

## Literature Review

**Cite this article:** Durnin R, Shepherd P, and Gilleece T. (2021) An evaluation of the information needs of radiotherapy patients and their families. *Journal of Radiotherapy in Practice* 20: 473–479. doi: [10.1017/S1460396920000497](https://doi.org/10.1017/S1460396920000497)

Received: 1 April 2020

Revised: 1 June 2020

Accepted: 4 June 2020

First published online: 9 July 2020

### Key words:

cancer patients; cancer patients' families; information needs; radiotherapy

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# An evaluation of the information needs of radiotherapy patients and their families

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## Abstract

**Purpose:** To evaluate the information needs of radiotherapy patients and their families. To explore influential factors regarding information-seeking behaviours. To identify the preferred formats of information and the optimum time for radiotherapy patients to receive information. To assess the implications for clinical practice in satisfying patient information needs.

**Method:** A Cumulative Index to Nursing and Allied Health Literature database search of literature was undertaken and publications screened for retrieval with 36 qualifying for inclusion in the evaluation.

**Results:** There was inconclusive evidence exploring the impact that patient age, diagnosis, family background, and educational status had on the information-seeking behaviours and preferences of cancer patients. There is an agreement that there are positive and negative benefits of using different formats of information: verbal, written, virtual, and so on, and ultimately healthcare providers must utilise a combination of information formats to satisfy the information needs and preferences of individual patients. Inconsistent data were found on the optimum time to deliver cancer information to patients and professionals, and therapeutic radiographers should not assume that their information priorities are the same as those of their patients—every patient has unique and individually specific information needs.

**Conclusion:** The information needs of patients and families are dependent on individual circumstances, and priorities have a tendency to change during the cancer management journey, presenting huge challenges for therapeutic radiographers who are required to regularly reassess and satisfy the varying needs and preferences. More research is needed within the area of information needs and preferences for cancer patients receiving radiotherapy.

## Introduction

The importance of effective information management for patients and carers was identified in the review of Health and Social Care in Northern Ireland<sup>1</sup> and has served to stimulate some professional debate with regard to the importance of the information needs for cancer patients and their families. While the physiological needs of radiotherapy patients may be seemingly well supported using information leaflets, the effectiveness of the personal information needs of patients receiving radiotherapy and the information needs for the families who support them appears to be less well managed.

Many national health service programmes are patient-centred, designed to empower patients to actively participate in decision-making regarding treatment and care.<sup>1</sup> Ethically and legally, health care providers have a duty of care to obtain valid consent for all investigations and treatments. In order for patients to provide valid consent, they must be in receipt of effective information to inform their decision-making.<sup>2,3</sup> While it is essential that important information is given at the consent stage, healthcare providers should not discount information needs at other stages in a patient's care pathway.<sup>4</sup> Receiving a cancer diagnosis is undoubtedly a distressing time for the patient and their families, catapulting everyone into an unfamiliar space, a space into which effective patient-centred information is essential for patient well-being and treatment success.<sup>5</sup>

There are a number of studies suggesting that healthcare providers are falling short of the required information expectations and that the satisfaction of the patients and their families may be below the standard expected.<sup>6–10</sup> Patients are instinctively motivated to find out information to make sense of new, unfamiliar, environments.<sup>7</sup> Families are often motivated to seek information to support loved ones and to obtain enough information to aid treatment decision-making.<sup>8</sup> When patients are included in the decision-making process, they report increased satisfaction.<sup>9</sup>

Healthcare providers and therapeutic radiographers in particular face the ongoing challenge of assessing individualised information needs of patients and their families in an ever-changing, fast-paced healthcare system. Specifically, what information is essential, what depth and amount

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**Table 1.** CINAHL database. Search Strategy

Search ID#	Search terms	Search options	Results
S13	S8 AND S11	Limiters—Full text; English language Search modes—Boolean/Phrase	63
S12	S8 AND S11	Search modes—Boolean/Phrase	91
S11	S9 OR S10	Search modes—Boolean/Phrase	32,797
S10	'radiation therapy'	Search modes—Boolean/Phrase	12,631
S9	(MH 'Radiotherapy+')	Search modes—Boolean/Phrase	25,077
S8	S4 AND S5	Limiters—Full text; Published date: 20120101-20190531; English language Search modes—Boolean/Phrase	77
S7	S4 AND S5	Limiters—Published date: 20120101-20190531; English language Search modes—Boolean/Phrase	104
S6	S4 AND S5	Search modes—Boolean/Phrase	607
S5	(MH 'Cancer Patients')	Search modes—Boolean/Phrase	22,492
S4	S1 OR S2 OR S3	Search modes—Boolean/Phrase	12,227
S3	'Information requirements'	Search modes—Boolean/Phrase	103
S2	'Information sources'	Search modes—Boolean/Phrase	1,263
S1	(MH 'Information Needs') OR 'Information needs'	Search modes—Boolean/Phrase	11,026

of information should be provided, what format should the information take and when is the optimum time for therapeutic radiographers to deliver information to patients.

