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## **Brittle words: the impact of health information on patients' compliance with treatment**

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**Brittle Words:**  
**The impact of health information on patients'**  
**compliance with treatment**

**by**

**Andrew D. Hampson, B.A.(Hons.).**

A Master's Dissertation, submitted in partial  
fulfilment of the requirements of the award  
of the Master of Arts degree of the  
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Supervisor: Janet Rolinson, B.A.(Hons.), M.H.S.M., Dip.H.S.M.  
Department of Information and Library Studies

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## ABSTRACT

There are numerous benefits associated with the provision of consumer health information. Recent government policy has identified health information as pivotal in order to affect behavioural changes in the lifestyles of individuals and increase compliance with recommended treatments. A study was undertaken to investigate the impact of health information on patients' compliance with treatment for postmenopausal osteoporosis.

Seventy women attending a menopause clinic based in a Letchworth general practice were surveyed, using a postal questionnaire and open-ended standardised interviews. There was a high level of satisfaction with the health information provided within the general practice setting. Health information had a positive effect on patients' compliance with treatment, enabling patients to improve their understanding of their condition and to follow instructions for prescribed drugs. A wide range of information sources were accessed beyond the general practice setting, although the newly established consumer health lines and information centres were consulted by only 3-5% of the sample population. However, the knowledge patients acquired from such external sources would always be discussed with health professionals in the general practice setting before a change in behaviour was implemented.

The general practitioner and menopause clinic nurse were identified as the most influential sources of health information affecting patients' compliance with treatment. Nevertheless, patients considered that written health information aided compliance with treatment, as they could refer to it in their own time without restrictions. It supplemented and reinforced the knowledge conveyed by health professionals.

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## INTRODUCTION

Consumer health information has expanded rapidly over the past ten years(1). This has been largely due to a shift in government policy, heralded by the NHS review in 1989, which highlighted the central role of information. The White Paper *Working for patients*(2) recommended that information for patients should be improved, and in 1991 *The Patient's Charter* defined the right

to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment.(3)

The White Paper *The Health of the Nation*(4), published in 1992, defined information as central to achieving targets for reducing the incidents of ill health. Health information was seen as pivotal in order to affect behavioural changes in the lifestyles of individuals; increase compliance with recommended treatments; and increase the take-up rate and participation in screening programmes.

The multiple benefits of providing health information to patients have been noted. Ley(5) suggests that it increases satisfaction with, and participation in, the health care process, thus positively impacting on compliance with treatment. However, the simple equation that participation in health care, enabled by health information, increases compliance with treatment is debatable. Other commentators think more work is needed. Gann has stated that:

The link between consumer health information and health outcome is difficult to measure in a meaningful way but it is an area of research which needs pursuing.(6)

Knight has asserted that:

Health information is necessary on an individual basis to aid compliance with treatment, recovery and in helping to communicate with health care staff...More in-depth evaluation and research is needed.(7)

Health information facilitates patient involvement and participation, which increases satisfaction. It enables individuals to make decisions and enter into discussions with their doctor. However, this means that patients are no longer passive; they have the opportunity and confidence to argue with health professionals. It is possible that health information could prompt non-compliance with treatment as patients access health information sources beyond the general practitioner's surgery. Maslow suggests that this is exactly what is happening, although she does not support her statement with any evidence:

Some women trust their physician and other health care professionals to provide good advice about treatments, but others are suspicious and trust the media reports instead.(8)

This study attempts, in part, to provide evidence for, or against, Maslow's assessment.

The study aims to investigate the impact of health information on patients' compliance with recommended life-style changes and prescribed treatment related to postmenopausal osteoporosis.

The objectives of the study are:

- To establish what sources of health information, related to osteoporosis, have been accessed by women in the sample population.
- To determine whether health information influences patients' compliance with recommended life-style changes and prescribed treatment related to osteoporosis.

