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The sum of all fears: Conceptual challenges with measuring fear of cancer recurrence

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Abstract

Fear of cancer recurrence (FCR) is increasingly recognised as a major concern for people with cancer once active treatment is completed. Several instruments have been designed to assess FCR, however no gold standard has emerged. Many instruments conceptualise FCR as a multidimensional construct. However this potentially conflates FCR as an outcome with its antecedents and consequences. This is problematic when an aggregate of distinct dimensions is calculated, as is commonly recommended. For example, the total score on the Fear of Cancer Recurrence Inventory is an aggregate of items from seven sub-scales: triggers, severity, psychological distress, coping strategies, functioning impairments, insight, and reassurance. Similarly, the total score on the Fear of Progression Questionnaire is an aggregate of affective reaction, partnership/family, work, and loss of autonomy. Arguably, the severity and affective reaction domains represent fear, and the other sub-scales represent related concepts, rather than “dimensions” of FCR. The total score represents a combination of concepts whose meaning is unclear. The same total score could be produced by patients with very different experiences, and patients with the same level of fear could have very different total scores. Therefore, we argue that although the level of FCR may be determined by a complex network of antecedents and modifiers and have variable consequences, FCR itself may be a simple concept, which can be assessed using a smaller number of items. Conceptual clarity in its research infancy should prevent FCR becoming a construct that is vaguely operationalised and interpreted.

As treatment improvements prolong the lives of people with cancer, fear of cancer recurrence or progression (referred to as *FCR* for simplicity) is an issue of increasing importance for many survivors. Accordingly research in this area has increased. Thewes et al (1) identified 20 multi-item instruments designed to assess FCR, including sub-scales of more general instruments, brief screening tools, and longer multidimensional instruments. However, no gold-standard instrument has yet emerged.

There is a growing tendency to conceptualise FCR as multidimensional, and there are undoubtedly cognitive, behavioural, and emotional expressions of FCR. For example, the Fear of Progression Questionnaire (FoP-Q) (2) and Fear of Cancer Recurrence Inventory (FCRI) (3), two of the instruments most widely used to assess FCR, include sub-scales addressing possible triggers, emotional consequences, and/or functional impacts of FCR. Although acknowledging the varied determinants, presentations, and consequences of FCR is important, the proliferation of sub-scales assessing various FCR-related concepts has led to conceptual confusion regarding the nature of the construct, what the essential components of FCR are, and how we best measure it. Using these instruments as illustrative cases (but noting that the issues raised are not unique to them), we will demonstrate some consequences of this confusion.

The FCRI (3) is a 42-item cancer-specific questionnaire with seven sub-scales: triggers, severity, psychological distress, coping strategies, functioning impairments, insight, and reassurance. The FoP-Q (2), a 43-item questionnaire designed to assess fear of progression in chronic illness, has five sub-scales: affective reaction, partnership/family, work, loss of autonomy, and coping. In the validation of both instruments, the authors calculated a total score additional to sub-scale scores, observing a high Cronbach alpha (0.95 in both cases).

Despite their strong psychometric properties it is unclear what total scores on these measures represent. The FCRI *severity* sub-scale seems to most appropriately represent fear. This appears to have been implicitly acknowledged, as the FCRI clinical cut-off is based only on the severity sub-scale (4). The remaining subscales may more accurately represent antecedents (e.g., *triggers*), modifiers (e.g., *coping strategies*) or consequences (e.g., *functioning impairments*). For the FoP-Q, the total score sums four sub-scales (all but *coping*). *Affective reactions* best represents the emotional state (fear, worry or anxiety), and *partnership/family, work* and *loss of autonomy* capture impacts on specific aspects of life associated with the emotional state. Some items in these latter three sub-scales resemble antecedents (e.g., 'I am nervous prior to doctors' appointments or periodic examinations'), others consequences (e.g., 'The worries about my health make me irritable with others').

The items in these (and other) instruments capture important information, but a score aggregated across all domains/subscales represents an uninterpretable combination of concepts. The same total score could be produced by patients with very different experiences; for example, a patient may experience significant psychological distress and fear about cancer returning but manage adequately in daily life, whereas another patient may experience fear about fewer aspects of life but manage poorly when triggers induce high levels of fear. Conversely, two patients with the same level of fear may have very different total scores, depending on the antecedents and consequences they experience. We are not suggesting that these antecedents and consequences should not be considered; indeed they may be useful indicators of when FCR levels are clinically significant. We simply argue that FCR should be considered separately from these related constructs.

The scope of a patient-reported outcome measure can be determined by the definition of the construct it is designed to assess. One possible cause of the confusion regarding FCR is that its most commonly adopted (but not universally accepted) definition is essentially a restatement of its label:

fear that cancer could return or progress in the same place or in another part of the body (1, 3, 5). This definition simply specifies the object of the fear. Moreover, some instruments also capture “worry”, “anxiety” and/or “concerns”, without consideration of whether these are synonymous with fear. A second issue relates to varying presentations of FCR, which in turn directly impacts the way we assess FCR. At present there is no coherent description of what this specific fear looks like – whether the fear is expressed emotionally, cognitively or behaviourally. For example, only certain individuals may display behavioural expressions of FCR, e.g., excessive body-checking, which begs the question whether this is a core component or consequence of FCR.

Thewes et al (1) state that “FCR seems to be a multidimensional construct and not simply a unidimensional emotional factor (e.g. fear), but this hypothesis needs to be validated” (p582). On the contrary, FCR may be unidimensional, and the other constructs included in FCR questionnaires may be theoretically related but logically independent. This can be gleaned from cursory conceptual analysis rather than empirical validation. In short, fear may be a construct that can be assessed using relatively few items, e.g., the four-item CAR-Q (6). What is complex about FCR may not be the construct itself but its varied antecedents and consequences for any one individual.

We propose that at its core FCR is a simple construct, with related antecedents, modifiers, and consequences worth assessing using questionnaires, but calculating and interpreting an aggregate of these related but distinct variables seems inappropriate. Empirical data can in fact obscure conceptual clarity. For example, the high coefficient alpha for the FCRI and FoP-Q total scales is considered evidence supporting the interpretation of the total score, but alpha assumes unidimensionality rather than proving it. A practical implication of this lack of conceptual clarity is that the meaning of a claim that an intervention reduced FCR depends on the instrument used and how it was scored. For example, an intervention may be designed to act specifically on severity of FCR, or it may be targeted at improving coping strategies or reducing functional impairment.

“Quality of life” is a vague and inconsistently-defined concept whose improvement is routinely claimed as an aim or outcome of research. Given that FCR research is in its infancy, ensuring conceptual clarity at this early stage may prevent FCR from following quality of life, with its abundance of definitions and instruments to match.

Conflict of interest

The authors have no conflicts of interest to declare.

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