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The long-term quality of life and information needs of prostate cancer survivors.

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ABSTRACT

Research Question: What are the quality of life (QoL) and information needs of long-term prostate cancer survivors?

Research problem: Numbers of prostate cancer survivors are increasing and it is vital that their QoL issues and information needs are understood.

Literature review: The long-term effects of surviving prostate cancer is poorly understood. Specialist nurses play a key role in their management.

Methodology: Cross-sectional survey using the questionnaire (EORTC QLQ-C30 and EORTC QLQ-INFO25) posted to 398 prostate cancer survivors attending an Irish centre managed by a clinical nurse specialist and consultant.

Results: Completed questionnaires (n=195) were returned (response rate 49%). Overall, the men demonstrated a Global Health Status/QoL score of 77.6 (SD 20.7), demonstrating a high or healthy level of functioning. Men on hormonal therapy demonstrated inferior physical function in comparison to other treatment options. Fatigue and insomnia were the most frequent symptom experienced, while age was the most significant demographic variable affecting symptom scales. Men undergoing active surveillance for prostate cancer management were least happy with information received (p=0.019). Comparison with EORTC QLQ-C30 international reference values suggests that this cohort report a high/ healthy quality of life. However, a significant proportion of men expressed a need for the receipt of further information, especially men on active surveillance.

Conclusions: Specialist nurses are in a unique position to meet the information needs of long-term prostate cancer patients. However, planning is needed to ensure there are enough specialist nurses to meet the information needs of a growing number of men surviving prostate cancer.

Funding/Competing interests: None

Key words: information, prostate cancer, quality of life, information, survivorship.

LITERATURE SEARCH

A structured search of the literature using relevant key words was undertaken for studies published between January 1st 2005 and Jan 1st 2016. The following databases were searched: Scopus, CINAHL, Embase, PubMed, Medline, Cochrane Library. A total of 611 papers were found, and following review of abstracts, 169 papers were found to be relevant to the research question. No systematic reviews on the topic were identified in the Cochrane library.

BACKGROUND

The European Association of Urology (Heidenreich et al., 2011) describes prostate cancer as one of the most important medical conditions facing men in Europe today. With an increasing number of men living with prostate cancer and its side effects, interest on Quality of Life (QoL) issues has become a major topic of interest among researchers. In the UK, Fleure (2015) reports that 41,000 men are diagnosed with prostate cancer annually. In Ireland, 3400 men are diagnosed with prostate cancer each year (NCR, 2016), with the number increasing from a figure of 1100 per year 20 years ago. It is estimated that there are currently over 28,400 men alive and living with prostate cancer in Ireland. This figure is expected to grow significantly in the coming years with Zucca et al. (2012) estimating that the number of men living with prostate cancer will triple by 2030. Consequently, prostate cancer has become an important health issue highlighting the need for more specialist urology nurses nationally (Leary et al., 2016). Moreover, internationally, it presents significant economic and social consequences (Bungay and Cappello, 2009).

Patients diagnosed with prostate cancer face multiple treatment options depending on various factors such as age, stage of the disease and individual patient preference. Local disease is most commonly treated by radical prostatectomy or radiotherapy (external beam or brachytherapy) while locally advanced and metastatic disease is managed with a combination of options including hormonal therapy (Lin et al., 2011; Voerman et al., 2006). Radical prostatectomy is reported as the treatment of choice for almost one third of patients (Robinson et al., 2008) and is a common option for younger men.

Side effects from prostate cancer treatment are numerous and are known to increase the burden of the disease (Brown, 2010; Jakobsson et al., 1997; Nicolaisen et al., 2014). Post treatment side-effects including bladder and bowel problems, erectile dysfunction and fatigue are frequently reported (Brunton et al., 2012; Galbraith et al., 2012; Lassen et al., 2013). Urinary incontinence is commonly reported following radical surgery while side effects associated with bowel function are more frequently associated with radiotherapy (Heidenreich et al., 2011; Lassen et al., 2013; Voerman et al., 2006; Ward-Smith and Kapitan, 2005).

