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

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%).

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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 prostate cancer and some studies have even alluded to the potential for greater harm. In a population-based study of prostate cancer and some studies have even alluded to the potential for greater harm.

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 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%).

\begin{table}
\centering
\caption{Characteristics of PBT websites.}
\begin{tabular}{|lll|}
\hline
\textbf{Characteristics} & \textbf{N} & \textbf{%} \\
\hline
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 \\
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 \\
\hline
\end{tabular}
\end{table}

\begin{table}
\centering
\caption{Claims made on PBT websites.}
\begin{tabular}{|lll|}
\hline
\textbf{Claims} & \textbf{N} & \textbf{%} \\
\hline
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 \\
\hline
\end{tabular}
\end{table}

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