Prostate cancer (PCa) patients face a myriad of issues associated with treatment that significantly impact quality of life. The primary localized and potentially curative PCa treatments are radical prostatectomy and radiation treatment (in the form of brachytherapy or external beam radiation). Systemic therapies such as androgen deprivation therapy (ADT) are also common. Although patients and their partners experience significant physical and psychosocial impacts from such treatments, support to address these issues is limited and inconsistently in Canadian cancer centres.

A number of Canadian cancer centres have been working diligently over the past six years to improve the supportive care offered to PCa patients and their partners. Two examples of these programs will be discussed, one focusing on sexual dysfunction arising from localized treatment for PCa and the second, addressing adaptation to androgen deprivation therapy.

Survivorship issues for men and partners

Despite improvements in treatments for localized PCa, an overall best estimate of the prevalence of long-term erectile difficulties following treatment is 40% to 80% (Cooperberg, Koppie, Lubeck, Ye, Grossfeld, Mehta, & Carroll, 2003; Lilleby, Fossa, Wæhre, & Olsen, 1999; Tanner, Galbraith, & Hays, 2011; van der Wielen, Mulhall, & Incrocci, 2007). The majority of these men will experience significant distress in response to erectile dysfunction (ED) (Cooperberg et al., 2003; Matthew, Goldman, Trachtenberg, Robinson, Horsburgh, Currie, & Ritvo, 2005; Mirone, Imbimbo, Palmieri, Longo, & Fusco, 2003). Other difficulties with sexual function include loss of sexual desire, difficulty achieving orgasm, reduced quality of orgasm, climacturia and dyssyngoria. The burden of sexual dysfunction is responsible for the single greatest impact on patient and partner health-related quality of life; even more so than concern for cancer recurrence (Crowe & Costello, 2003; Heathcote, MacTaggart, Boston, James, Thompson, & Nicol, 1998). Research examining the nature of the distress in these men reveals that the burden of sexual dysfunction reaches far beyond the ability to have an erection, and has complex psychosocial implications including intimacy loss (Helgason, Adolfsson, Dickman, Arver, Fredrikson, & Steinbeck, 1997), low self-esteem, guilt, depression, anxiety, and anger (Pedersen, Carlsson, Rahmqvist, & Varenhorst, 1993).

Psychological adjustment and mood are significantly associated with both sexual concerns and with dyadic adjustment (Wooten, Burney, Frydenberg, Foroudi, 2007). Predictors of psychological distress and low mood include the use of avoidant coping (Percez, Burke, Carver, Krongard, & Terris, 2002), low self-efficacy (Northouse et al., 2007), poor relationship quality (Perez, Skinner, & Meyerowitz, 2002), and poor spousal communication (Manne, Badr, Zaider, Nelson, & Kissane, 2010; Manne, Kissane, Nelson, Mulhall, Winkl, Zaider, 2011). These findings support the assertion that survivorship programs need to include the partners of patients.
The way that patients experience PCa and treatment, and their impact on a man’s sense of masculinity, has been described in a number of studies (Charmaz, 1995; Courtenay, 2000; Oliffe, 2002). Overall, men have a tendency to respond to illness with stoicism and silence. In the face of sexual disability many men view ED as their “problem to fix” (Oliffe, & Thorne, 2007). When men are faced with unsolvable ED, a common coping strategy is to withdraw and to become less communicative with their partner. Such a strategy has been found to be detrimental to couples in the long run (Roesech et al., 2005), limiting the potential for dyadic coping and problem solving, and increasing the distress of the patient’s partner.

Several reviews suggest that partners report as much, or in some cases more, distress than patients (Cliff & MacDonald, 2000; Couper, Bloch, Love, Macvean, Duchesne, & Kissane, 2006a; Hagedoorn, Buunk, Kuijfer, Wobbes, & Sanderman, 2000) and breakdowns in intimacy are a commonly identified problem (Boehmer, & Clark, 2001; Hawes et al., 2006; Navon & Morag, 2003; Schover, 2001). Significant predictors of spousal distress include: 1) greater patient distress, 2) less support from their partner, 3) lower marital quality, 4) low levels of positive reappraisal coping, and 5) searching for, but not finding, meaning in the illness experience (Etton, 2005).

