Involvement of Rabbinic and communal authorities in decision-making by haredi Jews in the UK with breast cancer: An interpretative phenomenological analysis

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A B S T R A C T

This paper examines how Rabbinic and communal authorities participated in treatment decisions made by a group of strictly orthodox haredi Jews with breast cancer living in London. Semi-structured interviews were conducted with five haredi breast cancer patients. The transcripts were analysed using interpretative phenomenological analysis. Demographic and personal data were collected using structured questionnaires. All participants sought Rabbinic involvement, with four seeking rulings concerning religious rituals and treatment options. Participants’ motivations were to ensure their actions accorded with Jewish law and hence God’s will. By delegating treatment decisions, decision-making became easier and participants could avoid guilt and blame. They could actively participate in the process by choosing which Rabbi to approach, by providing personal information and by stating their preferences. Attitudes towards Rabbinic involvement were occasionally conflicted. This was related to the understanding that Rabbinic rulings were binding, and occasional doubts that their situation would be correctly interpreted. Three participants consulted the community’s ‘culture broker’ for medical referrals and non-binding advice concerning treatment. Those who consulted the culture broker had to transcend social norms restricting unnecessary contact between men and women. Hence, some participants described talking to him as uncomfortable. Other concerns related to confidentiality.

By consulting Rabbinic authorities, haredi cancer patients participated in a socially sanctioned method of decision-making continuous with their religious values. Imposing meaning on their illness in this way may be associated with positive psychological adjustment. Rabbinic and communal figures may endorse therapeutic recommendations and make religious and cultural issues comprehensible to clinicians, and as such healthcare practitioners may benefit from this involvement.

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Introduction

Religious coping in illness

Coping is a search for significance in times of stress (Pargament, 1997) consisting of cognitive and behavioural efforts to manage specific demands (Lazarus, 1993). Whilst
not all coping during serious illness is religious in nature, religious coping during illness is commonplace; up to 85% of patients use religious resources in their coping (Thuné-Boyle, Stygall, Keshtani, & Newman, 2006). Amongst cancer patients, religion is frequently cited as a source of support (Dein & Stygall, 1997; Koffman, Morgan, Edmonds, Speck, & Higginson, 2008; Stefanek, Green McDonald, & Hess, 2005).

Despite the proliferation of research into religious coping during illness, there is conceptual confusion concerning ‘religion’ (Stefanek et al., 2005). In this paper ‘religion’ refers to an organised system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent that is defined as God, a higher power, or ultimate truth or reality (Koenig, McCulloch, & Larson, 2001). Authors have used diverse methods to examine religious involvement during illness (Hill & Pargament, 2003; Stefanek et al., 2005) resulting in a wide variety of definitions of religious coping that include turning to religion (Stanton, Danoff-Burg, & Huggins, 2002), reliance on religious beliefs (Ebright & Lyon, 2002; Holland et al., 1999), and religious problem-solving (Nairn & Meralzzi, 2003). Religious activities that patients undertake during illness include service attendance (Alferi, Culver, Arena, & Antoni, 1999; Musick, Koenig, Hays, & Cohen, 1998), prayer (Moschella, Pressman, Pressman, & Weissman, 1997; Spilka, Spangler, & Nelson, 1983), viewing or listening to religious television and radio programmes (Musick et al., 1998), and giving religious explanations for their illness (Koffman et al., 2008). However, methodological limitations mean it is frequently difficult to disentangle participants’ normal religious behaviour from activities specifically carried out as a result of illness (Thuné-Boyle et al., 2006). Further criticism concerning authors’ definitions of religious activities is raised by Thuné-Boyle et al. (2006) who observe, for example, that prayer is an inexact descriptor indicating neither contents nor purpose of prayer: prayers may serve different roles during illness (e.g. praying for strength, praying for forgiveness) potentially with different psychological outcomes for the patient.

Religious coping may confer benefits, providing a source of strength and helping patients to adjust (Stefanek et al., 2005; Thuné-Boyle et al., 2006). Strong religious belief in cancer patients is associated with decreased levels of pain, anxiety and higher levels of satisfaction with life (Dein & Stygall, 1997). However, other research indicates that religious coping may have harmful effects, including increased distress and anxiety, and decreased emotional well-being and adjustment (Stefanek et al., 2005; Thuné-Boyle et al., 2006). Elsewhere authors report no relationship between religious coping and adjustment (Dein & Stygall, 1997; Stefanek et al., 2005). Hill and Pargament (2003) interpret such mixed findings to suggest that religious struggles represent a crossroads leading to positive or negative effects.

