

Original Article

A review of the literature surrounding the provision of interpreters in health care, focusing on their role in translating information for non-English-speaking cancer patients and issues relating to informed consent

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Abstract

Informed consent is a fundamental principle of health care ethics. All patients should have equal opportunities in accessing information to help them make informed decisions about their treatments.

Literature on informed consent, translators in health care, non-English-speaking patients and the importance of communication and information, most specifically in radiotherapy, were reviewed. Western studies published between 1995 and 2005 were accessed and filtered through two eligibility screens and a critique framework to assess quality.

The evidence suggested that many non-English-speaking patients are not in a position to give true informed consent due to lack of interpreters. This may lead to health care professionals giving treatment without full consent. Written information for radiotherapy patients was often only available in English, apart from inner city areas.

There appears to be a scarcity of professional interpreters used in the health care setting; the most common practice is to use family members and friends to interpret. This practice results in breach of patient confidentiality, extra pressure on family members and filtration of information.

This patient group is often excluded from certain treatment opportunities such as clinical trials. Ideally, a fully accessible professional interpreting service should be available to allow non-English patients equal rights in accessing appropriate health care options and treatments.

Keywords

informed consent; non-English-speaking patients; radiotherapy; translators

INTRODUCTION

Almost a third of the population will develop cancer during their lifetime, resulting in one in eight people receiving radiotherapy.¹ Traditionally, the medical consultant was responsible for

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obtaining patients' informed consent for radiotherapy, but now this responsibility lies with radiotherapy radiographers as the practitioners.²

Informed consent is essential for patients to be aware of what their treatment involves and the possible side effects.^{3,4} Health care professionals may be faced with the possibility of future litigation if patients do not give informed consent.⁵

For non-English-speaking patients, it would appear logical that professional interpreters are made available to facilitate the information-giving process, but in reality professional interpreters are usually available only on request and must be pre-booked. In most circumstances, those most often called upon to translate are members of a patient's own family.⁶

It has been suggested that patients, especially radiotherapy patients, also need written information to consider all aspects of proposed treatments in order to give informed consent. For many non-English-speaking radiotherapy patients, literature in their own language appears to be scarce, often available in inner city areas only.⁷

It is therefore possible that some non-English-speaking patients will not be fully informed about the treatment and that has potential implications for both patients and practitioners.

The aim of this review is to explore through the literature, the provision of interpreters available for non-English-speaking cancer patients and also the process of obtaining informed consent from these patients.

METHODOLOGY

This review utilised mainly primary studies; however, secondary sources were also included to simplify and summarise some of the primary material and contribute to the background knowledge.⁸

The initial search involved a brief manual investigation of indices, shelved journals, books and relevant unpublished dissertations in the authors' HE institution to clarify and gain a general background of the topic as recommended

by Burns et al.⁹ An extensive collection of electronic databases related to health care was accessed, including PubMed, Cinahl, BNI and Medline.

References and bibliography lists of research papers were retrieved from selected articles, as suggested by Abbott,¹⁰ which led to a further collection of literature. The literature was then filtered through two screens as outlined by Fink.¹¹ The first screen is a practical screen and identifies potentially useful studies, whereas the second screen utilises criteria set by the authors to ascertain the reliability and validity of the articles.

The authors accessed relevant articles published in English between 1995 and 2005 from the Western world. Excluded were articles published in different languages and those published before 1995, except those of historical significance. A framework devised by Hek et al. was used to critique the literature.¹² Use of a framework has been recognised and recommended by other authors,^{13,8} and according to Evans et al. gives the critique process structure and enhances the transferability of findings to practice.¹⁴

LITERATURE REVIEW

Background to informed consent

The issue of informed consent came to the fore of the medical ethics debate following the atrocities that occurred in the name of medical science, during the Second World War.¹⁵ The Nuremberg Code clearly emphasised the importance of gaining voluntary consent from research subjects.¹⁶

The Human Rights Act (1998) that came into effect in October 2000 raised public awareness of individual rights, resulting in more stringent requirements on health care professionals to explain in some detail exactly what an investigation or treatment involved, known as informed consent. Kagan suggests that informed consent involves telling a patient what you would want to know if you were the patient, whilst making necessary modifications for culture and language.¹⁷

Shared decision-making between patients and health care professionals has been hailed as the

way forward for modern medicine, empowering patients to make informed decisions about their treatment.^{18,19} Informed consent is a patient's agreement to allow medical intervention based on a full disclosure of the facts necessary to make an intelligent decision. The most important requirements for this are information and critical thinking.²⁰ Informed consent is an agreement of trust between the doctor and the patient, where the doctor informs and the patient consents and ultimately trusts the doctors to do the right thing.¹⁷ According to UK law, patients must be competent and understand the benefits and risks of any proposed treatments or their alternatives, if there are any.^{21,3}