Gann(9) has noted that there are over 250 factors relating to compliance. This study has attempted to extract health information from the web of other factors which surround the issue of patient compliance. The sample population consists of two patient groups; one which has severe risk of osteoporosis and the other at minimum risk. This is in recognition of the major impact health beliefs have on patient compliance.

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## **1. CONSUMER HEALTH INFORMATION**

### **1.1 Cultural Upheaval in the National Health Service**

In 1995 it is easy to feel cosy about the seemingly undisputed need and value of consumer health information. Only by looking back over the past ten years, to the unprecedented speed and scale of change within the National Health Service(NHS), can the way in which this movement has taken hold be appreciated. When Gann confidently declared in 1991 that 'informed health care consumerism is now the orthodoxy'(1), he was paying testimony to the extraordinary power of an ideology that seemed to have left paternalism demolished in its wake.

The rise of consumer health information has to be located within the context of a major cultural change that has taken place over the past 15 years, in which the primacy of the individual within society has been asserted. The nature of the relationship between the citizen and the state has shifted from one in which the state assumed a paternalistic role of intervention, to an emphasis on individual choice and greater personal responsibility. The demands of society, fuelled by consumerism and an awareness of individual rights, has led to increased access to information in all areas, including the medical field. Whilst legislation, notably the Data Protection Act 1984 and Access to Health Records Act 1990(2), has gone some way to improving access to health information, government policies have prompted its availability and actively encouraged individuals to seek it out.

It was the NHS review in 1989 that brought information to the centre of policy as a new economic system was introduced, with the purchasing and providing

functions being separated to produce an internal market system. Consumerism was grafted on to the NHS when the White Paper *Working for patients*(3) recommended that information for patients should be improved, in terms of explaining the facilities and services available. Crucially, it stipulated that health authorities should ensure patients received

clear and sensitive explanations of what is happening- on practical matters...and on clinical matters such as the nature of an illness and its proposed treatment.(4)

The split between purchasers and providers of health care stressed the accountability of both to the public they serve. There followed a range of initiatives concerned with the quality of health services and this culminated in the introduction of *The Patient's Charter*(5) in 1991 which defined rights and standards that the public could expect. The concept of 'the patient' was effectively being redefined with the focus on empowerment. Information was central to this process and two rights (5 and 8) address this factor directly. They are the right

to be given a clear explanation of any treatment proposed, including any risks and any alternatives, before you decide whether you will agree to the treatment.(6)

and

to be given detailed information on local health services, including quality standards and maximum waiting times.(7)

This actively encourages patients to become involved in their own care and ask questions of health care professionals.



The barriers to health information continued to be dismantled with the government's decision to finally adopt a public health strategy, as set out in the White Paper *The Health of the Nation*(8) published in 1992. It defined information as central to achieving targets for reducing the incidents of ill health.

To seize the opportunity, people need information to help make the right choices. Reliable health education in its widest sense is essential for this- pervading education at school and also the many sources of information for people generally about health and its determinants.(9)

This strategic approach emphasised that prevention was better, and of course cheaper, than cure, with the responsibility for ensuring a healthy population being shared by individuals and other organisations who should work together to form 'healthy alliances'. The two key concerns outlined in the policy framework were to:

- Maximize the efficiency or output of the NHS.
- Change the behaviour of individuals.

Health education, promotion and information were seen as pivotal in order to affect behavioural changes in lifestyle, improve compliance with recommended treatments and increase participation in screening programmes, such as cervical smears. The Government defined one of its major responsibilities as 'providing reliable information on which individuals can base their decisions on matters which affect their health'(10) and it named key players such as local authorities, voluntary organisations and the media who would facilitate this.

Significantly, the role of health professionals was also addressed:

Health professionals, particularly health visitors who work with families in their homes, and general practitioners have a major role in providing information and help so that people based at home can secure healthier ways of life for themselves and their families.(11)

It signalled a radical shift in the nature of the doctor/patient relationship at the surgery.