Other researchers have found that PCa patients reporting stronger dyadic bonds experience less distress (Fergus, 2011). The role of the partner has also been found to be significant in ameliorating disruptions to the identity and self-esteem of PCa patients (Skerrrett, 2010; Fergus, 2011). Involvement of the partner in the survivorship programs is, thus, likely not only to help ameliorate partner suffering, but also to promote better coping by the patient (e.g., Kukula, Jackowich & Wassersug, 2014).

Some studies (Garos, Kluck, & Aronoff, 2007; Manne et al., 2010; 2011) have demonstrated difficulties in communication among PCa couples. There are a number of stressful topics that many couples avoid discussing such as the threat of death, body shame and embarrassment, and sexual dysfunction. Avoidance of important, but difficult, issues seems to contribute to an overall decrease in communication about other topics such as intimacy. The tendency for couples to engage in protective buffering, that is, not bringing a topic up for fear that it will cause one’s partner distress, has been identified as one contributor to decreased communication (Coyne, Ellard, & Smith, 1990). Reports of interventions that focused on enhancing communication for couples dealing with localized PCa suggest that communication is key to predicting adjustment and distress (Manne et al., 2010; 2011).

Given the lack of standardized survivorship programs in Canada, particularly programs that specifically define PCa as a couple’s illness, it is not surprising that both men and their partners identify needing more psychosocial support than is typically provided (Banthia, Malcarne, Varni, Ko, Sadler, & Greenbergs, 2003; Couper, Bloch, Love, Macvean, Duchesne, & Kissane, 2006b; Harden et al., 2002; Neese, Schover, Klein, Zippe, & Kupelian, 2003; Pitea, & Maguire, 2003; Resendes & McCorkle, 2006; Schover, 2001; Soloway, Soloway, Kim, & Kava, 2003; Steginga, Occhipinti, Dunn, Gardiner, Heathcote, & Yasley, 2001).

### Emerging Canadian programs to address survivorship issues

#### The Sexual Health and Rehabilitation Eclinic

Given the extensive impact of sexual dysfunction on patient/partner quality of life (QoL) (Manne, 1999; Meyer, Gillatt, Lockyer, & MacDonald, 2003; Steginga et al., 2001) there exists a need for rehabilitative intervention. The proposed Sexual Health and Rehabilitation e-Clinic (SHARE-C) is a Pan-Canadian, web-based sexual health and rehabilitation intervention facilitated by healthcare professionals (HCPs) with expertise in sexual health and PCa. Funded by Prostate Cancer Canada (PCC), the SHARE-C intervention is the product of a collaboration of three major centres: the Princess Margaret Cancer Centre Prostate Cancer Rehabilitation Clinic in Toronto, ON, the Sexual Health Program at the Tom Baker Cancer Centre and the Prostate Cancer Centre in Calgary, AB, and the Dalhousie/Capital Health Online Sexual Rehabilitation in Prostate Cancer program in Halifax, NS.

The SHARE-C goals are to improve sexual function and to support the maintenance of intimacy following PCa treatment. These goals are addressed through two complementary components: 1) a **bio-medical component**, focused on the long-term return of erectile functioning firm enough for penetration, and 2) a **psychosocial component**, to maintain or restore couples’ intimacy. Briefly, the biomedical approach to improving ED after PCa treatment, referred to here as “Erectile Rehabilitation (ER)”, involves the use of pro-erectile agents/devices to promote the oxygenation of penile tissue in order to reduce the likelihood of structural damage (Fode, Ohl, Ralph, & Sonksen, 2013). In this regard, patients will be supported in following an erectile rehabilitation algorithm developed by a multi-disciplinary Canadian expert consensus panel. The algorithm will be designed to accommodate differences in patient response to pro-erectile medication and in patient/partner acceptance/tolerance of pro-erectile treatments. The primary goal of the psychosocial component is to help couples maintain intimacy and engage in satisfying sexual activity, with or without penetrative sex.