In addition to physical side effects it is important to recognise the psychological effects of cancer treatment. Fear, anxiety, depression, reduced self-esteem and altered body image are recognised by many authors as having a negative effect on men with a diagnosis of prostate cancer (Chien et al., 2013; Hansen et al., 2013; Lassen et al., 2013; Watts et al., 2015). This is further demonstrated by Sharpley et al. (2010) who found levels of anxiety and depression of between 24 and 26% in men up to eight years post diagnosis. Studies have consistently shown that long-term survivors continue to experience side-effects from prostate cancer treatment which continue to

negatively impact on their quality of life (Avis et al., 2006; Foley et al., 2006; Zucca et al., 2012). It is none the less important to remember however that survivorship from prostate cancer is also recognised to have positive benefits, for example, improved self-esteem, greater appreciation of life, and greater feelings of peacefulness and spirituality (Muzzatti and Annunziata, 2013; Ng et al., 2006).

Information is considered to be at the foundation of supportive care, and offers many benefits for prostate cancer patients (Arraras et al., 2010; Bergenmar et al., 2014; Carter et al., 2011; Husson et al., 2013). The importance of information for prostate cancer survivors is highlighted by Lamers et al. (2016), where analysis of data from 697 men with prostate cancer identified a positive relationship between satisfaction with information received and quality of life. The degree to which patients will seek information depends not only on individual preference but also on their educational, cultural and financial background (Chien et al., 2013; Ross et al., 2011), and while as many men as women are diagnosed with cancer, men are reported to be poorer users of information services (Bungay and Cappello, 2009). However, despite the importance of providing information, it is reported that men with prostate cancer describe being poorly informed about many aspects of care including treatment side-effects and follow-up care (Fleure, 2015). However, men are also reported to be poorer users of information services (Bungay and Cappello, 2009).

It is clear from the literature that attention is now turning to the long-term effects of treatment (Avis et al., 2006; Pearce et al., 2008; Muzzatti and Annunziata, 2013; Drummond et al., 2015). 'Long-term' is generally considered to relate to the period 5 years or more post diagnosis (Avis et al., 2005; Zucca et al., 2012; Chopra & Kamal,

2012), Fransson (2008) suggests that there are limited studies addressing this time period. One reason for this maybe because the long-term effects of surviving prostate cancer are poorly understood and may not be recognised often by health care professionals (Galbraith et al. 2012)

STUDY AIMS

This study's research question was: What are the quality of life (QoL) and information needs of long-term prostate cancer survivors? The primary aim of the study was to determine the quality of life and information needs of long-term prostate cancer survivors attending a rural based University teaching hospital serving a largely rural population. One clinical nurse specialist and one urology consultant manage the urology services at the hospital and they wished to determine what quality of life issues may have been troublesome for these men and whether there were unknown information needs that the CNS could address. All patients at diagnosis meet with the CNS and receive one-to-one verbal and written information, generally lasting 30 minutes, but longer based on patients' information needs. The information is focused on treatment and management of side effects.

METHODOLOGY

The study design was a cross-sectional postal survey. This approach allowed for the collection of data from respondents at different stages of their cancer journey and also facilitates reaching large representative populations within a short time frame (Levin, 2006). Ethical approval was obtained from the Hospital's research ethics committee.

The postal questionnaire was accompanied by an information letter explaining the purpose of the survey and that participation was both voluntary and anonymous.

Setting

The study sample was drawn from a satellite Urology service based at a University Teaching Hospital in Ireland. While prostate cancer patients may initially present to the centre, primary treatment in the form of radiotherapy or surgery is delivered at two large urban regional referral centres. The teaching hospital is an acute 342 bed general hospital which serves a population of over 160,000 people, of which 21,000 are aged over 65 (CSO, 2011).

Sample

Following ethical approval, the cancer register of all prostate cancer patients attending the hospital for follow-up care was accessed in February 2016 to identify potential participants ($n=434$). All patients who were five years or more post diagnosis and who met the study inclusion criteria (histological proven prostate cancer, long-term survivor, attending regular follow-up) were invited to take part in the study ($n=398$). Exclusion criteria included patients with dementia/confusion, non-English speaking patients, and patients diagnosed with a second primary tumour. Those in the terminal phase of the disease were also excluded. Thirty-six men met the exclusion criteria.

Data Collection Methods

The European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 version 3.0 and information module QLQ-INFO25 were chosen as the most

suitable questionnaires for the study because they met the study's aims (i.e. they measured health related quality of life and satisfaction with information received).