## **1.2 Impact on the Doctor/Patient Relationship**

The effect of government policies dramatically changed the way doctors and patients perceived each other. The doctor was now charged with providing health information, which patients had long complained they were not receiving enough of(12, 13). As recently as 1994, this concern was still being voiced by patients(14). This resistance to information sharing is partly due to the threat perceived by doctors in removing a fundamental element of their authority. Knight(15) has quoted Osmond in defining the basis of this authority as:

- a) Sapiential- doctors must know or appear to know more about medicine than their patients,
- b) Moral- the right to control and direct with concern for the good of the patient, and
- c) Charismatic- which comes close to magical powers in that patients often do not understand what the treatment is doing to them, only that they are hopefully being healed.

But if some doctors equated clinging on to information with retaining power, they were fighting a losing battle. Forrester(16) has identified that the

conceptual framework has shifted from one of knowledge, culture and power to that of needs, access and provision. He ridicules the outdated notion that,

We as professionals consider ourselves as the holders of knowledge, which of course has been defined by us. We then pass this knowledge on to the passive recipients.(17)

Patients are no longer passive, merely complying with recommended treatments they know nothing about. Now they participate as informed consumers of their own health care in partnership with the general practitioner(GP). If GPs do not satisfy their information needs, then patients will get it from somewhere else. Sources of health information have increased, with *The Patient's Charter* requiring all Regional Health Authorities to establish a consumer health information service by April 1992. Patients now have the opportunity to bring health knowledge with them to the practice surgery and GPs have to be prepared to argue, convince and counter disinformation promoted in the media concerning the nature and treatment of illness.

Problems in communication can lead to barriers to information, prompting patients to use alternative sources. Doctors have been shown to overestimate the knowledge of patients(18) and provide more information to those from the same social background as themselves(19). There has been recent concern that doctors are using incorrect information by consulting outdated manuals(20). This could contribute to their sense of threat from the informed health consumer.

Despite this, doctors realise that providing information has major health benefits in leading to 'more truly informed consent, increased patient understanding and satisfaction, increased compliance with treatment, and

quicker and less stressful recovery from illness and surgery'(21). As doctors emerge from behind the barriers of their desks, to work in partnership with patients who are participating in their own health care, their authority is not diminished. Benjamin Zephaniah, after being told that he could not have children, has articulated this different relationship and the sense of release it can give both doctor and patient.

I felt like crying but just said "Thank you". Throughout my treatment I felt as if I was in partnership with my doctor, on a quest to find out if it would ever be possible for me to father a child. He really cared about my plight: somehow he seemed able to give me the kind of attention I was told you could not get on the National Health Service nowadays.(22)

### **1.3 Consumer Health Information in General Practice**

The move toward providing health information within the general practice setting was not only prompted by government policy, but was a response to the fact that many patients forget what they have been told verbally. In 1985 Fowler(23) quoted one study in which patients were able to recall only 50% of information given to them when they were asked to do so within five minutes of their consultation. Although this was common knowledge in the mid-1980s, Fowler admitted that 'in spite of this evidence...it appears that literature is rarely used by GPs'(24).

Yet the general practice setting is often the focus for the community when it comes to dealing with their health. The trust that is put in the health professionals working in that environment make it an ideal location, a nodal point, for the dissemination of health information covering a range of topics in various formats. A study(25) looking at the information needs of women

experiencing the menopause found that only 6% of women had sought help and advice from sources other than their doctor and Buckland(26) has found that GPs and health centres are considered to be the main source of advice and information.

Even so, it was only after *Working for patients* in 1989 that patient information provision in general practice began to be implemented. GP practices began to respond by setting up patients' libraries which aimed to provide patients with written health information at the time of consultation. From 1989-90, six Patient Information Collections(PICs) were established in GP practices throughout Hertfordshire, as a result of collaboration between local GPs and the Health Information Service(27). However, such developments were uncoordinated and no clear picture emerged of the overall provision of consumer health information in general practice.

