Treatment decision incongruence associated with lower health-related quality of life in prostate cancer survivors. Results from the Picture study: Beyond the Abstract

December 20, 2017

Treatment decision making (TDM) in cancer is complex involving balancing the benefits and risks of different treatments and uncertainty regarding treatment effectiveness and consideration of multiple potential outcomes. This TDM process can be difficult for prostate cancer patients and clinical teams - many prostate cancer treatment options are medically justified, but with few randomised controlled trials, a consensus on the most effective treatment for localised prostate cancer is lacking. Furthermore, each treatment carries the risk of acute and chronic adverse-effects into survivorship.

The relative roles of patients and doctors in TDM has evolved over the past few decades. There has been a move away from a paternalistic model of TDM where doctors know best and patients have a passive role, towards the shared and informative/active models where patients have more involvement. Few studies have investigated men's actual or preferred roles in prostate cancer TDM, or the impact of this experience. The effect of incongruence in the TDM has been little researched. To our knowledge, no studies have investigated the effect of TDM experience on prostate cancer survivor's long-term health-related quality of life (HRQoL). Our aim was to document actual and preferred TDM roles, congruence in TDM and associations between TDM and HRQoL of a large population-based sample of prostate cancer survivors 2 to 18 years post-diagnosis.

As part of the PiCTure Study we sent questionnaires to 6,559 PCa survivors 2-18 years post-diagnosis, identified through population-based cancer registries in Ireland. We used the Control Preference Scale to investigate respondents' 'actual' and 'preferred' role in TDM. The TDM experience was considered 'congruent' when actual and preferred roles matched and 'incongruent' otherwise. We used the EORTC QLQ-C30 to measure gHRQoL. Multivariate linear regression was employed to investigate associations between i) actual role in TDM, ii) congruence in TDM, and gHRQoL.

Completed questionnaires were returned by 3,348, giving a response rate of 54%. The percentages of men who reported that their actual role in prostate cancer TDM was active, shared or passive were 36%, 33% and 31%, respectively. Congruence between actual and preferred roles in TDM was reported by 58% of responders. Congruence was highest amongst men who had a shared role (65%) and lowest for those who had an active role (49%). The actual role

prostate cancer survivors assumed in the TDM process was not associated with gHRQoL in survivorship. However, in multivariate analysis, after adjusting for socio-demographic and clinical factors including treatment received and expectation of adverse effects post-treatment, survivors whose TDM experience was incongruent had significantly lower gHRQoL than those who had a congruent experience (-2.25 95%CI -4.09,-0.42; p=0.008). This effect was most pronounced among survivors who had more involvement in the TDM than they preferred (-2.69 95%CI -4.74,-0.63; p=0.010).

In conclusion, less than 6 in 10 PCa survivors experienced congruence between their actual and preferred roles in TDM. Having an incongruent TDM experience was associated with lower gHRQoL among survivors. These findings, to our knowledge are novel and suggest that involving patients in TDM to the degree to which they want to be involved may help improve PCa survivors' gHRQoL.

Written by: Frances J Drummond, PhD. University College Cork, Ireland.