The EORTC QLQ-C30 (Aaronson *et al.*, 1993) is a core questionnaire designed to be cancer specific, multi-dimensional in structure and suitable for self-administration over a range of cultural locations. It has proven validity and reliability (Bjordal *et al.*, 1999; Costa *et al.*, 2015; Fayers *et al.*, 2001) with Cronbach alphas reported at > 0.70 for functional and symptom scales. The QLQ-C30 has been used in a wide variety of clinical trials and research studies (e.g. Egan *et al.*, 2015) and has been used extensively in prostate cancer studies (e.g. Fransson, 2008; Green *et al.*, 2010; Lamers *et al.*, 2016; Queenan *et al.*, 2010; Spry *et al.*, 2006). All scales and single item scores are linearly transformed according to the EORTC scoring manual (Fayers *et al.*, 2001) to produce a scale from 0 to 100 where high scores in the functional scales and global quality of life measurement indicates a high or healthy level of functioning or high level of QoL. High scores in the symptom scale/items indicate a high level of symptoms or problems. Raw scores and linear transformation were calculated using the following formulae:

$$\begin{aligned} \text{RawScore} = RS &= (I_1 + I_2 + \dots + I_n) / n \\ \text{System scale /items: } S &= \{(RS - 1) / \text{range}\} \times 100 \end{aligned}$$

The EORTC QLQ-INFO25 module was developed to complement the core QLQ –C30 instrument (Arraras *et al.*, 2010). It has been shown to have satisfactory test-retest reliability, while internal consistencies for all scales (Cronbach's alpha) are reported as > 0.70 (Arraras *et al.*, 2010; Singer *et al.*, 2013). A high score represents a high level of information in all scales and items. This instrument has an additional question which invites the patient to specify on which topics they would like to have received more or less information.

Data analysis

Scores were expressed as means (\pm standard deviation) and compared with demographic information to determine if results were influenced by socio-demographic variables. Parametric ANOVA tests were performed where data was normally distributed and the alternative Mann-Whitney and Kruskal Wallis non-parametric tests where data was skewed. A *p*-value of <0.05 was considered statistically significant. To compare scales between EORTC QLQ-C30 and QLQ-INFO25 Spearman and Pearson's correlations were performed.

RESULTS

Demographic and clinical data

A total number of 195 completed questionnaires was returned, giving a response rate of 49%. The mean age of participants in the study was 75(6.8) years (range = 56-93 years). Nearly half of the participants had not progressed beyond primary education ($n=93$, 47%) and 85% ($n=166$) had retired from employment (Table 1).

Analysis of treatment modalities (Table 4) shows that the majority of participants received radiotherapy as their primary treatment ($n=91$, 47%) while a further 48 (25.3%) participants reported having received radiotherapy in combination with other modalities.

EORTC QLQ-C30

Analysis of EORTC QLQ-C30 individual items are presented in Table 2. Mean scores and standard deviations for the EORTC QLQ-C30 functional scales and symptoms

scores are presented in Table 3. The mean (SD) score for global health status/QoL was 77.6 (20.7) indicating a good overall health related quality of life. Functional subscales also scored well indicating a high or healthy level of functioning in the study population. Physical functioning (PF2) and role functioning (RF2) subscales scored best (85.2 and 86.6 respectively). Emotional (EF), cognitive (CF) and social functioning (SF) subscales demonstrated similar scores in the range of 83.0-83.9. Symptom scales range from 0 to 100, with higher scales indicating a higher degree of symptoms. (Table 2).

Analysis of the symptom scales and items identified that the Mean (SD) for fatigue 20.1 (22.1) and insomnia (19.8), scored highest followed by dyspnoea (15.8), constipation (12.8) and pain (12.4).

No statistical significance was identified between overall global health status/QoL and socio-demographic data. However, statistical differences were identified during analysis of the functional and symptom subscales. (Table 3).

In the physical functioning subscale the difference in mean rank (medians) between age groups 55-64, 65-74, 75-84 and 85 or over was found to be statistically significant, $p < 0.001$, as would be expected with physical functioning decreasing with age (Table 4). However length of time from diagnosis was not found to be statistically significant ($p = 0.663$).

