This is the peer reviewed version of the following article:

Feelings, and feelings, and feelings. Let me try thinking instead': Screening for distress and referral to psychosocial care for men with prostate cancer.

Published in the European journal of cancer care

First published: 10 September 2019

which has been published in final form at

https://onlinelibrary.wiley.com/doi/full/10.1111/ecc.13163

This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving."

Editorial for September 2019

"Feelings, and feelings, and feelings. Let me try thinking instead": Screening for Distress and Referral to Psychosocial Care for Men with Prostate Cancer:

C.S. Lewis, (1961)

Jeff Dunn AO PhD ¹⁻⁴ Suzanne K Chambers AO PhD ^{2,4-6}

- 1 Prostate Cancer Foundation of Australia, Sydney, New South Wales, Australia
- 2 University of Southern Queensland, Toowoomba, Queensland, Australia
- 3 Cancer Council Queensland, Brisbane, Queensland, Australia
- 4 University of Technology Sydney, Sydney, New South Wales, Australia
- 5 Menzies Health Institute Queensland, Griffith University, Brisbane,

Queensland, Australia

6 Exercise Medicine Research Institute, Edith Cowan University, Joondalup, Western Australia, Australia

Correspondence

Suzanne Chambers, University of Technology Sydney, Sydney, New South Wales, Australia.

Email: Suzanne.Chambers@uts.edu.au

In 1961 CS Lewis observed that grief felt like fear, or being concussed, with "an invisible blanket between the world and me" (Lewis, 1961). During his exploration of grief, Lewis observes that from feelings one can move to thinking, that is, to apply the rational self as a point from which to move forward. And so to prostate cancer.

The global burden of prostate cancer is escalating with over 1.2 million men diagnosed each year (Bray et al., 2018). The face of prostate cancer has changed over the past three decades since the advent of the prostate-specific antigen test and the promise of early detection and cure (Schroder, Hugosson, Carlsson, et al., 2012; Schroder, Hugosson, Roobol, et al., 2012), and new approaches to the treatment of advanced disease (Emmett et al., 2017). Clinical research and technological advances have expanded treatment possibilities for these men - theranostics and personalised medicine offer new hope (Huey, Hawk, & Offodile, 2019). However, the personal experience of prostate cancer, and the feelings that surround prostate cancer, are connected to physical, social, psychological, and relationship challenges that for many men will be long term, if not life-long (Chambers, Ng, et al., 2017; Chambers, Occhipinti, et al., 2019). The data is clear. After diagnosis up to one in four men experience anxiety and up to one in five report depression (Watts et al., 2015). Heightened distress occurs across all treatment approaches, exacerbated when disease or

symptom effects are advanced (Chambers, Ng, et al., 2017; Coughlin et al., 2018; Meissner, Herkommer, Marten-Mittag, Gschwend, & Dinkel, 2017). Risk of suicide is increased after a diagnosis of prostate cancer by comparison with controls (Bill-Axelson et al., 2010; Carlsson et al., 2013; Dalela et al., 2016), particularly in the first six to twelve months after diagnosis (Guo et al., 2018; Smith et al., 2018). Unmet needs for support for psychological care are widely prevalent (Hyde et al., 2016; Smith et al., 2007). For many, the diagnosis of prostate cancer will generate strong feelings and a life permanently changed.

And so to thinking, to act.

Brief distress screening for people with cancer is an accepted standard in oncology care (Holland, Watson, & Dunn, 2011); it is well validated in men with prostate cancer (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014); and evidence-based and accessible psychosocial interventions have been developed (Chambers, Hyde, et al., 2017; Crawford-Williams et al., 2018). Psychosocial care is at the core of best practice survivorship care (Andersen et al., 2014). Unless men experiencing high levels of distress are identified within the care pathway, and referred for intervention or support, they are unlikely to receive the care they need (Chambers & Heathcote, 2018). To date, in Australia and likely elsewhere, distress screening for men with prostate cancer has not been universally implemented and so, many men will have their psychological needs left both unnoticed and unaddressed. By and large, psycho-oncology research has not addressed implementation and systems-based interventions that focus on sustainable improvements in psychosocial care are scant (Sanson-Fisher et al., 2019). Consonant with this, for men with prostate cancer and their partners, psychosocial and survivorship care implementation studies are largely absent (Chambers, Hyde, et al., 2017; Crawford-Williams et al., 2018). Herein lies the problem.