A survey(28) of 312 general practice surgeries in East Anglia in April 1993 found that information about healthy lifestyles and medical conditions was available in most practices. Books were available in 98 practices with 91 producing their own leaflets, of which 36 practices made them available in languages other than English. 74 practices had patient information collections containing books, videos and audio tapes for patients to borrow. The conclusions drawn from this regional survey was that provision varied greatly and that many practices still relied on leaflets as the main way of communicating health information to their patients.

Concern has been expressed(29) that GPs are increasingly having to rely on written information to provide explanation and information as time in the consulting room becomes more limited. The provision of information does not necessarily mean that it will meet the needs of those patients who receive it.

Many commentators(30, 31) have noted that information needs to be relevant, available, easily understood, and closely matched to the educational level of the recipient. If these criteria are not met by what is available from the GP, either through interpersonal communication or written information, then the patient will look to other sources to satisfy their needs.

#### **1.4 Other Sources of Health Information**

There are many sources of health information now available to the public, comprising of the traditional sources, such as family and friends, magazines and pharmacists, to alternatives which have developed recently, such as consumer health information services and self-help groups.

The accuracy of the medical knowledge exchanged orally between friends might be questionable, but this does not make it any less valid. The male accusation that women are 'gossips' has historically been a veiled attempt at undermining this informal support network. Such an opposition is particularly evident in the male-dominated medical profession. Greer argues in *The Change*(32) that women have been dispossessed of their experiences of the climacteric by, what she terms, 'Masters of the Menopause'; those health professionals who have defined terminology, symptoms and treatments. She advocates the informal exchange of health information between women, formulated in a language they understand and based on their own experiences.

Magazines have always provided health information through the agony columns, and Gann(33) has discussed how previously they operated as a major source outside of the doctor's surgery. Newspapers have increasingly

covered health topics as the nature of such information has assumed political currency and this has also been reflected in programme coverage on television and radio.

Pharmacists have traditionally provided advice verbally but this has been supplemented by prescription information leaflets(34, 35) which advise patients on how to take their medication correctly and aim to improve their awareness of potential side-effects.

Consumer health information services have developed to provide lay health information to the general public. Their aim is to enable individuals to make informed decisions about health matters, providing a gateway to the network of other sources, such as self-help groups, which facilitate self-care. The public library service often complements these units and in Hertfordshire it is linked to the Health Information Service(HIS) based at Lister Hospital, Stevenage(36) so that requests which cannot be satisfied are passed on. The service at Lister Hospital has a collection of 3000 subject files made up of articles from medical and popular journals which the public can consult, but services provided do vary across regions. Help for Health(37) based in Southampton provides a mainly phone-in service using an extensive database of self-help and patient organisations. Sweetland(38) has recorded the success of Health Facts Information Centre in Bristol, receiving 1269 enquiries in 1988 which increased to 2336 enquiries in 1992 from both health professionals and the public. The number of professional agencies offering such services has continued to proliferate as government funding has poured into this area.

## **1.5 Types of Health Information**

There are different types of health information available to the public which have been reflected in some of the attempts to define consumer health information. While Knight(39) has limited her scope to that which is 'focused directly on informing an individual (sometimes, but not always, a patient) and/or his family of a particular disease or condition', Gann(40) has aimed to be more inclusive, specifying 'information about health and illness at a lay level; information about health care services available from the statutory and voluntary sectors; and information about choices in treatment and care'. MacDougall and Brittain(41) have identified ten types of health information required by individuals:

information on a whole range of services,

information on waiting lists and times,

information on how to complain,

lay books and journals with information on common diseases, conditions and treatments,

leaflets and books on specific conditions produced by self help groups, voluntary organisations and other national and local organisations,

information about self help groups, voluntary organisations and charities

articles on health issues, published in nursing and medical journals, women's magazines and self help group newsletters,

information on how to maintain and improve health (health promotion literature) including leaflets, booklets and posters,

information specifically for ethnic minorities with translations and interpreting services, and

different levels of accurate information.