**Participation of religious figures in patients’ coping**

Religious figures have a recognised role in healthcare and chaplains frequently are members of multidisciplinary teams in oncology and palliative care (Puchalski, Lunsford, Harris, & Miller, 2006; Strang & Strang, 2006). Patients approach chaplains for many reasons including religious support, for example through prayer and religious ritual (Flannelly, Weaver, & Handzo, 2007; Wright, 2001). Patients discussed religious issues including the nature of God and the afterlife, suffering and other existential issues (Strang & Strang, 2002; Wright, 2001). Patients asked chaplains for psychosocial support concerning family and relationships (Kernohan, Waldron, McAfee, Cochrane, & Hanson, 2007; Strang & Strang, 2002; Wright, 2001), unresolved issues (Kernohan et al., 2007), and preparation for death (Kernohan et al., 2007; Wright, 2001). Finally, patients approached chaplains to discuss diagnosis, prognosis and symptoms, particularly pain (Carey, Newell, & Rumbold, 2006; Strang & Strang, 2002; Wright, 2001). Patients value interactions with clergy, reporting that pastoral visits help maintain hope and optimism (Johnson & Spilka, 1991), provide an opportunity to think, and allow them to express feelings without being judged (Kernohan et al., 2007).

**Haredi Jews: religious and cultural characteristics**

Religious divisions within Judaism can be understood in terms of a spectrum of outlook ranging from the secular to the strictly orthodox. Jewish orthodoxy is measurable according to two criteria: the extent to which adherents view religious laws as God-given and unchangeable, and the degree of adherents’ immersion in the values and activities of the secular world.

Haredi (literally, ‘one who trembles’) Jews are strictly orthodox. Central to haredi belief is the Halacha (literally, ‘the way’); the corpus of Jewish law regulating all aspects of behaviour for orthodox Jews. Haredi Jews believe that the Halacha is of Divine origin and its observance obligatory. Matters covered include religious ritual, tort, ethical requirements and, in line with medical advances, medical Halacha is a continually developing specialised area (Bleich, 1998). Rabbinic authorities establish and maintain guidelines for behaviour, issuing general public statements and personal responses answering individual questions. Hence, haredi Jews aim to ensure that their behaviour accords with Halacha, and hence with God’s will.

Haredi life is structured around strict religious obligations including observance of the Sabbath, festivals and dietary laws, modesty in behaviour and dress, separation of men and women in public domains, and, for men, ongoing religious study and thrice daily prayer. Many features of the secular world are perceived as detracting from God’s sanctity and haredi Jews live in tightly-knit communities functioning in self-imposed cultural insularity.

**Religious coping by haredi patients**

Most research into religious coping has taken place in North America in predominantly Protestant Christian populations (Hill & Pargament, 2003). It is unclear to what extent such research relates to patients in other countries (Thuné-Boyle et al., 2006) or from other religious groups (Dein & Stygall, 1997). Few studies have examined healthcare behaviours and illness coping mechanisms among haredi Jews. These studies show that haredi Jews use...
Religion in several ways. Several report that haredi patients offer religious explanations for their health problems: Goddard and Helmreich (2004) found that participants held religiously deterministic views of illness whilst Goodman (2001) reports that psychiatric patients offered religious and mystical accounts to comprehend their illness. Coleman, Koffman, and Daniels (2007) found that cancer patients perceived their cancer as coming from God as a personal test and part of a pre-determined and meaningful plan. Patients also reframed distress in religious terms gaining comfort and encouragement. Hence, patients undergoing fertility treatment contextualised their experiences within a framework where Biblical figures have suffered similarly (Kahn, 1998). Mothers of children with autism constructed positive religious interpretations where their children’s disabilities signified that the children had a pure soul (Bilu & Goodman, 1997; Shaked, 2005). However, religious interpretations are not always positive. Mark and Roberts (1994) report that the spiritual impact of cancer could be destabilising: patients conceptualised their cancer in terms of punishment, abandonment, anger at God, and being subjected to spiritual testing. Further they observed that certain interpretations may be socially unacceptable, particularly those suggesting a lacking in one’s belief in God’s benevolence. Religion was also used as a direct source of healing: Shaked and Bilu (2006) found that mothers of autistic children sought healing for their children through prayers and blessings. Kahn (1998) found that patients sought to change their circumstances by participating in tehillim groups: tehillim (Psalms) are recited as an appeal for Divine intervention in times of distress. Patients also used religion to assist them during treatment uncertainty: patients undergoing fertility treatment attributed success to God thereby helping them avoid feelings of guilt should treatment fail (Kahn, 1998).

Rabbinic involvement in haredi patients’ coping

Rabbinic involvement in haredi patients’ coping has not been the direct subject of research. However, several studies conducted in Israel or the USA report Rabbinic involvement as a finding. Rabbis were approached for psychiatric referrals (Goodman & Witztum, 2002) and for medical referrals by cancer patients (Mark & Roberts, 1994), osteoporosis patients (Goddard & Helmreich, 2004), and patients undergoing fertility treatment (Kahn, 1998). Similarly, advice regarding treatment was requested by parents of children with autism (Shaked & Bilu, 2006), patients undergoing fertility treatment (Kahn, 1998), patients with eating disorders (Dancyger et al., 2002), and obsessive compulsive disorder (Greenberg & Shefler, 2002), and those receiving genetic counselling (Mittman, Bowie, & Maman, 2007).