Informed consent and radiotherapy

One method of providing proof of informed consent is the patient's signature on a consent form. However, there is some debate over how an individual's understanding of this information is evaluated to give written consent.²² In the UK, there is no law that gives guidance on when to use a consent form or directly specifying how informed consent should be sought.⁶ However, there are recommendations on obtaining written consent for complex treatments or where certain risks are involved.^{23,24} This latter category applies to radiotherapy, so it is vitally important that patients understand the information given to them and are able to communicate effectively with the health care team so that they can give their informed consent.^{25,26}

The ultimate aim of radiotherapy to cure or palliate must be discussed with the patient so that the patient can decide autonomously whether or not to have treatment. Schafer and Herbst suggest that a basic ethical principle of giving information is to provide hope; and if health care professionals fail to provide patients with sufficient information and time to give informed consent, they are in breach of their duty of care.³ This can make health care professionals potentially open to litigation.²⁶

Disturbingly one national survey revealed that 68% of Asian patients with cancer did not understand their diagnoses and 45% failed to understand the information about their treatment options.²⁷ These findings pose difficult challenges

for radiotherapy radiographers, as each stage of a patient's treatment requires informed consent by either verbal or non-verbal agreement to proceed.²⁶

Several authors have reported that the non-English-speaking population are disadvantaged in both accessing and using NHS services.^{28–30} In some cases, patients did not see a health care professional due to language barriers; and if a consultation took place, these barriers led to a lack of understanding of the health problem and the proposed treatment regimes.²⁹ These findings were also supported by Titmarsh, who stated that, 'Communication barriers leave some cancer patients in the UK understanding little about their diagnosis or planned treatment'.³¹

Added cultural complications can impede communication further when a woman feels unable to give consent without her husband's agreement. In this case, the situation may be compounded if the woman is also illiterate in her own language, making it difficult to determine who is doing the consenting.²⁵

One UK survey of information-giving practices in a radiotherapy department revealed that provision of information for non-English-speaking patients was variable nationally;⁷ however, this study was limited in that those surveyed were radiotherapy managers and not users of the service. The small number of participants (29 out of a sample of 63) reflects the overall small number of radiotherapy departments in the UK. However, the emerging themes are supported by other studies.^{27,31}

The 2001 Census revealed that 7.9% of the UK population considered themselves as coming from a non-White ethnic group.³² A growing proportion of this non-White ethnic group are English-born nationals, but there is also a growing recognition that it includes recent immigrants, asylum seekers and refugees, whose ability to speak English may be limited or non-existent.^{28,29} Under law, both asylum seekers and refugees have the same right to health care as any resident of the UK, but linguistic and cultural barriers make migrants a vulnerable group who risk suffering inadequate diagnoses and treatments.³³

Recent initiatives in the past 2 years to assist health care professionals with non-English-speaking users of the service have resulted in a range of translated resources (public health information leaflets). These initiatives have primarily been driven by the Asylum Seeker Co-ordination Team, and translation of written informed consent forms are now available for the frontline staff to access.³⁴

Clinical trials

Treatment options for cancer patients often includes the opportunities to enter clinical trials but those with ethnic minority background are often excluded from clinical trials in the UK.³⁵ It would appear that this exclusion might arise due to a language barrier that would potentially incur additional costs by employment of interpreters. However, these findings are further complicated by the assumption that these patients may be reluctant to participate in clinical trials.^{36,37} There does not appear to be the same recruitment issue for non-English-speaking patients in the USA, although the authors found one US study where non-English-speaking parents of paediatric cancer patients did not have key information such as randomisation, consent documentation and issues of informed consent explained to them due to language barriers.³⁸

Although, as Schafer suggests, there will always be cases when it is impossible for patients to give true informed consent, such as in emergency situations, the same cannot be said of clinical trials.³ This was confirmed by an observational study of 51 women by Hoornstra et al., which showed that if given time to grasp information and ask questions, the majority were able to make an informed decision about entering a trial.⁸

As randomised controlled trials are considered to be the gold standard in evaluating medical interventions and there is no scientific basis for excluding ethnic minorities, Hussain-Gambles suggests that this constitutes a form of institutional racism.³⁹

Research ethics committees in the UK acknowledge that there may be problems in obtaining informed consent and prefer special

arrangements to be made; however, there is no guidance on how to achieve these.³⁷ There have also been some attempts to provide training for health care professionals in cultural diversity, but little appears to have been done to provide a professional interpreter service. Luke suggests that delay to the implementation of policy is explained by the fact that 'Institutions work insidiously to shape people's thoughts, perceptions such that they accept their role in the existing order of things, either because they can see or imagine no alternative to it or because they see it as natural and unchangeable'.⁴⁰

What constitutes an interpreter?