The SHARE-C uses multiple modalities in order to support successful intervention including: online facilitated group counselling sessions, an electronic workbook of the program, and self-management approaches supported by mobile-device applications. Facilitated, web-based counselling through chatrooms, supported by Cancer Chat Canada (CCC), will be provided to patients and their partners both prior to definitive PCa treatment of curative intent and at five time points over two years following treatment. Importantly, the SHARE-C counselling times are chosen to reflect critical points of psychosocial and sexual healthcare needs after treatment for PCa.

The online counselling will take place in a password-protected chat-room and will involve either eight couples, or eight single patients. Participants will be grouped by treatment modality (e.g., surgery versus radiation) and post-treatment follow-up time-point. This will ensure that couples will be on a similar trajectory. Early counselling sessions focus on education, normalization of sexual health changes, and rehabilitation in an effort to mitigate maladaptive expectations. Topics include: effects of surgery and radiotherapy on sexual health, sexual health rehabilitation programming, encouraging early use of pro-erectile medication, and realistic expectations. Both single men and couples will receive intimacy counselling, aimed to highlight how communication and maintaining non-sexual intimacy are a foundation for overcoming sexual dysfunction, as well as strategies to achieve sexually satisfying experiences with or without penetrative sex. Significant efforts will be made during sessions to determine specific patient concerns (e.g., performance anxiety, lack of spontaneity and naturalness). Later sessions will focus on personalizing the pro-erectile treatment regimen and guidance in non-penetrative sexual activities. The final sessions will focus on long-term planning to maintain intimacy, and on acceptance and adaptation to the patient/couple’s new sex lives.

An interactive, online workbook will be available to participants. The workbook will be organized such that chapters will complement topics discussed by the facilitator during counselling sessions. Men, both those with and without partners, will be asked to read specific chapters prior to their online counselling session, and to complete goal-setting and journaling sections.
Of course, SHARe-C will only be as effective as our facilitators are skilled. Having enthusiastic, competent, and confident facilitators/counsellors is essential. Accordingly, we are developing a training program called the Sexual Health and Rehabilitation eTraining (SHARe-T). Also funded by PCC, its objective is to establish a specialized, PCA-specific, sexual health training program for HCPs across Canada in an effort to increase access to sexual health support for men and their partners following treatment for PCs. The training program will equip HCPs with the skills and knowledge necessary to deliver sexual health support to that community. The SHARe-T will be offered as an online, interprofessional training program through CAPO’s (Canadian Association of Psychosocial Oncology) Interprofessional Psychosocial Oncology Distance Education (IPODE; www.ipode.ca) project (McLeod, Curran, Dumont, White, & Charles, 2013; McLeod, Curran, & White, 2011).

Beyond increasing the number of skilled HCPs in Canada, SHARe-T also aims to provide education, support, and guidance in the development of PCs sexual health programs through site champions. Once trained, graduates can facilitate the SHARe-C intervention, using the technology and materials at their own institution.

SHARe-C and SHARe-T are complementary programs designed to facilitate HCP training and improve access to quality care, regardless of proximity to cancer centres and irrespective of geographical region. Interested HCPs are invited to contact the IPODE project in January 2015 to obtain more information about the SHARe-T training program.