However, this comprehensive list fails to mention a type of information which Coulter(42) has proposed should be provided; namely 'patient-focused outcomes research'. Her suggestion is based on the fact that many treatments in common use have never been rigourously evaluated by means of randomized controlled trials. Preferences for various treatments to deal with a particular medical problem can differ from doctor to doctor. Her conclusion is radically democratic:

The idea that 'Doctor knows best' is no longer tenable. We are moving into the era of 'shared decision-making', but patients cannot express informed preferences unless they are provided with sufficient information from well-conducted outcomes studies. Investment in this type of research and active dissemination of the results must become a top priority for the NHS(43).

If such information eventually becomes widely available then the GP's surgery will truly become a forum for debate where patients, laden with outcomes studies about specific treatments, will discuss the most suitable treatment for them. Many people will not want such information, preferring to leave the decision in the doctor's hands. But when individuals do choose to seek out health information, they are motivated by a multiplicity of reasons.

## **1.6 Reasons for Seeking Health Information**

Buckland(44) has identified five stages at which individuals may need or seek health information:

- 1) When healthy: health promotion/preventive information
- 2) Prior to diagnosis (when they think they might be ill)
- 3) When diagnosed or self-diagnosed as ill
- 4) When receiving or taking treatment/medication
- 5) When chronically ill/living with illness

She stresses that the timing of seeking and receiving information within each of these stages may influence its usefulness, as well as the extent that the information is absorbed and retained.

A failure in communication, or unmet information need, at the general practice surgery often prompts individuals to seek information from other sources. Knight(45) lists eight other reasons as follows:

- an inability to retain, or denial of, what was told at the surgery,
- an attempt at self diagnosis, and/or prognosis,
- a desire to seek complementary medicine or self help, because of shyness, reticence or apprehension,
- the seeking of knowledge from information providers seen as peers, rather than doctors who may be seen as superior,
- the opportunity to manipulate or fake illness
- the search for an answer to a medical problem where one does not yet exist, and
- a possibility of the formation of the basis for legal redress when operative techniques or treatments have failed.

There is also the assessment of risk in recommended treatments which is becoming an increasing priority with patients.

## **1.7 Benefits of Health Information Provision**

The multiple benefits of health information have often been stated(46, 47) and there follows a summary of the main factors.

### **Increased participation in the health care process**

Gann(48) has suggested that 'the key to increased involvement is access to information' as the knowledge acquired can then be used in discussions with health care professionals, facilitating the communication process. Self-care measures can also be implemented through improved awareness of actions which can be taken. The thrust of recent government policy has been that information enables individuals to exercise choice. This can be applied to the range of treatments available or to the health-care services offered by local authorities. It has been suggested(49) that providing health information increases patient satisfaction, which itself enhances participation.

### **Reinforce the oral consultation**

As patients do not retain information provided in consultation, then written information can provide a useful back-up. Fowler comments that 'it may reinforce and supplement the spoken word, save time, provide reference material and act as a reminder' and thus 'it may enhance the effectiveness of advice-giving'(50). This obscure reference to 'effectiveness' comes down to whether patients comply with the advice and treatments given by the doctor. It is concerned with whether people actually change their behaviour as a result of health information.

## **Improved compliance with prescribed treatments**

Even though the doctor prescribes treatments and recommends changes in behaviour, it is totally dependent on the patient whether these will be applied. Studies(51, 52, 53) have shown health information improves compliance, but limitations on this observation have been noted. Marshall and Haynes(54) have concluded that 'written and verbal instructions greatly enhance short-term compliance' but with long-term therapy other factors, including health beliefs, are more influential. Over 250 factors have been related to compliance, although

One of the major factors in non-compliance has consistently been found to be lack of information.(55)

Gann(56) has slammed the assumption that providing health information will lead to healthy actions as a fallacy, since it has to be matched to the needs of the user. Studies(57, 58, 59) have shown that such information is useless in affecting compliance if it cannot be understood by the recipient.