To understand the term interpreter requires some clarification. Translators or interpreters are often used when individuals do not share a common language. However, there is often more than language to consider as 'translation is by its very nature a rendering of culture, meaning, and innuendo, as well as literal meaning'; therefore, the process of translation is perhaps better described as interpretation.^{41,44} An interpreter is defined as a person who translates and facilitates communication between persons who are unable to communicate in a common spoken language.⁴²

Effective interpreting therefore relies on the interpreter gaining the trust of both the health care professional and the patient to facilitate accurate assessment of the patient's needs, and ensuring that both the patient and the professional understand each other.⁴³ Threats to the effectiveness of interpretation are complicated by the evidence that different types of interpreters are used in health care settings. These include: professional interpreters, ad hoc interpreters, bilingual health workers, friends, relatives and untrained volunteers.^{6,29,34,46,47}

Effective interpreter services could provide a way for non-English-speaking patients to find out their diagnosis and could be instrumental for the successful planning and implementation of accurate and reproducible radiotherapy for these patients.⁷ Fieler et al. reported that important aspects of the radiotherapy process are frequently misunderstood when English is the first language of both patient and practitioner; therefore, the

number of misunderstandings may well increase if there is no common language between practitioner and patient.⁴⁸

Although technological advances have been reported in the field of interpreting such as provision of telephone language lines, video teleconferencing and remote simultaneous interpretation (common in the diplomatic arena of international business), there is no evidence of this technology used for interpretation services in health care.⁴⁹

Professional interpreters

Professional interpreters should be trained and experienced, fluent in both English and the patient's mother tongue; they must understand medical terminology and should have been well briefed by health care professionals about the treatment objectives.⁵⁰

There may be issues for the NHS surrounding the cost of employing professional interpreters; however, in terms of resources, it has been reported to be more cost-effective in the long term as they not only facilitate the understanding of patients' problems but also increase the use of clinical and preventative services.⁵¹

One US study demonstrated that provision of professional interpreter services increased the delivery of health care, as more people obtained access to services.⁴⁶ However, in this particular study the number of participants in the limited English-speaking group was small (380), compared to those in the English-speaking group (4119), which may have affected the validity of the findings. Nevertheless, improved user satisfaction has been shown in other studies where professional interpreters are used such as Estevan et al.'s study set in a paediatric department.⁴⁷ However, Sheets et al. argue that even in situations where professional interpreters are used errors in translation may still occur due to the difference in dialects, and precise translations of medical terms may be meaningless to the speakers of other languages.⁵²

Ad hoc or informal interpreters

Using family members to interpret is the most frequently used option in health care settings.³⁴

Relatives are often readily available; their presence may put the patient at ease and they are cost-effective.⁴⁹ However, although relatives may be able to speak both languages, they may not know how to interpret; poor translation may lead to misunderstandings, wrong diagnosis and low compliance with treatments.^{41,42} Using family or friends to interpret breaches the patient's right to confidentiality. Relatives may also filter information where the information sought was sensitive or personal,⁵⁴ thereby causing difficulties in obtaining informed consent.³⁶

Rhodes showed that some patients preferred using their children to translate even when an interpreter was available.³⁰ Practices such as these lead to the information becoming filtered, subsequently there is poor understanding that in turn is linked to low adherence to treatment.³⁰ These views are supported by others.^{41,53,45,29,46} Using a child in particular increases the likelihood of misinterpretation, as interpretation is subject to the child's linguistic limitations.⁴⁹

Using a relative, especially using a child, to translate can lead to a change in the balance of power in families as exchange of roles may occur.⁴⁹ The relative who is translating may be at greater risk of stress when in potentially 'emotionally charged situations'.⁵⁴ Despite these findings, Bischoff et al. reported that 75% of physicians thought that family and friends would 'do well' as interpreters and only half of them found it problematic to use children.³⁴

Occasionally, non-health care staff may be used as interpreters, which can also breach confidentiality as often patient and interpreter may be from the same community and untrained interpreters are not bound by any code of conduct whereas many professional interpreters are.^{6,41} Ineffective translation is a risk when using ad hoc interpreters, as there may be a lack of understanding of the medical terminology or significance of the information they are translating,^{49,53} since they have no formal training or testing of fluency.⁴⁷

Sometimes ad hoc interpreters may act independently, ignoring the role of the health care professional and the patient;³⁰ this can result in

omission of information, addition of information and poor interpretation.⁵⁵ Errors may occur with legal implications if the patient does not receive all the information or the correct information.⁴¹