These findings are interesting because they do not correspond to results from studies examining contact between religious figures and patients from the wider population: haredi patients have different reasons for approaching religious figures. Flannelly et al. (2007), in their study of chaplains’ activities in an oncology centre in New York, note that Catholic patients are likely to expect a different type of contact from a Catholic priest, specifically ritual activity, than from non-Catholic clergy. This suggests that pastoral intervention may vary according to the religious group to which chaplain and patient are affiliated, with interventions reflecting the practices that are normative to that group. Similarly, Pargament (1997) notes that religious membership may predict different types of religious coping strategies. Haredi Judaism emphasises comprehensive orthopraxis as well as orthodoxy. This may mean that Rabbinic contacts with haredi cancer patients could be anticipated to include activities that patients from other religious groups would not expect of their clergy.

In light of this we conducted an in-depth cross-sectional qualitative study investigating the interface between Rabbinic and communal authorities and haredi breast cancer patients in London. The study aimed to examine whether and to what extent Rabbinic and communal authorities participated in treatment decisions. The research reported here is from a wider study investigating healthcare behaviours and beliefs of haredi breast cancer patients (Coleman, 2007; Coleman, in press; Coleman et al., 2007).

Haredi communities in London

Of the 169,000 Jews living in London an estimated 12% (approximately 20,000) is haredi (Carlowe et al., 2003). This number is rapidly increasing (Holman & Holman, 2002); a trend characteristic of haredi communities worldwide, including Israel and the USA (Dellapergolla, 2001). This reflects a high birth rate (Carlowe et al., 2003) and the fact that comparatively few leave the community (Greenberg & Witztum, 2001). The rapid growth rate contrasts with other sections of the Jewish community outside Israel, where numbers are diminishing. Contributing factors include emigration, low birth rate, and intermarriage (Vallins, 2002). As the number of haredi Jews increases in absolute terms and as a proportion of the Jewish population, their healthcare needs will assume greater significance both for mainstream healthcare providers and for healthcare organisations based within the Jewish community. Greater understanding of how haredi patients approach treatment decisions may facilitate the provision of culturally sensitive care.

Methods

This descriptive cross-sectional in-depth interview study used qualitative methods to investigate an under-researched area (Ritchie, 2003). Five haredi Ashkenazi breast cancer patients fluent in English were recruited between July and September 2005. Although the number of participants is relatively small, it is consistent with the methodological literature concerning qualitative research involving interpretative phenomenological analysis (IPA) (Smith, 1996; Smith, Jarman, & Osborn, 1999). The aim of IPA is to examine in great detail a small highly homogeneous sample as a series of in-depth case studies followed by comparison across cases. This intensity of analysis precludes large sample sizes. Whilst IPA does not aim to
Data collection

The first author (KC-B) conducted a semi-structured tape-recorded interview lasting between 45 and 90 min with each participant in their home. The interview guide was used flexibly, enabling participants to raise issues they considered relevant (Smith et al., 1999).

To maximise content validity, an advisory panel of orthodox Jewish healthcare and communal professionals (n = 9) assisted in devising the interview guide. Panel members were recruited on the basis of their professional involvement in providing cancer care and palliative care to haredi communities. Members included physicians and non-clinicians (three Rabbis and one culture broker). The guide was drawn up using a Delphi technique (Linstone & Turoff, 1975). This consensual-building tool collects and distils information from a group of experts through three phases: obtaining individual contributions; assessment of the group view; and opportunity for contributors to revise their views until consensus is reached.

The questions on the interview guide concerned:

- participants’ information needs;
- which issues would be important when considering medical treatment if the prognosis was terminal;
- which participants had spoken to about their cancer and the issues they had discussed;
- how participants believed their community perceived cancer patients;
- whether participants had made sense of having cancer.

Demographic data and other personal information were collected using self-completion structured questionnaires.

Data analysis

The interviews were transcribed verbatim and anonymised using pseudonyms. The transcripts were analysed using IPA (Smith, 1996; Smith et al., 1999). IPA involves the systematic qualitative analysis of verbatim transcripts from semi-structured interviews in an attempt “to explore the participant’s view of the world and to understand, as far as possible, an ‘insider’s perspective’ of the phenomenon under study” (Smith, 1996, p. 264). IPA entails an idiographic approach, beginning with individual cases and particular examples and then moving to general categorisations applicable to the entire group. Analysis of each transcript involves preliminary reading, initial analysis, higher-level abstraction, clustering and categorisation, and production of a master list of themes. Finally, a consolidated master list of themes is produced for the group of transcripts as a whole. Emergent themes may correspond to interview questions, whilst others may arise spontaneously. Considerations when selecting themes include the richness of the associated evidence and how far they illuminate other aspects of the narrative. An orthodox Jewish researcher familiar with IPA and otherwise unconnected with the study conducted an independent audit by reviewing each transcript, the corresponding initial analysis and the higher-level abstraction. Differences of opinion were discussed until consensus was achieved.

Results

Personal and demographic details

Participants were aged between 39 and 58 years, with a mean of 50 years. Date of diagnosis ranged from 1998 to the end of 2004; four were diagnosed during 2004. Three women were diagnosed after discovering a lump and one was diagnosed from a mammogram. Participants lived in the haredi communities of Stamford Hill, North London (n = 3) and North West London (n = 2). All participants were married and each had between five and nine children (mean = 7).