The evaluation aims to explore the information-seeking behaviours and the needs and preferences of patients referred for radiotherapy and the information needs of their families and discuss the implications for radiotherapy practice.

### Methodology

A literature search was conducted in order to inform the evaluation of the information needs of patients undergoing radiotherapy treatment using the electronic CINAHL (Cumulative Index to Nursing and Allied Health Literature) database. The CINAHL database was searched, 2012-19, for the following terms: information needs, information requirements, cancer patients, radiotherapy and radiation therapy. Full-text and English language articles were cross-referenced, and potentially relevant publications were screened for retrieval. Sixty-three potentially relevant publications were identified using the search strategy outlined in Table 1. Eighteen articles were excluded as they were not readily available in full text, and a further nine were excluded due to non-relevance to the subject area resulting in a total of 36 articles in support of the evaluation.

### Findings

Several authors agree regarding the motivating factors that drive patients and their families to seek information throughout the various stages of cancer management: diagnosis, treatment and follow-up/survivorship.<sup>7-10</sup>

#### Family and family support

The few studies that include family/partner motivations highlight the need to reduce a loved one's stress and anxiety, the need to get

information to help a loved one support decisions and for them to be directly involved in the decision-making.<sup>8,9</sup> The challenge to healthcare providers in assessing and satisfying family/partner information needs is that they are not always present during consultations.<sup>8</sup> Second, hospital consultations and appointments in general are time-limited engagements with the priority of the healthcare provider focused primarily on the needs of the patient. Information needs for families are not easily addressed, although the establishment of information and support radiographers in many radiotherapy departments makes great strides towards meeting the need. Additional signposting to support networks and charities is also crucial in this respect.

Family and home circumstances have also been controversially argued to impact on how much information patients require. Patients living without a partner/spouse having significantly greater information needs.<sup>5</sup> This result somewhat disagrees with other studies which show that patients who had a significant relationship (partner or spouse) had higher informational needs due to the motivational influence of their responsibility for others.<sup>11</sup> Mason<sup>8</sup> acknowledged the benefits of including a patient's family/spouse during information-giving sessions; she found that this reduced the time needed to educate patients. Including a patient's family is not without its disadvantages as patients may at times put up a 'façade' intended to mask a genuine need for support.<sup>12</sup> Particularly when in the company of their loved ones, the patient attempts to downplay their own needs in order to protect partners and family.

#### Timing

Few researchers have been able to specify the optimum time to provide cancer patients with information. There are many studies debating patient satisfaction rates in relation to information received at different times during the treatment journey.<sup>4,8,11-16</sup> None has given rise to a definitive approach with many

radiotherapy departments providing patient information at different stages of the cancer care pathway.<sup>17</sup> Studies have attempted to assess the effectiveness of information given to patients prior to beginning radiotherapy.<sup>13,16</sup> Some report that patients have a greater appetite for information at this time and that overall, patients prefer to receive information prior to treatment commencing.<sup>13</sup> However, the literature is not consistent, and evidence within a large questionnaire study of patient expectations for information, concluded that in addition to information prior to treatment patients needed information during and throughout the course of treatment.<sup>15</sup> Further studies showed patients had active information-seeking behaviours after the completion of a treatment course. This behaviour was noted to be at odds to that witnessed in the same patients prior to treatment.<sup>11</sup> Harrison et al.<sup>14</sup> reported that women receiving breast cancer treatment showed no change in information needs over the course of treatment and follow-up. The authors in the study accepted that this finding may be unreliable as a result of premature follow-up of the women immediately after the treatment ended rather than after an acceptable time period.<sup>14</sup> Many experts are now satisfied that patient preferences for information and information-seeking styles often change over time.<sup>4,11,13–17</sup> Hence, the overwhelming need for patients to have their information needs assessed frequently and for information to be personally tailored and provided throughout the treatment course.<sup>4,14</sup> The hypothesis that a patient's information needs will change with time emphasises the need for a dynamic approach rather than a one time is best approach. There may also be merit in revisiting and repeating information provision at differing time points in order to enhance the effectiveness of understanding.