### The Androgen Deprivation Therapy (ADT) Educational Program

ADT in advanced PCs patients can increase survival by as much as seven years (Flesher, Keane, Lawton, Mulders, Payne, Taneja, & Morris, 2007). However, patients must cope with the side effects of androgen suppression for the duration of treatment. PCs patients on ADT need far more supportive care than is currently provided, given the wide range of ADT-related effects (Armes et al., 2009; Elliott, Latini, Walker, Wassersug, & Robinson, 2010; Allibhai, Gogov, & Allibhai, 2006; Casey, Corcoran, Goldenberg, 2012; Freedland, Eastham, & Shore, 2009; Taylor & Smith, 2009). This is hardly surprising given that ADT’s side effects include: (i) body feminization (Ervik & Asplund, 2012; Zaider, Manne, Nelson, Mulhall, & Kissane, 2012), (ii) diminished sexual interest and function that often strains intimate relationships, (iii) cognitive and affective changes (McGinty et al., 2014), (iv) sleep disturbance, fatigue and depression (Hanesic, Gooneratne, Soin, Gehrmann, Vaughn, Coyne, 2011). ADT is associated with weight gain and increases the risk of osteoporosis (Ross & Small, 2002), cardiovascular disease, obesity, and insulin resistance (see review, Walker, Tran, & Robinson, 2013). Furthermore, the partners of ADT patients experience significant distress from loss of intimacy, and reduced overall QoL (Elliott et al., 2010). Prescribing physicians attempt to reduce the toxicity of ADT through the use of intermittent ADT. However, even with intermittent or short-term use, the adverse impact on psychosocial well-being and QoL remain substantial (Allan, Collins, Frydenberg, Mclachlan, & Matthiessen, 2014; Sharpley, Bitsika, Wootten, & Christie, 2014). Given these effects, medication management for example, pharmacological treatments can help reduce hot flashes and osteoporosis, while lifestyle interventions, such as exercise programs, can reduce fatigue, depression, and the risk of metabolic syndrome (Wolin, Colditz, & Proctor, 2011). To be effective though, management must start early, which means that patients need to know about the side effects and their management in a timely fashion.

Patients often report being inadequately prepared for ADT treatment (Allibhai et al., 2010). Simply stated, the incongruence between what HCPs know about managing ADT side effects and what actually reaches patients (and partners) suggests a failure in knowledge translation; i.e., there is a critical practice gap that unnecessarily reduces both patient and partner QoL (Hovey et al., 2012). Another study (Walker, Tran, Wassersug, Thomas, & Robinson, 2013) confirmed that both patients starting on ADT and their partners are poorly informed about the side effects of ADT. More than 50% in that study were unaware of side effects such as sarcopenia, osteoporosis, increased fracture risk, weight gain, genital shrinkage, and gynecomastia. This lack of awareness of ADT effects may partially explain why ADT results in significant decreases in QoL in that patients, who are uninformed about the adverse effects of ADT, are unable to engage proactively in behaviours to prevent or reduce these effects.

In an effort to explore why patients report such poor knowledge about ADT, a survey of 75 oncologists and urologists in Canada was conducted to determine what side effects they believed patients should know about, and what side effect management strategies they endorsed (Tran, Walker, Wassersug, Matthew, McLeod, & Robinson, 2014). There was a high level of agreement among specialists about the importance of informing patients about some of the side effects of ADT, however, they disagreed about many others. Examples where there was much disagreement included about the importance of informing patients about delayed orgasm, genital shrinkage, and type II diabetic risk. This is concerning because research demonstrates that men are highly distressed when they find their genitals shrinking, are no longer able to reach orgasm, and learn they are at increased risk of developing diabetes. Patients may feel betrayed by their medical team when they discover these issues on their own and have no management strategies to address them.

The study by Tran et al. (2014) also indicated that many physicians do not endorse evidence-based management strategies for ADT side effects. A comparable survey of Canadian primary care physicians reported similar findings (Soeyonggo, Locke, Del Giudice, Allibhai, Flesher, & Warde, 2014). The general practitioners did not feel qualified to manage the adverse effects of ADT and felt that the responsibility should rest with their specialist colleagues. Unfortunately, many supposedly reliable websites providing information about ADT directly accessible by PCs patients also contain inaccurate and outdated information (Ogah & Wassersug, 2013). Thus, access to standardized evidence-based information on ADT adverse effects and their management is simply not reaching PCs patients and their partners.

