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PRO-ACTIVE: Prostate Cancer Support Intervention For Active Surveillance Patients

Aim

The aim of this investigation is to assess the effectiveness and feasibility of delivering a psycho-educational support intervention entitled PROACTIVE (PROstate Cancer Support Intervention for ACTIVE Surveillance) to manage anxiety among prostate cancer patients being managed with active surveillance

Plain English summary

The research team have previously developed the PROACTIVE intervention to help prostate cancer patients being managed with active surveillance manage the high levels of anxiety and depression they commonly experience. This initial development was by PCaSO, a large South Coast patient led prostate charity covering Dorset, Hampshire and Sussex (website www.pcaso.org). We worked extensively with PCaSO to develop the PROACTIVE intervention through several rounds of individual qualitative interviews with patients, focus groups and getting patients to use the think-aloud technique to refine the web-based support package using LifeGuide software. PCaSO also donated £10,000 to help fund the development of the project. Their support was a key component of a bid to Prostate Cancer UK to enable funding for a further feasibility trial of the intervention.

Collaborations

PCaSO (Prostate Cancer Support Organisation), Faculty of Health Sciences at the University of Southampton, Departments of Urology at Southampton General Hospital and, MacMillan Centre UCLH.

Key impacts

In an earlier stage of this programme of research we completed a survey of depression and anxiety in over 300 people on active surveillance from 7 different hospitals. This showed men on AS experience a high level of anxiety that was three times higher than men in the general population without prostate cancer. This is important as anxiety represents the main precipitating factor of conversion to unnecessary radical intervention in the absence of any histological sings of disease progression. Crucially, opting for radical treatment in this way does not increase 12-year survival rates but is associated with a significantly greater risk of long term impotence, incontinence, bowel dysfunction and a reduced quality of life. The effective management of anxiety in this burgeoning patient group is therefore of fundamental clinical importance. We have piloted PROACTIVE on a single group of active surveillance patients from UCLH. The results were very positive and suggest that participation in PROACTIVE boosted health literacy, improved wellbeing and the ability to self-manage their health and wellbeing. This should ultimately lead to a reduction in unnecessary and harmful conversion to radical intervention (surgery and radiotherapy) triggered by anxiety.

Outputs

The long terms outputs of this investigation will focus on assessing how participation in PROACTIVE reduces anxiety, improves quality of life and lowers the number of men transferring to clinically unnecessary radical treatment that is precipitated by anxiety. These long term outputs will be assessed in a large, multi-centre randomised controlled trial.

However, before we progress to a RCT of this nature, it is essential that we assess the feasibility of delivering PROACTIVE within the NHS. Our immediate short term feasibility objectives are:

1. Can we identifying enough patients?
2. Can we recruit enough men?
3. Do men using PROACTIVE find it helpful? How?
4. Does PROACTIVE have effects on anxiety, depression and quality of life?
5. What is the best way to measure the numbers of men choosing unnecessary surgery comparing PROACTIVE and normal care.
6. What modifications are needed to PROACTIVE before we test its effectiveness in a larger nationwide study?

The answers will allow us to develop an improved version of PROACTIVE, which we will use to determine whether it works in a large national investigation.

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