Increased involvement and participation in health care, prompted by access to health information, may have a negative effect on compliance with recommended treatments. Information that the patient has obtained about alternative therapies might mean that the treatment prescribed by his/her GP is abandoned. Outcomes studies or information about side-effects and risks involved in prescribed drugs may result in a refusal to adhere to treatment (eg. Hormone replacement therapy). However, in relation to information about the effects of life-style changes on health, it would be expected that this would improve compliance. An increase in knowledge about the benefits of exercise, dietary changes and reductions in smoking and alcohol consumption should

improve compliance with recommended self-care advice. This study intends to contribute to research in this area.

### **Reduced anxiety and stress**

Communicating information to patients can aid recovery by reducing anxiety levels and increasing their sense of control over treatment being undertaken. This can be conveyed in various formats. An information tape for patients undergoing surgery has been found to reduce anxiety(60) and written information in a general practice setting reduced anxiety in 44% of users(61). However, Bolton and Brittain(62) have used the health belief model theory to suggest that not all patients want, or need, information. They conclude that 'patients require information tailored to their own individual requirements' to match their differing coping styles.

### **Faster post-operative recovery rates**

The psychological effects of preparatory written information prior to surgery have produced faster recovery rates(63) which can lead to shorter hospital stays, thus impacting upon the cost-effectiveness of treatment. It can also reduce return visits to the GP surgery, producing further budgetary savings.

The emphasis on the cost-effective use of NHS resources has meant that benefits and outcomes resulting from expenditure have to be measured. Measuring the impact and benefits of health information is problematic.

## **1.8 Measuring the Impact of Health Information**

The medical model of health education(64) assumes there is a linear progression from access to information, to an updating of knowledge, to a change in attitude, leading to changes in behaviour, which produces an outcome of better health. But as Marshall and Haynes(65) have noted, information is only one element in the factors influencing behaviour. Behavioural change can occur prior to knowledge, or indeed develop independently of it. This factor complicates an evaluation of the impact of health information.

Previous research into the impact of health information has focused on how it influenced the clinical decision-making of hospital doctors. Marshall(66) studied 448 doctors from 1990-91 and found that 97% said that the information provided contributed to better informed clinical decisions. The study concluded that information changed decisions made, with a dramatic 72% of doctors changing advice given to patients as a result of the information provided by the hospital library.

In order to measure the benefits of health information to doctors they were asked how it had changed their behaviour. This type of study is of importance to health policy-makers and planners. The same questions need to be answered as regards consumer health information. Although patient satisfaction with health information provided is a valid outcome measurement, it is even more important to find out if health information makes patients more likely to follow doctors' advice by complying with prescribed treatments and implementing behavioural changes according to life-style recommendations.

The link between consumer health information and health outcome is difficult to measure. A survey(67) of patient attitudes to health education in general practice found that 36 patients had changed to healthier living habits after receiving advice from their GP or other member of the surgery staff; but 55 had not. Despite this, 91 patients thought that they should be personally responsible for finding out about how to live a healthier life; as opposed to 4 who did not, out of a sample of 100. Such contradictions reflect the difficulty in trying to measure the impact of health information on patients compliance with GP advice and prescribed treatments.

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## **2. PATIENT COMPLIANCE**

### **2.1 The Problem of Compliance**

Doctors have always been trying to get their patients to do what they have told them to do. For equally as long, patients have failed to follow the instructions and advice conveyed by health professionals, as regards adhering to prescribed treatments and implementing behavioural changes in matters affecting their health. So initially the problem seems to be patient non-compliance although, as Boza(1) has suggested, over-compliance can also negate treatments prescribed in the best interests of the patient. Compliance taken to an extreme can lead to types of behaviour such as overdosing on prescribed medication. A balance needs to be struck.