The rationale for involving partners in survivorship care programs for PCs patients is strong, and is particularly supported in the context of ADT. For example, Walker and Robinson (2011; 2012) report that many couples were told by their HCP that sex would be impossible while on ADT. Believing this, some couples elected to cease striving to engage in sexual activity. Some of these couples adapted well to this change, while others drifted apart. Alternatively, other couples discovered ways of having satisfying sex despite the man’s androgen deprivation and reduced libido. Our observation that some men maintain satisfying sexual intimacy while on ADT is consistent with reports from other research groups (Ng, Corica, Turner, Lim, & Spry, 2014) and suggests that couples should not be uniformly told that ADT will end their sex lives. The question of whether more couples would continue to enjoy sex, if given suggestions on how to remain sexually active, is the focus of ongoing studies (e.g., Wibowo, Wassersug, Warkeantin, Walker, Robinson, Brotto, & Johnson, 2012) and is also supported in the guest patient editorial by Richard Wassersug included in this journal issue on page 306.

Most cancer centres have well-established programs to educate patients about managing the side effects of chemotherapy and...
radiation therapy. ADT has arguably as many substantial, life-altering side effects as chemotherapy and radiotherapy, yet comparable programs for educating patients about how to deal with ADT side effects are only now being developed. Anecdotally, HCPs tell us they try to compensate for the lack of formal educational programs by spending considerable time talking to their patients about ADT, its side effects, and how to manage them. However, they indicate frustration because patients continue to report poor knowledge about ADT. One reason for this is that patients are often overwhelmed by the volume of information provided them in those consultations. As such, little information appears to be retained. Against this background, we set out to develop a comprehensive patient education program for all PCa patients starting on ADT.

Implementation of our ADT Educational Program begins with educating HCPs involved in the care of men on ADT. It includes an introduction to motivational interviewing (MI), which has demonstrated effectiveness (Lundahl & Burke, 2009; Lundahl, Moleni, Burke, Butters, Tollefson, Butler, & Rollnick, 2013; Miller and Rollnick, 2013; Rubak, Sandøe, Lauritsen, & Christensen, 2005) in helping people to make changes in behaviour. MI is still new to many HCPs, although it is an empirically supported semi-directive, patient-centred counselling style for eliciting behaviour change (Lundahl and Burke, 2009; Lundahl et al., 2013; Miller and Rollnick, 2013; Rubak et al., 2005).

One of the things that HCPs learn in our in-service sessions on MI is how to use a carefully designed script when they first prescribe ADT to men. Our script was developed with the input from urologists, radiation oncologists, nurses and psychologists, and is specially worded to increase the likelihood that men and their partners will attend the ADT educational classes (See Figure 1 for this script). The script is included here, as a general resource; HCPs are encouraged to adapt and use the script when introducing ADT to their patients.

**Figure 1: Suggested ADT script**

Androgen deprivation therapy is an effective way to manage prostate cancer and to improve the effectiveness of external beam radiation therapy. ADT has been strongly recommended as an important part of the management of your prostate cancer. However, you should be aware it may cause many changes in your body. You may experience fatigue, weight gain, loss of muscle mass, and increased risk of osteoporosis, diabetes and cardiovascular disease. As I’m sure you are aware, many of these changes can pose significant health risks. When prescribing ADT we weigh the risks and benefits of treatment.

If you choose to go on this treatment, it is essential that you manage these increased risks through important lifestyle changes, such as engaging regularly in exercise and practising healthy eating habits, much like the changes people make to help men and partners remain close, both emotionally and physically, even when ADT suppresses the man’s libido and erectile function.

The ADT book offers specific suggestions for how to remain sexually active while on ADT, despite changes in the man’s sexual function and level of sexual desire. At the same time, the authors recognize that not all men on ADT are partnered or sexually active. Chapters are free-standing so that readers can focus on issues that may specifically concern them (e.g., diet, exercise, physical side effects, psychological impact, sexuality).

The education program built around the ADT book, as it is currently constructed, has an introductory and a follow-up group session; each approximately 1.5 hours in duration. The first session introduces the major side effects of ADT, including the ones that are most bothersome to patients (e.g., hot flashes, weight gain, fatigue, and loss of sexual function), as well as those that are medically of most concern (e.g., metabolic syndrome, cardiovascular disease, osteoporosis). Attendees at that session are introduced to self-management strategies and during the session are asked to complete an “action plan” in which they identify a specific goal for behavioral change. This exercise is designed to encourage patients to make specific lifestyle changes, most notably to increase their level of physical activity, in order to avoid or reduce many of the adverse effects of ADT.