### Rapport

The perception and development of the key relationships between health professionals and patients is greatly influenced by the time spent together.<sup>5,7,9,18</sup> In recent years, the duration of patient appointments has greatly reduced impacting on the amount of time healthcare professionals have to spend with patients.<sup>8,12</sup> If the time is not sufficient, the health professional and patient relationship can be negatively impacted.<sup>12</sup> The result of an unestablished trusting relationship with healthcare professionals can result in patients displaying a 'façade' when asked about their informational needs.<sup>12</sup> Furthermore, due to staff rotation, multiple staff members may be involved in any one patient's treatment. This can ultimately lead to a lack of continuity in care and can further worsen the patient's perception of the information received.<sup>8,12</sup> The extent to which patients accept unmet informational needs within a failing healthcare system was demonstrated within a small study of patients; 'I had no perception of them as advisors [and therefore I did not ask questions]'.<sup>12</sup> Another striking insight into patient perception was revealed when information was given while staff completed other tasks; the information was seen as 'random'.<sup>12</sup> A striking finding from the studies showed that patient preference for information and information-seeking styles is influenced by individual characteristics and demographics such as, age, gender, socio-economic status and educational achievement.<sup>11</sup> For information provision to be effective, the establishment of trust and a good rapport with the patient appears vital.

### Information format

A unique study by Häggmark et al.<sup>19</sup> looked at the effects of the format of information being given. They compared three methods

of providing information to patients: standard information with a brochure, standard information only and standard information with repeated individual information. The results were that the patients who received standard information with repeated individual information were significantly more satisfied with all aspects of the information in comparison to the other two groups. This result substantiates previous thinking that providing information to cancer patients is a continuous process. A patient's ability to recall and understand information can also impact their perception of information received, especially if information has been delivered in a single episode. Despite the positive results shown by patients who preferred repeated individualised information, the authors of this study made no changes to clinical practice due to the increased expense associated with this approach to information provision.<sup>19</sup>

With National Health Service (NHS) hospitals becoming increasingly busier, the demand for specialist supportive charities has increased. In a recent study, a prostate cancer charity revealed the reasons behind the popularity of a telephone information hotline; patients benefit by receiving uninterrupted time, complete confidentiality and access to specialist nurses. Furthermore, families of men with prostate cancer can also receive support via the telephone. The option of emailing questions to specialist charity nurses has also proven popular.<sup>20</sup>

The modern world of technology has also witnessed patients, and their families utilise the Internet as a cancer information source.<sup>6,12</sup> Similar to the benefits of a telephone hotline, online support has been described as convenient and an easy method of sourcing information.<sup>12</sup> One study revealed that cancer patients went online to source bio physiological information. Furthermore, younger, well-educated patients expected more bio physiological information from the Internet than other users.<sup>15</sup> Other authors have supported this claim that younger patients are more active online than older patients at sourcing information outside the hospital setting.<sup>11,21</sup>

These findings are supported as experts have shown that older patients with breast cancer placed more value on face-to-face or telephone conversations with peers or other patients as opposed to seeking information online. Those older patients that did go online for information explained the challenges of filtering information and examining the reliability of information.<sup>22</sup> Interestingly Jahraus et al.<sup>21</sup> highlighted the great benefit of the Internet use for patients who have an unquenchable need for information. This theory could be utilised in clinical practice as a means to satisfy patient informational needs while in a time-restrictive environment. Authors have also acknowledged a fundamental issue that while the past decade has witnessed more people 'surfing the web' not everyone has access to the Internet and is proficient in its use.<sup>21–23</sup>

Sherman et al.<sup>24</sup> accept the valued role of external sources of information like the Internet, but their study suggested that those utilising the Internet were reluctant to trust sources outside their healthcare provider's advice. They demonstrated that information provided in a brochure format and from a clinic staff member played a leading role in convincing a patient group to comply with risk minimisation behaviours in comparison to other information sources. This view is validated by Wiljer et al.<sup>25</sup> agreeing that while patients actively sought information outside the clinical setting patients rated the members of the healthcare team as the best source of information.