The Prostate Cancer Foundation of Australia and Australian National Health and Medical Research Council Centre for Research Excellence in Prostate Cancer Survivorship partnered with key Australian medical, nursing and research leaders to develop a position statement on screening for distress and on providing psychosocial care for men with prostate cancer (available at https://www.pcfa.org.au/). The statement was launched on September 11th 2019 in Canberra to encourage and guide advocacy to enhance psychosocial outcomes for men and their families as well as cancer survivorship more broadly. Importantly, the statement is endorsed by the Urological Society of Australia and New Zealand; Australia and New Zealand Urological Nursing Society; Royal Australian and New Zealand College of Radiologists; Medical Oncology Group of Australia; Australia and New Zealand Uro-genital and Prostate Cancer Trials group; European Association of Urology Nurses and universities across Australia. The statement recommends:

- After the diagnosis of prostate cancer and regularly through treatment and surveillance men who have been diagnosed with prostate cancer should be screened for distress and their psychological and quality of life concerns should be explored
- 2. Men who have high levels of distress should be further evaluated for anxiety and/or depression and evidence of suicidality
- 3. Men who have high distress or need for support should be referred to evidencebased intervention matched to their individual needs and preferences for support
- 4. Research is needed to develop effective methods to identify partners of men with prostate cancer with high distress or who are at risk of high distress as well as effective interventions for partners and for couples where the man has a diagnosis of prostate cancer
 - 5. Investment in prostate cancer survivorship research is a national health priority

It does not seem a difficult or insurmountable health system change to screen for distress after a diagnosis of cancer and to refer to relevant support, yet implementation continues to lag (Lazenby, Tan, Pasacreta, Ercolano, & McCorkle, 2015). The administration time for a single item distress thermometer and problem checklist can be measured in brief minutes. But most importantly, this brief screen initiates the patient's self-appraisal of distress, and guides clinical staff not only on the level of distress, but also on the source or sources of concern for the man. An evidence-based monograph has been produced to guide the health sector in taking action to implement screening for distress and referral for men with prostate cancer to psychosocial health care resources (Chambers, Galvão, et al., 2019; available at https://www.pcfa.org.au/). Learning tools have been developed and are in trial. Recently, Lazenby and colleagues reported the successful dissemination and implementation of psychosocial distress screening at 72 cancer centres in North America (Lazenby et al., 2019). The involvement of key stakeholder groups was crucial to the success of this program, and with this involvement came the commitment of resources.

Awareness, education, and skills training to support actual implementation needs to be context-relevant and accessible. Our approach is consistent with this.

For men with prostate cancer in our setting, the first key steps for implementation are in play: a published and context-relevant evidence base developed with the support of key stakeholders by a dedicated community-based consumer organisation, the Prostate Cancer Foundation of Australia, advocating independently for change. Position statements are only of value when adopted into routine practice, and therein lies the challenge: we must move beyond feeling to thinking and acting. Returning to CS Lewis (1961), the observation that "attention is an act of will", and "intelligence in

action is will *par excellence*". This is our challenge as health professionals in oncology. We have the knowledge. Do we have the will?

