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Abbreviations: HES, Hospital Episode Statistics; PCNL, percutaneous nephrolithotomy; SCTS, Society of Cardiothoracic Surgeons.

Proton Therapy Websites: Information Anarchy Creates Confusion

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Introduction

Proton beam therapy (PBT) is a form of external beam radiotherapy (RT) that has been in therapeutic use for almost half a century. The advantage over the more commonly used photon-based RT lies in its ability to deliver maximum tumour doses at the end of the beam range with minimal exit dose, thus reducing dose to adjacent healthy tissue [1].

Evidence is emerging for the superiority of PBT for certain paediatric cancers and those of the eye, spine and skull [2], but no evidence currently exists showing any clinical superiority for PBT over brachytherapy or intensity modulated RT (IMRT) for the treatment of localised prostate cancer. In response to recent public concern the American Society for Radiation Oncology (ASTRO) released recommendations against the use of PBT 'outside of a prospective clinical trial or registry', stating 'there is no clear evidence that proton beam therapy offers any clinical advantage' [3]. The other consideration with respect to PBT clinical development is the extraordinary outlay for the facilities, each of which costs \$150–200 million (American dollars) to build. Despite this dearth of evidence and expenditure, many internet-based resources aimed at both patients and professionals claim the superiority of PBT over photon-based RT and other interventions.

In the USA, the number of PBT facilities expanded from three to 13 between 2001 and 2013. The number of Medicare beneficiaries receiving PBT nearly doubled between 2006 and 2009 due to a 68% increase in use for 'conditions of possible benefit' mostly accounted for by prostate cancer [4]. Given the relatively rare incidence of paediatric, eye, skull and spinal cancers, PBT centres have come under scrutiny for possibly seeking a more 'common cancer' as a means of recouping

the massive capital and running costs. USA Medicare reimbursements for PBT peaked at \$28 million in 2007, of which prostate cancer treatment accounted for 83.3% of this (\$23.3 million), a mean total cost of \$34 954 per patient [4]. It is noteworthy that due to lack of evidence of superiority, a few major insurance companies in California recently announced they will no longer cover the costs of PBT for prostate cancer [5].

Patients considering prostate cancer treatment increasingly rely on web-based resources, in 2010 the number of internet users in the USA who searched online for health information increased from 25% to 80% over the prior decade [6]. Additionally, a recent study of men aged <50 years with Gleason 6 prostate cancer, revealed the internet was the second most frequent information source, after their doctor, in dictating treatment decision-making [7]. However, the anarchic nature of the internet means consumers could be making healthcare decisions based on low quality or inaccurate claims.

Shah et al. [6] analysed 37 websites with information pertaining to PBT and found 38% had commercial affiliations with shortcomings in quality and accuracy of consumer-oriented health information. This potential for misleading web-based material has been previously highlighted for robotic surgery where sites have purportedly overestimated benefits, neglected risks and were strongly influenced by the manufacturer [8]. We thus sought to evaluate PBT websites with respect to characteristics of website information and claims made.

We identified websites using snowball-purposive sampling to emulate a consumer searching the internet. This methodology has been used in previous studies [6] and captures additional

Table 1 Characteristics of PBT websites.

Characteristics	N	%
Number of websites analysed	36	
Region of origin:		
North America	22	61.1
Europe	8	22.2
Australasia	6	16.7
Development status of facility:		
In operation	21	58.3
Under construction	10	27.8
Under development	4	11.1
Other*	1	2.8
Indication:		
Prostate cancer	26	72.2
Other – eye, brain, face	5	13.9
Not specified	5	13.9
Proton therapy information located through within main institution website	20	55.6
Average number of clicks away from main institution homepage	2	
Use of referencing throughout text to peer-reviewed material	2	5.6
Use of manufacturers text/imaging	1	2.8
Link to manufacturers website	1	2.8
Use of emotive language	8	22.2
Information pertaining to risks	6	16.7
Hair loss, skin reaction and/or fatigue	4	11.5
Information on capacity for treatment or numbers of patients treated	14	38.9
Information on insurance coverage	12	33.3

*PBT representative body, not a facility for therapeutic delivery.

websites referenced within the initial sample [9]. We evaluated ‘Google’ search items for ‘proton therapy’ in September 2013 and prospectively defined inclusion criteria as English-language websites with information on PBT for therapeutic use; this included hospitals, proton therapy centres and PBT representative organisations. Excluded from the search were websites of manufacturers, research facilities and sites with no information on the therapeutic use of PBT. Our search yielded 36 websites from which we collected characteristics of information and claims of clinical, institutional and manufacturer superiority (Table 1). Claims were mostly generalised for all PBT treatment and not specific to cancer type.