Involvement of Rabbinic authorities

Participants were asked whether they had consulted a Rabbi concerning their illness and treatment. All had approached a Rabbi, and four had asked shailohs – questions put to a Rabbi for determination of a point of Jewish law. Gitti, who had not asked any shailohs, had approached her Rabbi for spiritual and emotional support. Participants raised several issues: the advantages of asking a shailoh, Rabbinic judgements as exclusive and binding, choosing the ‘right’ Rabbi, and situations when participants felt conflicted about Rabbinic involvement. Whilst these issues were of common concern, participants occasionally expressed varying attitudes.

Advantages of asking a shailoh

Leah typified participants’ attitudes when she described the advantages of asking a shailoh. She explained that the strength of this approach was that by acting according to
Rabbinic judgement, a person knew they were acting with 'Daas Torah' (literally, 'wisdom of the Torah'), i.e. according to the Torah and God's word. She saw distinct advantages in requesting Rabbinic rulings when making decisions. By delegating the decision, decision-making became easier. Allowing the Rabbi to decide also meant that the individual could escape feeling guilt and blame:\footnote{1 In the interview excerpts that follow, italics denote emphasis. Dots within a quotation indicate a pause in speech. Material in square brackets \([\] \) has been added by the authors for the purpose of clarification. Three dots within square brackets \(\ldots\) \) indicates where non-relevant material has been omitted to save space and aid coherence.}

“If you ask a Rabbi… and a Rabbi tells you… don’t take any more treatment… or do take more treatment… the patient that is in this situation [...] she won’t blame herself.” (Leah)

However, she distinguished these secondary benefits from the main reason for asking a shailoh, which is that one wishes to act according to God’s will:

“... you don’t do it for not blaming yourself... You don’t do it for that reason... But the outcome is it is easier for the family. It is easier to make a decision when you have asked... You have to believe for that... If you’re not like this then... you won’t do it. Because you’ll think why should he decide for me?” (Leah)

Exclusive and binding

All participants understood Rabbinic judgements as exclusive and binding; once a question had been asked, the Rabbi’s ruling had to be followed, with no possibility of a second opinion. Nechama explained:

“You cannot go to different Rabbis you know. You can’t hear it from one person and say well it’s not what I want to hear I’ll go to someone else [...] you’re supposed to choose one Rabbi.” (Nechama)

Nechama described that answers could contradict one’s expectations. This unpredictability, coupled with the binding nature of the answer, meant that asking a shailoh could be hazardous.

Ruthie discussed her strategy when she did not like the answer. In these situations, she asked other religious authorities to help her clarify and accept the answer. An influential figure she often approached was her mashpiah, or spiritual mentor. She explained that a mashpiah is “somebody who you admire, who you would like to emulate”, who you ask for advice. Another time, she had approached a Dayan (Rabbinic judge) when she did not understand the Rabbi’s answer:

“I said I’ve asked a question, I don’t understand the answer. I know I’m not allowed to ask again, but I’m asking is if you can check with him and clarify what the... answer is...” (Ruthie)

No participant suggested that ignoring a Rabbi's answer or asking a second Rabbi were options. Ruthie described her attempts to influence Rabbinic rulings. This involved explaining, when asking the question, the answers she would find easier to accept. She preferred to do this via the Rabbi’s wife:

“Sometimes I’ve asked through their wives...... cos it’s easier.... Because then... you can say... how you feel... So you can say, I know I have to ask this question, I really would like the answer to be... this way or that way...... I’ll need convincing if it’s the other way... And then [...] you might not want to say that to... to the Rabbi directly. If you say that to their wife and their wife can have a little chat with them [...] because they do answer [...] for the person quite, quite often... But they can’t... answer for the person that doesn’t explain themselves to start with.” (Ruthie)

Other participants considered avoiding all uncertainty and risk by refraining from asking a shailoh at all (see below).

Choice of Rabbi

Participants were asked how they chose which Rabbi to ask. This was an important issue to all the women. Their answers showed that they valued different qualities in a Rabbi. It was important to Leah that the Rabbi interpreted the Torah accurately. Similarly, Nechama considered it important that the Rabbi was expert in Jewish law. However for Ruthie, a personal relationship with the Rabbi was paramount. She explained that Rabbis adopted a holistic approach and provided answers suitable for each individual’s particular situation. Without a personal relationship, the Rabbi would be unable to consider all aspects of the individual’s circumstances.

Whether to ask

Participants expressed different attitudes concerning when to involve a Rabbi: Gitti had not asked any shailohs, explaining that she saw no reason to because she knew what to do and was clear about permitted and forbidden acts in Jewish law. By contrast, Ruthie frequently approached her Rabbi. Nechama and Devorah were each occasionally conflicted over Rabbinic involvement; Nechama partly because she was uncertain of who to ask, Devorah because she was concerned that answers might not be in her best interests.