REFERENCES

- Andersen, B. L., DeRubeis, R. J., Berman, B. S., Gruman, J., Champion, V. L., Massie, M. J., . . . Rowland, J. H. (2014). Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *Journal of Clinical Oncology*, 32(15), 1605-1619. doi:10.1200/jco.2013.52.4611
- Bill-Axelson, A., Garmo, H., Lambe, M., Bratt, O., Adolfsson, J., Nyberg, U., . . . Stattin, P. (2010). Suicide risk in men with prostate-specific antigen-detected early prostate cancer: A nationwide population-based cohort study from PCBaSe Sweden. *European Urology, 57*(3), 390-395. doi:10.1016/j.eururo.2009.10.035
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, 68(6), 394-424. doi:10.3322/caac.21492
- Carlsson, S., Sandin, F., Fall, K., Lambe, M., Adolfsson, J., Stattin, P., & Bill-Axelson, A. (2013). Risk of suicide in men with low-risk prostate cancer. *European Journal of Cancer*, 49(7), 1588-1599.
- Chambers, S. K., Galvão, D. A., Green, A., Lazenby, M., Newton, R. U., Oliffe, J. L., . . . Dunn, J. (2019). A psychosocial care model for men with prostate cancer. Prostate Cancer Foundation of Australia and University of Technology Sydney, Australia. ISBN-13:978-0-646-80446-0
- Chambers, S. K., & Heathcote, P. (2018). The psychological toll of prostate cancer. *Nature Reviews Urology*, 15(12), 733-734. doi:10.1038/s41585-018-0111-0
- Chambers, S. K., Hyde, M. K., Smith, D. P., Hughes, S., Yuill, S., Egger, S., . . . Dunn, J. (2017). New Challenges in Psycho-Oncology Research III: A systematic review of psychological interventions for prostate cancer survivors and their partners: clinical and research implications. *Psycho-Oncology*, 26(7), 873-913. doi:10.1002/pon.4431
- Chambers, S. K., Ng, S. K., Baade, P., Aitken, J. F., Hyde, M. K., Wittert, G., . . . Dunn, J. (2017). Trajectories of quality of life, life satisfaction, and psychological adjustment after prostate cancer. *Psycho-Oncology*, *26*(10), 1576-1585. doi:10.1002/pon.4342
- Chambers, S. K., Occhipinti, S., Stiller, A., Zajdlewicz, L., Nielsen, L., Wittman, D., . . . Dunn, J. (2019). Five-year outcomes from a randomised controlled trial of a couples-based intervention for men with localised prostate cancer. *Psycho-Oncology*, 28(4), 775-783. doi:10.1002/pon.5019
- Chambers, S. K., Zajdlewicz, L., Youlden, D. R., Holland, J. C., & Dunn, J. (2014). The validity of the distress thermometer in prostate cancer populations. *Psycho-Oncology*, *23*(2), 195-203. doi:10.1002/pon.3391
- Coughlin, G. D., Yaxley, J. W., Chambers, S. K., Occhipinti, S., Samaratunga, H., Zajdlewicz, L., . . . Gardiner, R. A. (2018). Robot-assisted laparoscopic prostatectomy versus open radical retropubic prostatectomy: 24-month outcomes from a randomised controlled study. *Lancet Oncology*, 19(8), 1051-1060. doi:10.1016/s1470-2045(18)30357-7
- Crawford-Williams, F., March, S., Goodwin, B. C., Ralph, N., Galvao, D. A., Newton, R. U., . . . Dunn, J. (2018). Interventions for prostate cancer survivorship: A systematic review of reviews. *Psycho-Oncology*, *27*(10), 2339-2348.
- Dalela, D., Krishna, N., Okwara, J., Preston, M. A., Abdollah, F., Choueiri, T. K., . . . Trinh, Q. D. (2016). Suicide and accidental deaths among patients with non-metastatic prostate cancer. *BJU International*, 118(2), 286-297. doi:10.1111/bju.13257
- Emmett, L., Willowson, K., Violet, J., Shin, J., Blanksby, A., & Lee, J. (2017). Lutetium (177) PSMA radionuclide therapy for men with prostate cancer: a review of the current literature and discussion of practical aspects of therapy. *Journal of Medical Radiation Sciences, 64*(1), 52-60. doi:10.1002/jmrs.227