For patients who have unmet informational needs, using the Internet may have negative consequences and inherent risk. A patient who shared their Internet experience with Pedersen

et al.<sup>12</sup> described the feeling of ‘self-blame’ after following online advice that could have had a potential detrimental effect on their cancer treatment. Experts agree that health professionals have a responsibility to support patients regarding the appropriateness of information searched online.<sup>4,11,23</sup>

A unique pilot study by Sule-Suso and colleagues<sup>26</sup> provided radiotherapy information using a virtual reality system. Using such unique software, patients and their families were shown graphically the equipment involved in treatment, the treatment environment and the critical importance of patient compliance to reproducibility and reduce side effects. The results of this pilot demonstrated that patients had a better understanding of their treatment and the linked side effects. The unique factor of this study was the inclusion of families and partners with many reporting feeling more involved.<sup>26</sup> The main limitation of the study was the cost of the initial purchasing of the Virtual Environment for Radiotherapy Training (VERT) system and the time factor for staff to provide demonstrations to patients on a one-to-one basis. There was a small majority of patients who opted out of this study explaining that they had already been fully informed and other families’ members and partners declined the invitation as they felt they had received sufficient information.<sup>26</sup>

### Information content

The greater focus of literature within this review addresses the preferred subject and content of patient information.<sup>4,8,10,12,13,15,18,20,22,27–31</sup> Information regarding cancer treatment side effects is a common area where patients felt that information was lacking particularly amongst NHS care providers.<sup>4,12,20</sup> This finding is supported by a research charity who recorded the subject of telephone calls received annually reporting treatment side effects as the most frequent subject area.<sup>20</sup> A small study examining patient preference for information surrounding late effects found that nearly half of the participants would have liked more information and none of the patients wanted less.<sup>4</sup> Providing patients with information regarding treatment side effects was linked very strongly to patient satisfaction and the benefit of engaging patients in treatment decision-making.<sup>22</sup> Healthcare providers have a duty of care and are legally and ethically obligated to ensure valid informed consent is obtained.<sup>2</sup> In order for patients to be active in treatment decision-making processes, they must be provided with sufficient information including treatment side effects.<sup>2,4,9</sup>

### Less information and knowledge gaps

Within the literature, there was limited research discussing circumstances where patients preferred less information or deemed information as invalid.<sup>13</sup> This may be a minority group but one that should not be ignored. Further research is needed in order to evaluate the needs of this sub-group of patients in order for their preferences to be better understood and respected.<sup>13</sup> A study focusing on patients starting radiotherapy treatment found that information regarding complementary therapies, other patients’ experiences and what patient support organisations offer were topics patients least wanted to be fully informed about.<sup>13</sup> The findings contradict other valid studies where the cancer patient’s preference was to receive information about other patients’ experiences.<sup>20</sup> One of the assessments that nurses working in cancer charity organisations carry out routinely, is the service users need for peer support. It is felt that peer support can be valuable with users appreciating hearing the personal experiences of others.<sup>20</sup> Another study found peer support to better prepare patients for

treatment and its implications, it allowed participants to personalise information conveyed by health providers.<sup>22</sup> A justification of the isolated finding that patients may have a lower preference for information regarding other patients’ experiences could be related to Maslow’s hierarchy of needs theory.<sup>29</sup> Patients who had a lower preference for information about other patients’ experiences were by definition ‘new radiotherapy patients.’ Starting radiotherapy can be a daunting experience, and many are still coping with the impact of a cancer diagnosis. It is therefore not surprising that patients in this stage of the journey are more focused on satisfying their own basic needs for safety and understanding of radiotherapy treatment rather than psychological needs of support. This theory is supported by findings from studies of women with gynaecological cancers and information needs during diagnosis versus needs during rehabilitation and survivorship phases. During the cancer diagnosis phase issues and information regarding sexuality were not as prominent compared to women who had completed treatment.<sup>28,32</sup> Sadly, within the literature patients reported unmet information needs regarding sexual health.<sup>4,8,28,29</sup> The issues around sexual health is not only important for the patient but also significant for partners and spouses.<sup>8</sup> When sexual health is examined holistically, outside the act of intercourse alone, not having sufficient information to maintain closeness and a level of intimacy can greatly impact a partner or spouse ability to provide emotional support to a person with a cancer diagnosis.<sup>8</sup> Within the literature, few researchers have addressed sexual health information and provision of sexual health information or training among service providers.<sup>4,20,33</sup> The challenge for therapeutic radiographers is to accurately gauge and identify what stage of the patient journey the patient is in and tailor information needs accordingly. This will not be easy as it will not be the same for every patient.