Nechama was resolute that she would request Rabbinic involvement when making treatment decisions. However, she had previously refrained from asking a question concerning the timing of her surgery, which had been scheduled on a Jewish religious festival when there are constraints on permissible activities. Significantly, Nechama hypothesized that had she done so, the answer would have supported her decision, which had been to have the surgery on schedule. Hence, she simultaneously justified her decision, affirmed her belief in the correctness of involving a Rabbi, and excused her decision not to ask a shailoh:

“I am sure any question I would have asked would have told me to have had the operation done immediately. You know there’s no... question as to what comes first so I opted for... although usually one asks a question but...
it was serious enough to even have necessitated being done on a holiday. Obviously.” (Nechama)

Nechama’s future use of Rabbinic authorities was uncertain since the Rabbi she used to ask was deceased. It was important to her that answers were grounded in Halachic expertise and she had felt secure approaching him because his reputation meant he could easily consult other Rabbinic experts when necessary. Now she felt discomfort about the prospect of asking shailohs. She mentioned Rabbinic experts when necessary. Now she felt discomfort because his reputation meant he could easily consult other Halachic expertise and she had felt secure approaching him was important to her that answers were grounded in requested rulings on matters of religious ritual arising from afraid she would be obligated to follow a ruling that might one hand, it was important that her actions accorded with beliefs about Rabbinic involvement were conflicted. On the ward in asking the relevant questions. In other ways, her

In matters of religious ritual, Devorah was straightforward in asking the relevant questions. In other ways, her beliefs about Rabbinic involvement were conflicted. On the one hand, it was important that her actions accorded with Jewish law. Hence, consulting a Rabbi was important. Yet there could be questions that strictly speaking she ought to ask, but that she might not want to ask, because she was afraid she would be obligated to follow a ruling that might not be in her best interests:

“Cos I suppose sometimes it’s better to stay in ignorant bliss. And yes you know as a [religious] woman I would want to do everything according to the Torah. But unless it was something that was put to me that was really against the Torah… Then I suppose I would ask for sure. But if it was something that was put to me and… to save my life I'm talking about […] perhaps I wouldn't want to ask a Rabbi” (Devorah)

Devorah believed that some potentially life-saving treatments could be forbidden to her according to Jewish law. Although it was important to follow the Torah’s commandments, she might not want to risk receiving an answer that would prohibit her from undergoing potentially life-saving treatment. Things were further complicated by doubts that her situation could be understood by someone who had not experienced cancer.

Involving the culture broker

Three participants consulted the community’s culture broker, Mr. Y, variously asking him to recommend an oncologist, to provide reassurance concerning a doctor’s competence, and which course of treatment to take. All three demonstrated high levels of trust and faith in his knowledge. Unlike Rabbinic rulings, a culture broker’s answers are not binding. However, one participant still felt unease at ignoring his advice and following someone else’s.

Gitti had asked Mr. Y to recommend an oncologist in preference to arranging a referral through her GP. She valued medical expertise and appreciated Mr. Y’s assurances that her physicians were excellent, particularly because she did not like her doctors, finding them rude and abrupt. Leah had also approached Mr. Y for reassurance that her doctor was competent. She explained:

“Because I felt that probably he would know. Because he knows so many doctors. He would know if this doctor is maybe a good doctor or not.” (Leah)

Devorah approached Mr. Y twice. The first time her Rabbi referred her to him concerning whether she should have a lumpectomy or a mastectomy. She had followed Mr. Y’s advice and had elected for a mastectomy. The second time concerned whether she should participate in a clinical trial. This time she had not followed his advice and had instead followed the opinion of someone else in the community. Interestingly, Devorah felt uncomfortable about approaching someone else after consulting Mr. Y, likening this to putting the same question to more than one Rabbi:

“I did feel a bit naughty kind of asking two people. Cos you certainly wouldn’t go to a Dayan [Rabbinic judge] and ask a shailoh and not like his answer and then go to another one…” (Devorah)

Interestingly, Leah conceptualised medical training and competence in the same way that haredi Jews understand Rabbinic training. She described how Mr. Y had assured her of her surgeon’s competence:

“You see [Mr. Y] told me that… Ms X [Leah’s surgeon] learned under Mr. B. Now I know Mr. B from… something totally different. But Mr. B was… one of the greatest in Hospital A at the time […].” (Leah)

When considering Rabbinic competence, it is important to know a Rabbi’s ‘pedigree’ including which yeshiva (institution for religious studies) he studied in, or ‘learned in’ to use haredi terminology, and which Rabbi ordained him. Competence is in part assured by virtue of whom the Rabbi trained under (‘learned under’). Leah felt reassured when Mr. Y said that her surgeon Ms X ‘learned under’ Mr. B. She had independent knowledge that Mr. B is an excellent doctor and consequently felt more confident in Ms X’s abilities. Nechama also conceptualised medical competence this way saying of a particular doctor that he was “a talmid [student]. The one doctor learned under this consultant and he went with this consultant.” A more junior Rabbi is expected to issue rulings consistent with those issued by the Rabbi he was ordained by. Similarly, Nechama expected the doctor to recommend treatment according to how the consultant he trained under would.