In his discussion of non-compliance and over-compliance, Boza defines compliance as,

a reasonable understanding on the part of the patient regarding the need for treatment and the different approaches available, followed by appropriate action; ie, taking the medication or following the plan prescribed.(2)

It has been estimated that 40% of patients do not comply with doctors' advice on treatment(3). In the definition above, Boza defines patient knowledge and understanding about recommended treatments as essential prior to complying with advice through taking appropriate actions. However, it has been found that behaviour change can precede knowledge gain or be independent of knowledge level(4). Of course, patients need to have an understanding of the treatments they are undertaking if they are ever going to comply with

prescribed regimens. However, the issue of patient compliance is extremely complex. Gann(5) has noted that there are over 250 factors relating to compliance. Lack of knowledge about the quantity and frequency of prescribed drugs to be taken will automatically lead to non-compliance. Such types of patient behaviour can be inadvertent; they simply haven't been told or, more likely, have forgotten the information necessary for compliance. Thus, the aim of the treatment to produce a complete, or at least partial, positive health outcome is disrupted. Non-compliance is also a deliberate type of behaviour grounded in a range of factors which will be discussed in the following sections.

Before exploring the plethora of explanatory factors for non-compliance, it is necessary to take a step back. The language in which this phenomenon is embedded partly contributes to the problem itself. Non-compliance is a common response from patients. In fact, it is probable that more than 40% of patients display non-compliance, as there are barriers to the reporting of it. These barriers are bound up in the nature of the doctor/patient relationship. Traditionally this relationship has been characterised by a lack of power-sharing(6) and an authoritative approach on behalf of the doctor. This relationship is expressed at semantic level. *The Concise Oxford Dictionary* defines compliance as,

action in accordance with request, command; unworthy submission; yielding under applied force.(7)

Language is political, reflecting the shifting power-relationships within society as it mutates. The definition of compliance embodies the imbalance of power between doctors and their patients. The deference shown towards health professionals may lead to non-compliance remaining unreported by patients

who fear, or seek approval from, such figures of authority. Non-compliance can also be seen as a reaction against such authority, expressed by patients resisting the influence and advice of those in the medical profession.

## **2.2 Measuring Compliance**

In almost every medical encounter advice is offered to the patient. However, the spectre of non-compliance looms as a possible response, no matter at what stage of an illness the intervention takes place. As such recommendations are genuinely made in the best interest of the patient, then such seemingly irrational behaviour is bound to generate frustration amongst those in the medical professions. The situation has been summed up as follows,

Deliberately or not, many patients ignore, totally forget, or erroneously implement their treatment recommendations.(8)

The problem is further complicated by the difficulty of assessing which patients are complying with medical advice. Compliance is a difficult parameter to measure. Ley(9) has identified seven methods used for assessing the extent to which patients are following advice:

- patients' reports
- pill and bottle counts
- blood and urine tests
- mechanical devices
- direct observation
- outcome- the progress of the illness or condition

- clinician's judgement

Patients' reports of their adherence to the prescribed regimen have often been the most popular method, as noted by Ley(10), due to the ease with which they can be obtained. This method can be unreliable due to barriers to patient reporting of non-compliance. Inaccurate reporting of compliance can occur where the patient has simply forgotten an incident, or due to a lack of understanding when,

the patient may have misunderstood the regimen in the first place and thought he fulfilled its requirements completely.(11)

Where pill and bottle counts are involved, the amount of pills or medicine remaining in the bottle is recorded and compared with the amount which should have been consumed, in order to estimate patient compliance. This method was used by Lorenc and Branthwaite(12) in a study of whether age was a factor in compliance with treatment. The study focused on antibiotic taking amongst three groups of 25 patients. Patients were visited at home five to six days after their consultation with the doctor and a pill count was conducted and a questionnaire administered in order to ascertain health beliefs. Ley(13) has identified three problems with this method. Patients can dispose of medicine and thereby deceive the examiner. They can also forget to bring their medical containers with them to the consultation, although this factor can be avoided by home visits. Thirdly, this method only assesses the amount of medicine consumed and not the frequency or scheduling of the doses.