### Cancer diagnosis and site-specific challenges

Some of the research regarding patient information needs is focused on site-specific cancers and their comparison with other cancer sites. Cleary et al.<sup>29</sup> describe how patients with gynaecological cancers have higher unmet information needs as a result of patient embarrassment and lack of knowledge with inadequately trained staff and limited resources compounding the issue. The finding of the study is echoed by D’Alimonte et al.<sup>32</sup> describing the ‘unique’ informational needs of women with gynaecological cancers. Many of the studies surrounding gynaecological cancers and the psychosexual needs of these patients discuss the limited qualitative literature and patient information available.<sup>29,32</sup>

A cross-sectional study comparing information needs between malignancies found that patients with advanced melanoma have greater information-seeking needs compared to other cancer sites.<sup>30</sup> Hertz et al.<sup>10</sup> study focusing on supportive needs of melanoma patients highlighted the contrast between the greater resources available for melanoma patients with that available for other malignancies.

Another cross-sectional study revealed that lung cancer patients rated information and emotional needs as most important.<sup>25</sup> Interestingly, for the majority of patients included within the study, these needs were most important during the pre-diagnosis stage. Previous literature supports the finding within this study that lung cancer patients feel anxious during the pre-diagnosis phase.<sup>11</sup> Commonly complex symptoms and poor prognosis characteristics of lung cancer lead to high levels of anxiety resulting in greater information needs at the pre-diagnosis phase.<sup>25,34</sup> This finding is well founded with studies showing that

lung cancer patients seek information more actively in the pre-treatment phase than at any other time. In comparison to other cancer site groups, lung cancer patients were found to be more passive in their information-seeking behaviours in the post-treatment phase. Ehemann et al.<sup>11</sup> reported within their longitudinal study comparing information-seeking styles among different cancer patient groups and during different phases of treatment found lung cancer patients to be more passive overall in their information-seeking styles.

There is, however, ambiguity surrounding lung cancer patients needs as the study by Douma et al.<sup>34</sup> found that this group of patients were associated with lower information needs despite having higher anxiety traits in comparison with other malignancies. Zeguers et al.<sup>13</sup> revisits this finding claiming that lung cancer patients who are often older males with higher anxiety levels need less information. Specifically, within this study, lung cancer patients reported lower information needs surrounding prognosis. This has been based on the assumption that patients wanted to know less information when the content is perceived as negative.<sup>13</sup> An alternative hypothesis might be that patients with lung cancer are often smokers/ex-smokers and the influence of feeling guilt and embarrassment impacts the information-seeking behaviours. Patients believe that they do not deserve to know – further research is warranted to clarify why this patient group demonstrates low information needs.

Rectal cancer patients were found to be similar to lung cancer patients in that they require less information than other malignancies, particularly if they are male, older and more anxious.<sup>13,34</sup> They were also found to have lower information needs regarding treatment itself. The theory that the influence of embarrassment may result in lower information-seeking behaviours is similar to that experienced among patients with gynaecological cancers.<sup>13</sup>

### Prognosis

Patient preference and need for information regarding prognosis remains a subject for debate. Historically, patients struggle to receive information regarding prognosis and professionals can feel that pressing the subject can be stressful and detrimental for the patient.<sup>13</sup> The majority of studies, however, showed a high demand for prognosis information.<sup>10,13,15,16,22,30,35</sup> While one large study highlighted that new cancer patients in general preferred extensive information regarding prognosis, the lung cancer patient subgroup reported lower prognosis information needs than the other cancer sites.<sup>13</sup>

### Other factors

Other factors that have been thought to influence information needs and information-seeking behaviours are age, culture, socio-economic status and education standard. A number of studies have examined the impact of age and found that older patients (51–60 years) required less bio physiological knowledge than younger groups although the older patients did seek more social knowledge than their counterparts.<sup>15</sup> Bergenmar et al.<sup>5</sup> revealed that age was also a significant factor when examining how satisfied patients were with the information that they received from healthcare providers. Younger patients reported to be less satisfied with the information received with the majority of patients studied seeking more information.<sup>5,33</sup> A study by Ehemann et al.<sup>11</sup> also supported this finding that the older generation patients (65 and older age group) were more passive in their information-seeking styles than younger patients (20–64 age group).<sup>11</sup> That said,

Wong et al.<sup>22</sup> argued that age alone cannot determine the level of information need. Within their study, they specifically looked at elderly breast cancer patients and pointed out that although they were satisfied with medical information, they were unsatisfied with the format and type of information given.<sup>22</sup> The finding highlighted that age alone cannot be relied upon as a predictive quantifier for information provision.<sup>7,36</sup>

### Discussion

Healthcare professionals face many challenges in light of the findings. There are currently no information standards established for healthcare providers with regard to the provision of information for cancer patients.<sup>37</sup> This is supported by Caprici et al.<sup>37</sup> who point out that a professional standard would be questionable due to individual preference differences, one standard would likely not address patient-specific needs and expectations. The accepted standard is that of a subjective standard. Informational needs are subjective, and health professionals are required to dedicate time and resources to assess each patient, at every encounter, to ensure tailored information is provided.<sup>18,37</sup>

Cleary et al.<sup>29</sup> recognise the pressure upon healthcare providers and highlight the need for additional measures like the provision of patient-specific information, structured assessments and educational resources.