Social norms and privacy

Although participants felt they had benefited from talking to Mr. Y, the experience was not without difficulty.
Talking to him contradicted usual social norms where men and women minimise their interactions, whilst the preference for privacy could limit the desire to involve him.

“Being a woman and the nature of the cancer it was... a bit uncomfortable as well. [...] Talking about one’s bosom... you know is one thing. But to talk about it [...] with a religious man sitting there that normally in the street you know, pass you like that (gestures with her hands demonstrating two people ignoring each other as they pass).” (Deborah)

Talking to Mr. Y required Deborah to disregard usual haredi behavioural codes. For example, a man and a woman who are unrelated will not interact socially or even make eye contact. The intimate location of her cancer increased her discomfort. Leah also discussed the incongruity of discussing matters such as breast reconstruction with an extremely religious man. Gitti had asked her husband to make initial contact with Mr. Y. This may have been due to her emotional vulnerability post-diagnosis. However, it is possible that these deeply ingrained codes of behaviour played a part.

Mr. Y, in his role as culture broker, occupies a central position in the London haredi community. Leah described how “everybody phones him” and that he knows “anything that’s happening in this community.” Leah expressed a strong need for privacy and this may have influenced her decision to have minimal contact with him.

Discussion

This is the first study conducted in the UK examining the involvement of Rabbinic authorities and communal figures in medical decision-making among haredi cancer patients. The study found that when making treatment decisions, participants generally involved Rabbis. In so doing, participants were strongly influenced by a wish to act according to God’s will. The process of deciding whether to involve a Rabbi in a particular decision was complex and participants were sometimes conflicted. Reasons for this included uncertainty regarding the Rabbi’s expertise, and concerns that their situation would not be adequately understood. The binding nature of Rabbinic rulings meant that seeking Rabbinic opinion was seen as potentially hazardous. Participants also approached the culture broker regarding different issues including referrals, treatment options, and reassurance concerning physician competence. Those who consulted the culture broker were required to transcend social norms restricting unnecessary contact between men and women. This meant that some participants felt uncomfortable talking to him. Other concerns related to confidentiality.

Decision-making roles and responsibilities

Opinions differ concerning patients’ optimum role in decision-making concerning treatment. Charles, Gafni, and Whelan (1999) analyse the processes of information exchange and deliberation involved in different models of decision-making: the shared, physician-as-agent, and paternalistic models. In the paternalistic model the physician dominates both information exchange and deliberation processes while the patient remains passive. These roles are justified by the physician’s clinical expertise and the assumption that physicians will make the most appropriate treatment decisions for patients. In the physician-as-agent model, the patient participates in information exchange making contributions about their personal history, psychosocial context and treatment preferences. The physician assumes sole responsibility for deliberation, intending to reach the decision the patient would choose were the patient to have the same expertise as the physician. The justification is that physician and patient each possesses knowledge vital to decision-making. As in the paternalistic model, the assumption is that physicians’ expertise renders them most appropriate for the decision-making role. Finally, in common with the physician-as-agent model, the shared decision-making model sees information exchanged in both directions. This time, decisions are negotiated between physician and patient with each expressing treatment preferences. Patient involvement through shared decision-making is a policy aim in the UK (Department of Health, 2004).

Cursory examination of Rabbinic decision-making might suggest that it is paternalistic: the Rabbi assumes full responsibility for making a decision that the patient is bound by. However, the example of Ruthie shows the physician-as-agent model fits more closely: by providing information concerning her personal situation and treatment preferences, Ruthie participated in the exchange of information in a way she believed was meaningful and vital. The justifying assumptions shared by study participants were that personal information is necessary to the decision-making process, and that the Rabbi would make the most appropriate Halachic decision on their behalf because of his technical expertise.

A further point to consider is whether patients decide which physician to consult. Whilst this choice may not be available to some patients, in other situations they may be able to decide who provides treatment. Whether patients play an active or a passive role in this decision impacts on these models of decision-making: a patient who refrains from participating in treatment decision-making having concluded that this physician possesses excellent technical knowledge and will make appropriate treatment decisions on their behalf participates in their care in a different way from the patient who makes decisions concerning neither physician nor treatment. In this study, participants actively chose the Rabbi with the necessary skills to make the best decision on their behalf. Whilst involving a Rabbi in treatment decisions does not conform to the shared model that is the current focus of policy recommendation in the UK, patient involvement remains possible by choosing which Rabbi to approach and by contributing personal information.