- Guo, Z., Gan, S., Li, Y., Gu, C., Xiang, S., Zhou, J., . . . Wang, S. (2018). Incidence and risk factors of suicide after a prostate cancer diagnosis: a meta-analysis of observational studies. *Prostate Cancer and Prostatic Diseases*, 21(4), 499-508. doi:10.1038/s41391-018-0073-6
- Holland, J., Watson, M., & Dunn, J. (2011). The IPOS new International Standard of Quality Cancer Care: integrating the psychosocial domain into routine care. *Psycho-Oncology, 20*(7), 677-680. doi:10.1002/pon.1978
- Huey, R. W., Hawk, E., & Offodile, A. C., 2nd. (2019). Mind the Gap: Precision Oncology and Its Potential to Widen Disparities. *Journal of Oncology Practice*, 15(6), 301-304. doi:10.1200/jop.19.00102
- Hyde, M. K., Newton, R. U., Galvão, D. A., Gardiner, R. A., Occhipinti, S., Lowe, A., . . . Chambers, S. K. (2016). Men's help-seeking in the first year after diagnosis of localised prostate cancer. *European Journal of Cancer Care*, n/a-n/a. doi:10.1111/ecc.12497
- Lazenby, M., Ercolano, E., Tan, H., Ferrucci, L., Badger, T., Grant, M., . . . McCorkle, R. (2019). Using the RE-AIM framework for dissemination and implementation of psychosocial distress screening. *European Journal of Cancer Care*, e13036. doi:10.1111/ecc.13036
- Lazenby, M., Tan, H., Pasacreta, N., Ercolano, E., & McCorkle, R. (2015). The five steps of comprehensive psychosocial distress screening. *Current Oncology Reports, 17*(5), 447-447. doi:10.1007/s11912-015-0447-z
- Lewis, C. S. (1961). A Grief Observed. New York: Harper & Row.
- Meissner, V. H., Herkommer, K., Marten-Mittag, B., Gschwend, J. E., & Dinkel, A. (2017). Prostate cancer-related anxiety in long-term survivors after radical prostatectomy. *Journal of Cancer Survivorship*, 11(6), 800-807. doi:10.1007/s11764-017-0619-y
- Sanson-Fisher, R., Hobden, B., Watson, R., Turon, H., Carey, M., Bryant, J., & Freund, M. (2019). The new challenge for improving psychosocial cancer care: shifting to a system-based approach. *Supportive Care in Cancer*, *27*(3), 763-769. doi:10.1007/s00520-018-4568-4
- Schroder, F. H., Hugosson, J., Carlsson, S., Tammela, T., Maattanen, L., Auvinen, A., . . . Roobol, M. J. (2012). Screening for prostate cancer decreases the risk of developing metastatic disease: Findings from the European Randomized Study of Screening for Prostate Cancer (ERSPC). *European Urology, 62*(5), 745-752. doi:10.1016/j.eururo.2012.05.068
- Schroder, F. H., Hugosson, J., Roobol, M. J., Tammela, T. L., Ciatto, S., Nelen, V., . . . Auvinen, A. (2012). Prostate-cancer mortality at 11 years of follow-up. *New England Journal of Medicine,* 366(11), 981-990. doi:10.1056/NEJMoa1113135
- Smith, D. P., Calopedos, R., Bang, A., Yu, X. Q., Egger, S., Chambers, S., & O'Connell, D. L. (2018). Increased risk of suicide in New South Wales men with prostate cancer: Analysis of linked population-wide data. *PloS One*, *13*(6), e0198679. doi:10.1371/journal.pone.0198679
- Smith, D. P., Supramaniam, R., King, M. T., Ward, J., Berry, M., & Armstrong, B. K. (2007). Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer. *Journal of Clinical Oncology*, 25(18), 2560-2566. doi:10.1200/jco.2006.09.8046
- Watts, S., Leydon, G., Eyles, C., Moore, C. M., Richardson, A., Birch, B., . . . Lewith, G. (2015). A quantitative analysis of the prevalence of clinical depression and anxiety in patients with prostate cancer undergoing active surveillance. *BMJ Open, 5*(5), e006674. doi:10.1136/bmjopen-2014-006674