Differences were also apparent between physical functioning and both employment status ($p = 0.041$) and type of treatment administered, $p = 0.012$ (Table 4). Men retired from employment typically had a lower physical functioning score than those in employment. Men who underwent brachytherapy or were managed with active

surveillance enjoyed a high physical functional status while those who underwent hormone therapy demonstrated significantly poorer physical function.

Analysis of the role functioning subscale highlighted further variance with age and length of time from diagnosis, also demonstrating p-values < 0.05 (Table 5). Whether men lived in urban or rural areas was also found to be statistically significant with men in urban areas having lower role function scores compared to those living in rural settings. (Table 5).

No statistical disparity was found between emotional functioning (EF) and cognitive functioning (CF). Men diagnosed between 1990-2001 demonstrated lower social functioning (SF), $p=0.014$, when compared to those with a more recent diagnosis suggesting that social functioning diminishes with time. As may be expected, fatigue (FA) was statistically influenced by age (Table 6), with increasing age directly related to increasing fatigue ($p=<0.0001$).

As with fatigue, other symptom scales and items were found to be strongly related to increasing age, with dyspnoea (DY) $p=0.005$, appetite loss (AP) $p=0.02$, constipation (CO) $p <0.0001$ and financial difficulties (FI) $p=0.011$ all showing significance.

No statistical inference was drawn from relationships between the remaining symptom scales/items and socio-demographic variables with the exception of pain, where those treated with hormonal therapy and surgery demonstrated higher symptom scales than those managed by other treatment modalities, $p= 0.006$ (Table 7).

Comparison of study population with EORTCQLQ-C30 reference data set

Comparison was made with EORTC QLQ-C30 references values (Scott et al., 2008). This demonstrated superior scores in all functional subscales and in global health/QoL status for the study population (Table 3). Analysis of symptoms scales and individual symptoms items also revealed lower scores in the study population, with the exception of cognitive function and diarrhoea which demonstrated similar ratings.

EORTC QLQ-INFO25

A greater variation in scores was found between the individual subscales of the QLQ-INFO25 (Table 8). The highest score was recorded in the domain 'information received on medical tests' (INFOMEDT) with a mean score of 60/100 (SD 28.9) while the lowest score was found in the domain 'information about other services' (INFOTHSE) evidenced by a scale of 18/100 (SD 26.5, median(min-max) 0(0-100)) Scores for 'information about different places of care' and 'things to help yourself get well' were also considered low. (Table 8).

Comparison with socio-demographic variables suggested that unemployed men were less happy with information received about treatments (INFOTREAT) than persons in employment ($p=0.041$). Furthermore, men who were managed with surgery and brachytherapy scored significantly higher in the subscale 'information about treatments' than those on active surveillance, $p=0.019$ (Table 9).

The analysis also noted that younger men (55-64 years) had a greater wish to receive more information than other groups ($p=0.03$).

Qualitative data

Question 53 of the QLQ-INFO25 offered respondents the opportunity to provide comment on “which topics do you wish to receive more information?” In total 51 men (26.1 %) chose to make remarks (Figure 1). The majority of respondents 17 (33%) wished to receive more information on side effects. Information on prostate cancer and general health issues were also highlighted as important (20% and 14% respectively). Of the many side effects men wished to receive more information on, bowel, urinary and sexual dysfunction were the most frequently requested.

Correlations between quality of life and information received

Both questionnaires (EORTC QLQ-C30 and QLQ-INFO25) were compared to see if associations between scales could be established. Spearman’s correlation identified a small positive correlation between overall global health status and satisfaction with the information received ($p=0.01$, $r=0.193$). Similarly, positive correlation was observed between global health status and participants’ belief that information received was helpful ($p=0.003$, $r =0.216$). Increased satisfaction with information received was also noted to be positively correlated with role function ($p <0.0001$, $r=0.310$).

Correlation (Spearman’s rho) between EORTC QLQ-C30 symptom scales/ items and functional scales identified as expected, medium and strong correlations. In particular fatigue ($p<0.0001$, $r= - 0.553$) and pain ($p<0.0001$, $r= - 0.481$) were significantly associated with decreased global health status/QoL scores.

While 62.2% of respondents were ‘quite a bit’ or ‘very much’ satisfied with the information received during the course of treatment and follow-up, it is noted with interest that 28.3% of men expressed a wish to receive more information (Table 10).