Patients’ preferred roles

Whilst research demonstrates that healthy individuals prefer an active role in treatment decision-making in hypothetical situations of ill health, cancer patients generally prefer a more passive role (Beaver, Luker, Owens,
Leinster, & Degner, 1996; Degner & Sloan, 1992). The findings of this study, where haredi breast cancer patients had some involvement in decision-making where deliberation rests entirely with the Rabbi, fit with this research. By refraining from active participation in deliberation, patients may experience relief and avoid regret, with responsibility for treatment failure resting with the physician (Degner & Sloan, 1992; Ubel & Lowenstein, 1997). Participants’ beliefs about the advantages of Rabbinic involvement are consistent with this; whilst the main reason was to ensure that one acted in accordance with God’s will, other advantages were that the patient could avoid feelings of guilt and blame. Individuals operate within a cultural multiplicity (Goodman & Witztum, 2002). This study demonstrates that these diverse cultural spheres are interrelated and not discrete. Hence, activities in one cultural sphere (consulting a Rabbi concerning Jewish law) informed actions performed in another (undertaking medical treatment). A framework of interpretation belonging to one cultural sphere was applied to another to describe and comprehend the expertise and actions of people operating within this second cultural sphere. Hence, participants appropriated the framework used to understand Rabbinic authority and used it to comprehend their physicians’ expertise (“he told me that Ms X learned under Mr. B”) and impose a sense of predictive order on the recommendations they made (“the one doctor learned under this consultant and he went with this consultant”).

A sense of control and continuity of meaning following a cancer diagnosis is associated with positive psychological adjustment (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). In choosing to consult a Rabbi, haredi Jews participate in a religiously and socially sanctioned method of decision-making continuous with their beliefs. By subjecting treatment decisions to these methods of decision-making, haredi patients impose meaning on their illness and on the activities that take place in connection with it. Research is required to determine whether seeking Rabbinic involvement is associated with positive psychological adjustment.

Haredi patients may vary concerning the degree of Rabbinic involvement they desire. Deciding not to ask a shailoh (a question put to a Rabbi for determination of a point of Jewish law) may reflect a general inclination for limited Rabbinic involvement. Alternatively, a decision not to seek Rabbinic involvement may be specific to a particular issue. Whilst such a decision might be grounded in an accurate assessment of the medical and Halachic situation, it could also be based on incomplete or mistaken understanding. For example, Devorah’s fears that some life-saving treatments could be forbidden do not reflect normative interpretations of Jewish Law: all standard medical treatment is permissible to save a life (Sinclair, 2005).

Participants were aware the answer to a shailoh was binding. Hence, delegating a decision to a Rabbi is unlike delegating decisions to other professionals, carrying an element of risk. This perceived risk contributed towards Devorah’s reluctance to ask a shailoh when she believed the “wrong” answer could have negative implications for her survival. Inability or reluctance to ask a shailoh may cause spiritual distress to a person who strives to live within the framework of Halacha. Indeed, Gattellari, Butow, and Tattersall (2001) report that failure to achieve a preferred decision-making role negatively impacts on patients’ emotional well-being.

Research suggests that cancer patients’ preferences for involvement in decision-making change as their disease progresses: patients with more advanced disease tend to prefer a more passive role and to delegate decision-making to others (Beaver et al., 1996; Butow, Maclean, Dunn, Tattersall, & Boyer, 1997; Degner & Sloan, 1992). Haredi patients’ wishes for involvement in decision-making may similarly change and longitudinal studies are required to determine whether there is increased preference for Rabbinic involvement as disease progresses.

The culture broker

Participants also consulted the culture broker regarding treatment decisions. Involving a culture broker offers an advantage over asking a Rabbi a shailoh because a culture broker’s answers are not binding. Indeed, only a Rabbi is able to issue a binding ruling. Hence, patients are free to ignore a culture broker’s advice and remain able to seek additional opinions, options not available to those who ask a Rabbi to provide a ruling concerning Jewish law. Hence, a culture broker can advise those who want guidance from someone knowledgeable and religiously acceptable, yet who do not wish to be bound by Rabbinic judgement. Nevertheless, Devorah felt unease at ignoring the culture broker’s advice and asking someone else drawing parallels with asking a question of more than one Rabbi. Whether similar unease could inhibit a haredi patient from seeking a second opinion from a physician is an interesting question.

Lightman and Shor (2002) report that concerns over confidentiality meant that some members of the haredi community in Toronto decided not to involve a culture broker, despite recognising the benefits of seeking his input. In this study, Leah expressed similar concerns and had limited involvement with Mr. Y. Concerns over confidentiality have also been reported regarding Jewish community-based support groups in London with negative implications for service take-up (Loewenthal & Rogers, 2004). Interestingly, participants did not voice this concern in respect of Rabbinic involvement. Perhaps this is because haredi Jews are accustomed to involving Rabbis concerning a variety of issues. The social norms governing interaction between men and women place restrictions upon unnecessary interaction: asking a Rabbi for determination of a point of Jewish law constitutes necessary interaction and haredi social norms allow for such contact.

Methodological considerations

The findings from this study should be viewed in light of the following methodological considerations. First, the number of participants, although consistent with the method of data analysis, is small. In larger studies the themes identified here could be explored further. Nevertheless, this in-depth study, the first examining these issues in this population, makes an important contribution.
towards understanding the experiences of haredi breast cancer patients. Second, the cross-sectional design did not permit exploration of whether patients’ attitudes and behaviour change over time. There is a place for longitudinal studies to examine this. Third, all participants were known to each other. Despite assurances of confidentiality, participants may have been reluctant to express beliefs that they perceived to be particularly personal or conflicting with normative haredi values. Fourth, interviews took place at home, although participants were free to request an alternative venue. Gunaratnam (2003) observes that conducting interviews at home may impede open communication because the participant may not want traumatic experiences to encroach upon their home territory. Possibly different results would have been obtained had interviews been conducted elsewhere. Notwithstanding these final two considerations, participants were forthcoming and we believe that the findings reflect their experiences and beliefs.

