10 over the same period, the observed group mean will remain at 5 out of 10 and the conclusion would be there is no change in distress. This of course is the wrong conclusion. Analyses using Mixture Growth modelling, a method that decomposes samples into distinct trajectories, reveal patterns of distress distinctly different to the accepted wisdom of a steady decline over time (Helgeson *et al*, 2004; Deshields *et al*, 2006, Henselmans *et al*, 2010; Lam *et al*, 2010, 2011, 2012a, 2012b). These studies consistently show that a broad majority of cancer patients, around 60% are resilient, experiencing persistently low distress with only marginal and transient peaks throughout the cancer trajectory. A second subset of patients who have low distress early in the cancer trajectory report gradually increasing distress levels that peak around the end of treatment and quickly decline thereafter. A third set follow the classic pattern mentioned by Coyne, 2013, with high levels early in the trajectory declining over time thereafter. Finally, a fourth group, 5–20%, show stable levels of high distress persisting over the duration of the cancer trajectory. (Henselmans *et al*, 2010; Lam *et al*, 2010, 2011, 2012a, 2012b) Patterns of distress in the first year following diagnosis predict distress outcomes up to 6 years following diagnosis (Helgeson *et al*, 2004; Lam *et al*, 2011, 2012a). These patterns broadly mirror the resilience model of response to trauma (Bonanno *et al*, 2011).

(2) Evidence increasingly points to unresolved symptoms as being a major predictor of cancer-related distress trajectories (Lam *et al* 2010; 2012b). This suggests that more effective symptom management would be a more cost-effective approach to cancer-related distress. However, there are always going to be patients who need distress-support services and such patients need to be

identified. In particular, there is a pressing need to differentiate and identify the chronic distress patients who would benefit most from supportive interventions from those with transient distress.

(3) Given the above, the timing of any programme for distress screening in cancer patients will give quite different results depending on when screening is performed. Currently, evidence suggests that the greatest proportion of patients (~80%) experience some signs of distress at around 1 month following primary treatment. Mostly, this distress is transient, and patients and their families cope well with it; for some it is part of a longer decline from an earlier peak, for others it is increasing, only to decline later. Only about 1 in 6 to 1 in 8 of those positively screened as distressed would have chronic distress that is unlikely to remit on its own. Any one point estimate will not tell you to which group a screened distressed patient belongs and hence whether they would, or would not benefit from additional intervention; this is relevant to Coyne's point about outcomes. Coyne suggests the effects reported by Carlson *et al*, 2012 are due to recognised declines in distress over time. Of greater concern to us is that most patients show very little distress for most of the cancer trajectory, although they might get picked up if repeatedly screened, during a fleeting peak of distress, probably at critical points in the cancer trajectory (diagnosis, treatment cessation, recurrence). Hence, including them in any randomised controlled trial is unlikely to confer much benefit and, potentially, both dilute any group-intervention effects and increase dropout, a phenomena clearly evidenced in Carlson *et al*'s cohort where around one out of three patients dropped out. This is misleading, as for the chronically distressed group the benefits of supportive interventions may be more substantial than published studies suggest.

(4) It is well recognised that uptake and completion of interventions tends to be much greater in randomised controlled trials than in everyday clinical practice. This is likely to be the case for therapeutic interventions targeting cancer-related distress. In everyday practice, most people cope with cancer. The challenge is to identify and help those who don't.

(5) Frankly put, it seems that most cancer patients are resilient and it is not cost-effective to include them in distress-support programmes, because they will simply not attend or drop out. Identifying the approximately one in eight distressed patients who

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would benefit from interventions remains a challenge to be resolved.

(6) Finally, we agree with Coyne's view that greater emphasis needs to be placed on aspects of behaviour and care that make a difference to outcomes in cancer. In particular, prompt recognition and response to symptoms by patients and rapid recognition and onward referral by primary providers, and access issues to service utilisation remain critical influences that will improve outcomes (Li *et al*, 2012) but which currently receive far too little attention.

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