A significant number of respondents (n=20, 10.3%) failed to answer question 2 in the demographic section “In what year were you first diagnosed with prostate cancer?” Missing data for individual questions ranged from 0-1.5% for the QLQ-C30 questionnaire and were considered to be missing at random. However, slightly higher rates were noted for QLQ-INFO25, ranging from 2.1% to 8.7% for individual questions.

DISCUSSION

The results from this study show that the overall global health status/QLQ score of 77.6. (SD 20.7) is higher than the score of 68.4 reported by the EORTC as the reference range for prostate cancer patients (Scott *et al.*, 2008). Several recent studies (Spry *et al.*, 2006; Voerman *et al.*, 2006; Zucca *et al.*, 2012) have also reported higher global health status/QLQ scores. This may be partly explained by Nicolaisen *et al.*, (2014) who suggest that cancer patients adapt over time to a reduced functional level and symptoms become less bothersome. For example, the mean time since diagnosis for the study by Voerman *et al.*, (2006) was 44.3 months while the 863 participants in the study by Zucca *et al.*, (2012) were 5 to 6 years post diagnosis. Moreover, Spry *et al.*, (2006) found that Australian men had better functional and less symptom scores when compared to the EORTC reference group, and they suggest that this may in part relate to advances in treatments methods in more recent years.

The most compelling demographic factor affecting QoL in the study was age, which had statistically significant p-values in physical and role functioning (p <0.0001 and p=0.004 respectively). Age was also significant in the symptom items categories and in particular fatigue (p <0.0001), dyspnoea (p=0.005), appetite loss (p=0.02) and constipation (p <0.0001). These findings may be explained as both age and cancer related. However, both role functioning and social functioning were noted to diminish

as time from diagnosis increased ($p=0.02$ and $p=0.01$ respectively). For reasons that are unclear, role functioning was also statistically better for those living in urban areas ($p=0.002$).

Interestingly, individual treatment options only demonstrated statistical effect in the physical function subscale where active surveillance and brachytherapy scored best. Hormonal therapy was found to have the greatest impact on physical function ($p=0.012$). This is further supported by the findings of Voerman *et al.*, (2006) who report that men with prostate cancer ($n=238$) who had combinations of radical prostatectomy and radical radiotherapy or radical prostatectomy alone had better physical function than those on hormone therapy.

A greater variance in scores was found in the symptom domains compared to the functional scales, with scores ranging from 2.5 for nausea and vomiting to 20.1 and 19.8 for fatigue and insomnia respectively. This is not a universal finding; Zucca *et al.*, (2012), while acknowledging the presence of pain and insomnia, found that constipation was the most common symptom for prostate cancer survivors ($n=131$).

Green *et al.*, (2011), in a study of 105 prostate cancer men identified that the older a man gets, the greater his likelihood of being treated with hormonal therapy. Pain affecting QoL for those on hormonal therapy was a significant finding of this study, and is consistent with the findings of others (Spry *et al.*, 2006; Voerman *et al.*, 2006). However, this finding should be viewed cautiously because other causes of pain, for example arthritis, are common in older age groups, and it is unclear if the pain reported by respondents related exclusively to cancer and its treatment.

Men in employment reported increased levels of satisfaction with information received about treatment ($p=0.04$) compared to those who were in retirement or unemployed. Men who underwent surgery and brachytherapy also scored well in this domain, however men who undertook active surveillance scored poorly ($p=0.019$). This would suggest that there is a need for specialist nurses to examine the information needs of this subgroup. This is important as Watts et al. (2015), in a study of 313 men on active surveillance for prostate cancer, reported significantly higher levels of anxiety compared to that found in the general population.

Age was identified as the significant factor in those wishing to receive more information ($p=0.03$), with those in the age group 55-64 expressing the greatest need for further information. Also, in contrast to Bergenmar *et al.*'s study (2014), we found no statistical variance in the domain of information received for those who lived alone, or in the different treatment and age groups.

As would be expected, symptoms scales demonstrated strong correlations with functional status and overall quality of life. Interestingly those who were most happy with the information received also demonstrated high scores in role function ($p<0.0001$).