The majority, 61.1% of websites, originated from the USA, with a smaller contribution from Europe (22.2%) and Australasia (16.7%). Most of the websites (58.3%) were from institutions currently in operation. Prostate cancer was listed as an indication for PBT in 72.2% of all websites; 13.9% indicate treatment only for the cancers, such as brain and eye, where the strongest evidence base lies.

For website navigation, PBT content in 55.6% of websites was not located on the main homepage but on average two clicks into the site. The influence of manufacturer text or links was infrequent at 2.8%. Emotive language was noted in around one fifth of all websites and was more likely to be found within patient testimonials. Information on number of patients treated and reference to insurance coverage was noted

Table 2 Claims made on PBT websites.

Claims	N	%
Clinical superiority:		
Precision of localisation	28	77.8
Non or least invasive	15	41.7
Less damage to surrounding healthy tissues	33	91.7
Fewer complications	5	13.9
Reduced or minimal side effects	27	75
Short treatment times	5	13.9
Normal lifestyle in peri-treatment period	11	30.6
Maintained or better quality of life	8	22.2
Painless	10	27.8
Improved cancer control	12	33.3
Decreased likelihood of secondary malignancies	7	19.4
Can treat recurrent tumours	4	11.1
Short half-life therefore minimal radiation exposure to others	1	2.8
Comparatively better than ‘conventional’ RT	18	50
Institutional superiority	13	36.1
Manufacturing superiority	5	13.9

in 38.9% and 33.3% of websites, respectively. Importantly, information on risks was only documented in 16.7% of cases, of which the most commonly documented side-effects included hair loss, skin reaction and/or fatigue (66.7%).

Claims of superiority are shown in Table 2. The most common claims were of less damage to surrounding healthy tissues (91.7%), precision of localisation (77.8%) and reduced or minimal side-effects (75%). Half of all websites made comparative claims in relation to ‘conventional’ RT; the other half had no comparative group. Claims of superiority for any cancer type were supported by peer-reviewed evidence throughout the text in only two of the 36 sites (5.6%).

Claims of institutional prestige were noted in around one third (36.1%) of websites for example ‘#1 cancer hospital in the world’. Claims of manufacturing superiority were noted in 13.9% of websites such as ‘the first compact scanning gantry worldwide’.

The USA Institute of Medicine has prioritised comparative effectiveness research for the treatment of localised prostate cancer acknowledging the variety of management options and costs involved [10]. Currently the literature does not favour the use of PBT over other therapies in the treatment of prostate cancer and some studies have even alluded to the potential for greater harm. In a population-based study of morbidity using the Surveillance, Epidemiology, and End Results-Medicare-linked (SEER) database between 2000 and 2009, Sheets et al. [11] compared RT methods showing significantly less risk of gastrointestinal morbidity with IMRT compared to PBT for prostate cancer (risk ratio 0.66, CI 0.55–0.79). In another Medicare based study, PBT was associated with a statistically significant reduction in genitourinary toxicity at 6 months compared with IMRT (odds ratio [OR] 0.6, CI 0.38–0.96); however, at 12 months there was no difference (OR 1.08, CI 0.76–1.54) [12].

With capital costs three to six times that of IMRT [13], PBT is currently difficult to justify, especially for prostate cancer. A recent study comparing costs and outcomes for radical prostatectomy and RT showed surgical methods tended to be more effective than RT methods, with the exception of high-risk disease; however, RT methods were consistently more expensive than surgical methods for both the payer and patient [14]. Some have speculated a multicentre randomised controlled trial comparing PBT to IMRT [15] may hold some answers; however, is only enrolling low- and intermediate-risk men for whom neither PBT nor IMRT has been shown to be cost-effective [14].

With this in mind, claims of clinical superiority on PBT websites with minimal peer-reviewed reference become all the more concerning. Our present study provides evidence that claims on PBT websites may overestimate benefits and underestimate risks. The unregulated nature of web-based health information has led to a dilution of quality upon which consumers are potentially basing treatment decisions. Claims must be founded on high-quality evidence with accurate reporting of risks and benefits so consumers can make informed healthcare decisions.

Conflict of Interest

None declared.

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Abbreviations: PBT, proton beam therapy; (IM)RT, (intensity modulated) radiotherapy.