The benefits of physical exercise for ADT patients have been well documented in many studies (Cormie, Newton, Taaffe, Spry, & Galvão, 2013; Culos-Read et al., 2010; Wall, Galvão, Fatehee, Taaffe, Spry, Joseph, & Newton 2014), but it is particularly hard to get patients to exercise once treatment side effects such as fatigue, depression, and osteopenic obesity have set in. The educational program recognizes that for many Canadians, major adjustments in their lifestyle are necessary to maintain a good quality of life on ADT.

The second session of the educational program comes two to three months later, at a time when most of the side effects of ADT, which patients and those close to them might observe, have emerged. Patients (and partners) are invited to share their experiences about what they have found most effective in managing ADT side effects. The follow-on session is also meant to be a motivational “booster session” to check in on the goal setting that was

MI is also paired with self-management strategies in our ADT educational classes to help patients explore and resolve ambivalence, and work toward making lifestyle changes to avoid the more debilitating side effects of ADT. This is done in addition to enhancing individual resources (e.g., wisdom, strategies, social support) for making changes. Such an approach contrasts the more traditional model of patient education that often uses the extrinsic force of the HCP (persuading, compelling, advising and demanding) to provoke change. External force often, paradoxically, increases individuals’ resistance to making a change (Miller & Rollnick, 2013).
done in the first session, in order to help patients adhere to a lifestyle that can mitigate ADT adverse effects.

Currently the ADT educational program is being offered in Calgary, Vancouver and Victoria. In Vancouver, it is one of the educational modules in the Prostate Cancer Supportive Care (PCSC) Program at the Prostate Centre. That PCSC program itself was initiated with support from the Specialist Service Committee of the Doctors of British Columbia and the Ministry of Health. Because it is funded at the provincial level, it has the mission of making its services available at other cancer centres in the province. The recent initiation of an ADT educational program in the British Columbia Cancer Agency is a first step toward serving that provincial mandate. The program in Calgary is currently offered out of the Prostate Cancer Centre there with plans to make it accessible online (see below), to residents living elsewhere in Alberta.

With ongoing PCC funding, we aim to have versions of the ADT educational program up and running in both Halifax and Toronto within the 2014 calendar year. We anticipate making the program available in French, and hope to offer it in at least one Quebec cancer centre by 2015. A long-term goal is to provide the program online so that it can be accessible to Canadian PCa patients outside of major metropolitan areas currently offering or planning on offering the live program.

From a research perspective, we intend to evaluate and compare both the in person and online versions of the ADT education program, to see how successful they are in: 1) accruing patients starting on ADT, 2) helping patients manage ADT side effects, and 3) keeping dyadic bonds strong for patients and partners challenged by the psychological and psychosexual impact of ADT.

**Conclusions**

There are a myriad of post-treatment challenges facing men and partners who are affected by PCa that are not consistently addressed by HCPs. Although a great deal is known about how to help address these, far too often sexual and supportive care is difficult to obtain in a timely manner in all but the largest Canadian centres. ADT is a particularly difficult treatment with serious side effects, the effects of which can be ameliorated by early education and coaching, with MI-informed strategies holding particular promise.

Partners also experience psychosocial challenges after treatment, but are often overlooked as a recipient of care in cancer centres, being seen (and understanding themselves) only as support for the man. This is understandable. Men are often stoic and hide their distress, and partners do not want to distract health professionals from the primary bio-medical concerns. Also, they do not want to appear unsupportive by raising concerns, particularly if the patient does not raise them himself. This protective buffering results in misunderstandings, poor communication for the couple and with the health care team, and increased distress for both patients and partners.

Standardizing approaches to address the effects of PCa treatment is essential if QoL is to be maintained. A better understanding of the issues on the part of HCPs, development of better knowledge and skills in how to address these, and specific knowledge translation activities to expand survivorship programs in Canadian centres are needed. The initiatives described here will address that need, contributing to improved care for Canadian PCa patients and partners. Furthermore, provision of services and education via the internet will ensure that care is available no matter where one lives in Canada.

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