The educational background of the population was noteworthy in that almost half of the participants had not progressed beyond primary school education. This, in part may be explained by the age profile of survey population. This study failed to statistically identify any correlation between education level and any of the quality of life or information subscales. However, other studies have reported that those who have attained a higher level of educational are more likely to feel informed on topics

related to their cancer (Chien *et al.*, 2013; Ross *et al.*, 2011). The older age profile of this study's participants may have contributed to our finding.

The study has a number of limitations. The sample was drawn from a single satellite cancer centre with a largely rural population, the findings are therefore not generalisable. Moreover, stage of cancer was not recorded, and therefore it was not possible to distinguish between those with early disease and those with more advanced cancer. The length of time from diagnosis may be significant as a lot of information is generally imparted at the time of diagnosis and this may have been forgotten over-time since diagnosis. A further limitation is the 49% response rate, as men with a poorer quality of life may not have responded.

As outlined in the results, a significant number of respondents (n=20, 10.3%) failed to answer question 2 in the demographic section. Whilst this is unexplained, possible explanations may include length of time since diagnosis, age profile and respondents' understanding of the question asked. Nevertheless, missing data was found to be in line with expected values as reported in the literature for both EORTC QLQ-C30 and QLQ-INFO25 (Fayers *et al.*, 2001). Moreover, slightly higher rates of missing data were noted for QLQ-INFO25 on individual questions. It is known that supplementary modules can have higher missing rates than the core QLQ-C30 questionnaire, and similar rates of missing data for QLQ- INFO25 have previously been reported (Singer *et al.*, 2013).

CONCLUSION

In comparison with EORTC QLQ-C30 reference values, this study reveals that long-term prostate cancer survivors in general enjoy a high/healthy quality of life. However the study also reveals that these men continue to have unmet information needs and information about disease, treatment, side effects and follow-up care continues to be important long after initial management is completed. This is evidenced by men expressing a need for the receipt of further information years after treatment. The study also identified an association between satisfaction with information received and specific domains of quality of life.

Although long-term prostate cancer survivors demonstrate a relatively high level of quality of life, this study highlights the importance for nurses to be cognisant of the age related increase in bothersome symptoms (e.g. fatigue, insomnia and dyspnoea) among this cohort of patients. Furthermore it is clear that prostate cancer survivors continue to have significant information needs long after diagnosis and treatment, and continue to require advice and direction in order to be able to access the required information. In addition, the sub-group of men undergoing management by active surveillance are identified as a particular group requiring additional information throughout their cancer trajectory.

The study highlights implications for practice and research. There is a need for specialist urology nurses to remain cognisant of the information needs of long-term prostate cancer survivors. The information needs of younger men and those on active surveillance in particular should be regularly reviewed. Those on active surveillance do not experience the same regular contact with their treatment centre as those being actively treated and therefore have limited opportunity to meet with specialist nurses.

Further research with this cohort of patients is needed to explore their unique information needs and how specialist nurses can meet these needs.

In conclusion, the clinical focus of the specialist urology nurses and clinical nurse specialists in urology involves the assessment, planning, delivery and evaluation of care needs of their patients. Urology nurses are therefore in a unique position to meet the information needs of long-term prostate cancer patients. However, concerns have been raised that there are not enough specialist nurses to meet the growing number of men surviving prostate cancer in the UK (Leary *et al.*, 2016).

Planning is needed to meet the needs of a growing number of prostate cancer survivors so that there are sufficient specialist nurses nationally (Leary *et al.*, 2016).

This is essential if the quality of life and information needs of a rapidly growing number of long-term prostate cancer survivors are to be met.

What is already known

Long-term survivors of prostate cancer continue to experience side-effects which negatively impact on their quality of life. Information is essential for prostate cancer survivors, however men with prostate cancer can feel poorly informed about many aspects of care including treatment side-effects and follow-up care.

What this paper contributes

Comparison with EORTC QLQ-C30 reference values reveal that the Irish population in this study score better in all functional scales and symptom scales, suggesting that long-term prostate cancer survivors in general enjoy a high/healthy quality of life.

However the study also reveals that men continue to have unmet information needs and follow-up care continues to be important long after initial management is completed. This is especially the case for the sub-group of men undergoing management by active surveillance who were identified as a particular group requiring additional information throughout their cancer trajectory.

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