Some studies have evaluated the use of instruments or tools to determine information needs. One study developed the Women with Vulvar Neoplasia – Patient-Reported Outcome (WOMAN-PRO) instrument as a measure of patient experience and information needs.<sup>28</sup> The results were largely positive although this was a small study, and further research would be necessary to guarantee validity. The Edmonton Symptom Assessment System and the Needs Evaluation Questionnaire have also been used to evaluate information needs for individual patients.<sup>30</sup> These two tools were targeted at patients with melanoma, and the authors were able to demonstrate the unique information needs of patients with this cancer diagnosis. The study demonstrated that using the tools can support professionals and facilitate a more consistent approach for needs assessment.<sup>30</sup>

A growing body of literature has indicated that more studies and research are necessary for better understanding of the information needs of cancer patients and their families. Ehemann et al.<sup>11</sup> concluded that public health researchers and clinicians have a responsibility to investigate ways to meet changing patient information needs. They discuss how research can support the use of a variety of educational and information interventions in order to meet individual patient preferences.<sup>11</sup>

One of the debates in the clinical setting is who is best placed and has the authority and responsibility for providing patient information and identifying unmet information needs. The study by D'Alimonte et al.<sup>9</sup> found that patients classified the radiation oncologist as being the most relied upon and influential in comparison to other health professionals. A study by Bolderston<sup>18</sup> showed that despite the daily interaction that therapeutic radiographers have with patients, there remains significant differences in what patients wanted to know and what radiographers presumed patients wanted to know.<sup>18</sup> Capirci et al.<sup>37</sup> concluded that of the professional groups, doctors (urologists and oncologists), nurses and therapeutic radiographers were found to have the most similar priorities to that of the patients.<sup>18,37</sup> While the three groups largely agree the questions essential to address for patients, there remained considerable variation of opinion within individual professional

groups with the doctors demonstrating the most significant variation. Professionals should not assume that their information priorities are the same as those of their patients—every patient has unique and individually specific information needs.

Zeguers et al.<sup>13</sup> describe how due to a lack of patient education or confidence patients often rely on ‘faith’ and comply with the medical opinion of the doctor when engaging in medical health decision-making. This feeling of ‘faith’ or ‘trust’ that has been described frequently within the literature and been strongly linked between the patient and doctor relationship.<sup>25</sup>

The expanding role of nurses in the clinical consenting stage could also impose challenges as previously highlighted when patients may not identify information sessions if they are often given simultaneously alongside other clinical tasks. This poses a large challenge for staff, like nurses and therapeutic radiographers, who juggle workload and activities in a variety of clinical settings.<sup>12</sup>

Nurses have been identified within the literature as playing a large role in providing information and identifying needs; however, the equal responsibility of all healthcare professionals to provide adequate information has been well cited.<sup>4,10,19</sup> Nurses have been shown to be the most active in providing educational informative material to patients compared to radiographers and doctors.<sup>4</sup>

Many studies have discussed the clinical challenges for health professionals to ‘get it right,’ evaluating the information needs of patients and their families undergoing cancer treatment. One study highlighted the ever-growing role of cancer information charities as NHS Clinical Nurse Specialist roles are being reduced.<sup>20</sup>

Furthermore, as patients often have numerous appointments, family or partners/spouses are not always in attendance further increasing the difficulty for professionals to assess informational needs.<sup>8</sup> None of the research within this review has focused on meeting the informational needs of patients who prefer to receive information away from loved ones.

## Conclusion

Professionals should not assume that their information priorities are the same as those of their patients—every patient has unique and individually specific information needs. Benefit is to be gained when therapeutic radiographers and oncologists share information providing responsibilities and collaborate. There is an agreement that there are positive and negative benefits of using different formats of information: verbal, written, virtual etc. and ultimately healthcare providers must utilise a combination of information formats to satisfy the information needs and preferences of individual patients. While patients should be considered individually, research has shown that some commonality exists in the topics of information. Evidence suggests that information regarding the stage of the disease, treatment options, side effects and prognosis are high priorities for many cancer patients. The approach for all health professionals to reiterate and revisit significant information throughout a course of treatment has been favoured by patients and healthcare providers and appears to be preferred practice.