Inter-racial and inter-ethnic research is a focus of methodological concern to researchers (Nazroo, 2006). Assumptions that shared ethnicity facilitates the generation of ‘better’ data mean that arguments are often made for ‘ethnic matching’ between interviewer and interviewee (Grewal & Ritchie, 2006). However, evidence concerning the effects of ethnicity is mixed (Grewal & Ritchie, 2006; Gunaratnam, 2003): whilst shared ethnicity may confer ‘insider’ status and facilitate communication, it can also be detrimental if interviewer or interviewee assumes shared knowledge and adequate explanation of issues is neither requested nor proffered. Fears of being judged may also deter a participant from speaking freely.

Research in haredi communities has used interviewers from the target community (Albert, Harlap, & Caplan, 2004; Cinnirella & Loewenthal, 1999; Holman & Holman, 2002; Loewenthal & Rogers, 2004). However, these studies suggest that haredi Jews are ambivalent about discussing sensitive issues with fellow community members. Typically, they believe that someone who does not share their belief-system will misunderstand them. However, they also express concerns about breaches of confidentiality that may arise from talking to a member of the same community. It has not been reported whether this disquiet leads to bias.

The authors of this paper are orthodox Jews (one of us, JS, is haredi). Generally, we resemble participants in our religious beliefs, and share the same religious and cultural concepts. We differ from participants as their adherence to the laws may be stricter than our own (excepting JS). Additionally, whilst participants avoid the secular world, we move in both secular and religious spheres. Furthermore, the participants and we belong to different social communities. Hence, we are neither insiders, nor complete outsiders. Our hope was that this status would be advantageous. As Jews who share their belief-system, we hoped participants would consider us appreciative of the issues they face with this facilitating communication. As individuals outside their community, we hoped concerns over confidentiality would be reduced. We believe that we were successful in undertaking these in-depth interviews and elicited meaningful accounts of their experiences.

Conclusions

This is the first study exploring the role Rabbis and communal figures play in medical decision-making by haredi cancer patients in the UK. The study adds to the existing literature on religious coping and decision-making, and explores one way that haredi cancer patients use religion to cope during their illness. The results demonstrate that decision-making is most likely not confined to a dyadic interaction between physician and patient; within a larger framework of decision-making Rabbis and the culture broker also have roles.

Although religious figures have a recognised role in both cancer care and palliative care, this most usually consists of the provision of religious, spiritual and psychosocial support (Puchalski et al., 2006; Strang & Strang, 2006). The existing literature concerning care of Jewish patients is unlikely to cover Rabbinic involvement in decision-making or even mention a culture broker. This literature usually describes aspects of Jewish practice that may impact upon delivery of care (Clarfield, Gordon, Markwell, & Alibhai, 2003; Katz, 1996) and Jewish attitudes to hospice and palliative care (Byrne et al., 1991). Therefore, clinicians may be unfamiliar with the type of Rabbinic involvement described here, which is unlike pastoral interventions between patients and clergy from other religious groups (Strang & Strang, 2006; Wright, 2001). To date, no research has investigated clinicians’ reactions to such involvement in the UK. Shuper, Zeharia, Balter-Seri, Steier, and Mimouni (2000) report that the majority of a sample of Israeli paediatricians were open to Rabbinic involvement in decision-making concerning treatment. However, the prevalence of traditional Jewish values in Israeli society and familiarity with Rabbinic authorities mean that these results are unlikely to transfer to non-Israeli clinicians.

Results reported by Lightman and Shor (2002), that social care professionals in Toronto were unwilling to work with culture brokers because of their non-professional status, may transfer more readily to the UK. This study demonstrates that haredi patients are strongly influenced by the treatment decisions their Rabbis make. If Rabbis are to base their decisions on comprehensive understandings of patients’ medical situations, effective communication with the medical team is essential, subject to patient consent. Further research on these points is required.

Clinicians caring for a haredi patient may benefit from the involvement of a Rabbinic or communal figure. Firstly, this involvement may endorse therapeutic recommendations and reframe treatment options in terms religiously understandable and acceptable to the patient (Greenberg & Witztum, 2001). Secondly, this involvement gives clinicians the opportunity to determine whether a patient’s expressed preferences are religiously normative or based on mistaken religious beliefs (Mazanec & Tyler, 2003). For example, a patient may not realise that during serious illness religious obligations may change; activities forbidden to the healthy may be permitted to the ill (Sinclair, 2005). Therefore medical treatment that might appear to violate Jewish law may be unproblematic. Thirdly, a culture broker or Rabbi may make religious and cultural issues comprehensible to healthcare practitioners.

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Research ethics committee approval

King’s College London Research Ethics Committee, reference 03/04-82, granted ethical approval for the study.

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