THE IMPORTANCE OF COMMUNICATION AND INFORMATION IN RADIOTHERAPY

Good communication and information are essential in radiotherapy so that not only the patient can give informed consent³ but also patients are better able to cope with stress, anxiety and the side effects of their treatment.^{56,4} The Calman Hine report stated that 'Patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards'.⁵⁷

Evidence shows that patients want to know about the side effects of treatment, but sometimes feel they do not have enough information. Hammicks' small qualitative study of 30 patients in 1998 concluded that this group were satisfied with the information given,⁵⁶ but of concern are the other studies revealing that patients sometimes feel that they take no part in the decision-making process.^{49,58,59} Graydon's study based on 70 participants found that information needs were highest in those 23 patients having radiotherapy compared to those having other forms of therapy.⁵⁸ These findings are supported by others.^{60,61}

Communication is a central aspect to health care, and cultural competence is seen as an important aspect in caring for many non-English-speaking patients.⁶² Cultural competence is described as a process whereby health care professionals work within the cultural context of an individual or community from a background that is different to theirs.⁶³ It has been cited as a critical issue of communication for both the health care professional and the patient to have a cultural knowledge of each other.⁶⁴ Hammick suggests that 'respect for the different cultural and

spiritual backgrounds of our patients is as much part of the professional practice of therapeutic radiography as giving accurate and reproducible radiotherapy'.²⁵

The mode by which information is given is also important. Bakker's study of 210 radiotherapy patients showed that written information was felt to be very beneficial to them,¹ although often written information has only been given as standard to English-speaking patients.⁷ Additional information in the form of audiotapes has also achieved positive effects in subjective understanding.⁶⁵

The timing of information-giving is also key. D'Haese et al.'s study of 68 radiotherapy patients revealed that if information was given simultaneously, patients were more anxious than if it was given in a stepwise fashion over a period of time.⁶⁶ However, one limitation of this study was lack of a no-intervention control group.

DISCUSSION AND CONCLUSION

The literature has shown that language is a significant barrier to communication for non-English-speaking patients, which can prevent them from accessing health care, making informed choices about their treatments or even participating in clinical trials.²⁸⁻³⁰

Professional interpreters appear to be more widely used in health care services in the USA⁶² compared to the UK, where lack of interpreters and cost to the NHS appear to be prohibitive combined with no clearly agreed protocol for their use.²⁸ Many studies have highlighted the use of professional interpreters as a gold standard, because they are trained to interpret what is being said and are aware of cultural issues and work within a code of conduct to respect patient confidentiality.^{34,47,51} It is therefore ethical to use professional interpreters in order for patients to receive the best standard of care.

The most common practice reported in the literature is the use of ad hoc interpreters,⁴ usually members of the patient's family, which

can have impact on family relationships and dynamics.^{41,42,46,49} Information can be compromised or altered, and patient confidentiality can be threatened.⁵³ If there is a poor grasp of the interpreter's own English, the translation becomes ineffective. Sometimes it becomes difficult for the health care professional to know whether it is the patient or interpreter who is speaking, as there is no way of evaluating exactly what is being translated.²⁵

There is limited literature available directly related to non-English-speaking radiotherapy users in the UK, but there are some reports of good practice in place for English-speaking patients.^{7,4} Nevertheless, there needs to be a more thorough evaluation of English-speaking patients' understanding of the information given to them.²² The mode and timing of information-giving needs more consideration.

The most important ethical principle of patient information is the autonomy of the patient consisting of free will, the ability to communicate, speak and make decisions, as a precondition for informed consent.³ Radiotherapy is a complex treatment, often accompanied by anxiety and stress for the patient.¹ Information and the ability to communicate with health care professionals are essential so that feelings of anxiety and stress can be overcome.^{4,56}

Not only is informed consent a legal requirement for radiotherapy treatment but is also an ethical issue for patients to have enough information to make an informed decision.^{3,5,21,26} Although there is lack of clarity in the legal area of gaining informed consent from patients who have limited or no English, informed consent can only be possible if patients can comprehend verbal information given to them by health care professionals and have written information available in a language they can understand.^{5,25,26}

RECOMMENDATIONS

Good practice of communication should be adopted for both English- and non-English-speaking patients; also consideration should be

given to the mode and timing of information-giving.

There needs to be further research involving non-English-speaking patients and users of the service, particularly in respect of information-giving and receiving. There is a particular need to investigate the non-English-speaking needs of patients receiving radiotherapy, as there is little research in this area.

There needs to be an assessment of when formal interpreter services are needed in the NHS and especially in respect of gaining informed consent for radiotherapy, so that patients are offered equal information-giving service regardless of their ability to speak and understand English.

There needs to be further investigation of the use of technology for the purpose of interpretation in health care settings.

Further studies should be performed to establish the reasons why non-English-speaking patients and those from ethnic minorities are mainly excluded from clinical trials.

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