With clinical appointment times shortening, there is less opportunity for health professionals to evaluate patient and family information needs. The pressures and strains upon the capacity of the National Health Service have and continue to be well debated and undoubtedly influence the public and patient perspective of what in reality can be expected as good practice. This, however, should not be used as an excuse for failing to meet patient and

family information needs. The next decade is likely to witness increasing pressures with a growing ageing population, and health-care professionals and therapeutic radiographers must be prepared to rise to the challenge.

**Acknowledgements.** The authors thank the staff of the Radiotherapy Department, Western Health and Social Care Trust, for their support.

**Financial support.** This evaluation received no specific grant from any funding agency, commercial or not-for-profit sectors.

**Conflicts of interest.** None.

## References

1. Transforming Your Care. Review of Health and Social Care 2011. Health and Social Care Board (Northern Ireland). <http://www.hscboard.hscni.net/our-work/review-health-social-care-2011/> Accessed on 24 Feb 2020.
2. Faden RR, Beauchamp TL. A history and theory of informed consent. New York: Oxford University Press; 1986.
3. White N. Principles and practice of radiation therapy. *Radiography* 2009; 15 (4): 357–358.
4. Taylor C. Patient satisfaction with information on late effects: Claire Taylor explores what patients who have undergone radiotherapy for pelvic cancers want to know. *Cancer Nurs Pract* 2014; 13(1): 16–22.
5. Bergenmar M, Johansson H, Sharp L. Patients’ perception of information after completion of adjuvant radiotherapy for breast cancer. *Eur J Oncol Nurs* 2014; 18 (3): 305–309.
6. Simon MA, Ragas DM, Nonzee NJ, Phisuthikul AM, Luu TH, Dong X. Perceptions of patient-provider communication in breast and cervical cancer-related care: a qualitative study of low-income English- and Spanish-speaking women. *J Commun Health* 2013; 38 (4): 707–715.
7. Orellana-Rios CL, Radbruch L, Kern M, Regel YU, Anton A, Sinclair S, et al. Mindfulness and compassion-oriented practices at work reduce distress and enhance self-care of palliative care teams: a mixed-method evaluation of an “on the job” program. *BMC Palliat Care* 2017; 17 (1): 3.
8. Mason TM. Wives of men with prostate cancer postbrachytherapy: perceived information needs and degree of being met. *Cancer Nurs* 2008; 31 (1): 32–37.
9. D’Alimonte L, Hahn S, Makhani L, Adams L, Szumacher E. The informational needs of prostate cancer patients treated with radical prostatectomy regarding adjuvant or salvage radiotherapy: determinants of community health pilot project. *J Med Imaging Radiat Sci* 2011; 42 (4): 198–209.
10. Hetz SP, Tomasone JR. Supportive care needs of Canadian melanoma patients and survivors. *Can Oncol Nurs J* 2012; 22 (4): 248–256.
11. Ehemann CR, Berkowitz Z, Lee J, Mohile S, Purnell J, Marie Rodriguez E, et al. Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun* 2009; 14 (5): 487–502.
12. Pedersen B, Koktved DP, Nielsen LL. Living with side effects from cancer treatment—a challenge to target information. *Scand J Caring Sci* 2013; 27 (3): 715–723.
13. Zeguers M, de Haes HCJM, Zandbelt LC, Ter Hoeven CL, Franssen SJ, Geijsen DD, et al. The information needs of new radiotherapy patients: how to measure? Do they want to know everything? And if not, why? *Int. J. Radiat. Oncol. Biol. Phys* 2012; 82 (1): 418–424.
14. Harrison DE, Galloway S, Graydon JE, Palmer-Wickham S, Rich-van der Bij L. Information needs and preference for information of women with breast cancer over a first course of radiation therapy. *Patient Educ Couns* 1999; 38 (3): 217–225.
15. Siekkinen M, Salantera S, Rankinen S, Pyrhoenen S, Leino-Kilpi H. Internet knowledge expectations by radiotherapy patients. *Cancer Nurs* 2008; 31 (6): 491–498.
16. Wolpin SE, Parks J, Galligan M, Russell KJ, Berry DL. Information needs of men with localized prostate cancer during radiation therapy. *J Cancer Edu* 2016; 31 (1): 142–146.
17. Sutherland J, McLaughlan L. The timing of breast cancer patient education: its influence on satisfaction. *Radiat Therap* 2013; 22 (2): 131–138.

18. Bolderston A. Mixed messages? A comparison between the perceptions of radiation therapy patients and radiation therapists regarding patients' educational needs. *Radiography* 2008; 14 (2): 111–119.
19. Häggmark C, Bohman L, Ilmoni-Brandt K, Näslund I, Sjöden P-O, Nilsson B. Effects of information supply on satisfaction with information and quality of life in cancer patients receiving curative radiation therapy. *Patient Educ Counseling* 2001;45(3): 173–179.
20. Lynch T. Telephone helpline supports patients with prostate cancer: Teresa Lynch outlines the role of specialist nurses responding to callers asking for information about testing, treatment and side effects. *Cancer Nurs Prac* 2012;11(3): 30–34.
21. Jahraus D, Sokolosky S, Thurston N, Guo D. Evaluation of an education program for patients with breast cancer receiving radiation therapy. *Cancer Nurs* 2002; 25 (4): 266–275.
22. Wong JJ-W, D'Alimonte L, Angus J, Paszat L, Soren B, Szumacher E. What do older patients with early breast cancer want to know while undergoing adjuvant radiotherapy? *J Cancer Educ* 2011; 26 (2): 254–261.
23. Grinyer A. The late effects of mantle field radiotherapy: the information and support needs of women survivors of Hodgkin's disease. *Eur J Oncol Nurs* 2010; 14 (3): 183–189.
24. Sherman KA, Koelmeyer L. The role of information sources and objective risk status on lymphedema risk-minimization behaviors in women recently diagnosed with breast cancer. *Oncol Nurs Forum* 2011; 38 (1): 27–36.
25. Wiljer D, Walton T, Gilbert J, Boucher A, Ellis PM, Schiff S, et al. Understanding the needs of colorectal cancer patients during the pre-diagnosis phase. *J Cancer Educ* 2013; 28 (3): 402–407.
26. Sule-Suso J, Finney S, Bisson J, Hammersley S, Jassel S, Knight R, et al. Pilot study on virtual imaging for patient information on radiotherapy planning and delivery. *Radiography* 2015; 21 (3): 273–277.
27. Morley L, McAndrew A, Tse K, Rakaric P, Cummings B, Cashell A. Patient and staff assessment of an audiovisual education tool for head and neck radiation therapy. *J Cancer Educ* 2013; 28 (3): 474–480.
28. Senn B, Mueller MD, Hasenburg A, Blankenstein T, Kammermann B, Hartmann A, et al. Development of a postsurgical patient-reported outcome instrument for women with vulvar neoplasia. *Oncol Nurs Forum* 2012; 39 (6): 489–498.
29. Cleary V, Hegarty J, McCarthy G. How a diagnosis of gynaecological cancer affects women's sexuality: Vicki Cleary and colleagues explore patients' perceptions of themselves and their sexual relationships after diagnosis and treatment, noting in particular their comments about their information needs. *Cancer Nurs Prac* 2013; 12 (1): 32–37.
30. Di Rocco ZC, DStat CDP. Information needs of patients with melanoma: a nursing challenge. *Clin J Oncol Nurs Oncol Nurs Soc* 2012; 16 (6): 625–632.
31. Sherminie G, Cottrell J. Experiences of breast cancer patients undergoing radiation therapy in Sri Lanka. *Radiat Therap* 2014; 23 (1): 101–104.
32. D'Alimonte L, Ackerman I, Barbera L, Barnes T, Thomas G, Di Prospero L, et al. Empowering patients through education: a needs assessment to develop a novel educational tool. *J Med Imaging Radiat Sci* 2015; 46 (1): S23.
33. Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, et al. Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *J Adv Nurs* 1997; 25 (6): 1175–1183.
34. Douma KFL, Koning CCE, Zandbelt LC, de Haes HCJM, Smets EMA. Do patients' information needs decrease over the course of radiotherapy? *Support Care Cancer* 2012; 20 (9): 2167–2176.
35. Bakker M, Weug D, Crommelin M, Lybeert M. Information for the radiotherapy patient. *Radiography* 1999; 5 (2): 99–106.
36. Gülezer GN, Taşci S, Kaplan B. The experience of symptoms and information needs of cancer patients undergoing radiotherapy. *J Cancer Educ* 2012; 27 (1): 46–53.
37. Capirci C, Feldman-Stewart D, Mandoliti G, Brundage M, Belluco G, Magnani K. Information priorities of Italian early-stage prostate cancer patients and of their health-care professionals. *Patient Educ Couns* 2005; 56 (2): 174–181.