These two methods are the easiest, and most popular, ways of measuring compliance. With such a complex phenomenon, all such methods of measurement have flaws.

## **2.3 Factors Affecting Compliance**

Any discussion of patient compliance focuses on the question of why people behave in the way that they do. Human behaviour is governed by an intricate web of social, psychological and environmental factors which inter-relate and vary according to different individuals. In separating the factors affecting compliance, they are severed from their interdependent relationship as they coalesce in any one individual. Nevertheless, simplification is inevitable when concerned with the complexities of behaviour. DiMatteo and DiNicola suggest that there are two specific targets for patient non-compliance. They focus on process and content as key themes:

the patient may resist the influencer (the practitioner) or the advice.(14)

The primary vehicle by which patients receive the advice is through the communication process with the medical practitioner. When this process is perceived as unsatisfactory by the patient, then this can prompt non-compliance.

### **2.3.1 Patient Satisfaction**

Although deemed a desirable goal in itself, Ley(15) considers 'patient satisfaction is an important determinant of patients' compliance with advice'.



Such satisfaction is centred on three aspects of the doctor/patient relationship; namely, the amount and quality of information provided, the extent to which the patient feels the doctor listens and understands them, and the patient's evaluation of the doctor's competence in consultation. Ley(16) quotes the 1968 study performed by Korsch et al. of 800 consultations in a paediatric clinic which found that satisfaction was associated with:

- the doctor being friendly rather than businesslike;
- the doctor being seen as understanding the patients' concerns;
- patients' expectations about treatment being met;
- the doctor being perceived as a good communicator;
- the provision of information.

Ley summarises data from a range of studies to support his claim that,

patients are frequently dissatisfied with the quality and amount of information they receive from medical and other hospital staff, and from their general practitioners. Patients feel that they have not been given enough information.(17)

He lists results from 11 studies of patients' satisfaction with communication in the general practice and community setting. Four of these studies focus on satisfaction with information provided about treatment. Basksas and Helgeland in 1980 found 58% dissatisfaction with the information provided on treatment by 787 hypertensive patients; Winkler et al. in 1981 recorded 42% dissatisfaction amongst 793 patients prescribed erythromycin; while Kanouse et al. in 1981 found only 16% dissatisfaction amongst 518 patients prescribed oestrogens.

Non-compliance can be seen as an act of subversion by patients as they engage in a conflict with the doctor for control over their treatment. The perceived lack of information-sharing felt by patients only contributes to their sense of an unequal struggle.

### **2.3.2 The Doctor/Patient Relationship**

The communication of information in the doctor/patient relationship is essential, as incidents of non-compliance reflect that patients are hardly the traditional passive partners in such a relationship. DiMatteo and DiNicola(18) suggest that there are three models for such a relationship: active-passive, guidance-cooperation and mutual participation. An active patient orientation is beneficial to compliance, but at the same time the input of the health professional is required. The level of supervision which patients receive increases compliance; but again the balance of these factors will depend on the individual involved. It is true that,

Patients must know specifically what to do to fulfill their required regimens. This is one important reason why information is important to compliance.(19)

However, the amount of information patients require beyond the immediate instructions will depend upon the individual, as will the amount of supervision required.

The elements of trust and interpersonal communication are also significant in affecting compliance with treatments. The expectations of patients impact upon compliance and health professionals require listening skills to be aware of these structures of thinking.

### **2.3.3 Type of Treatment**

The duration of treatment and the complexity of the regimen, as assessed by the number of drugs or treatments involved, affect patient compliance. Compliance decreases with increasing duration of treatment. This also affects the impact of information. Marshall and Haynes(20) have noted that 'written and verbal instructions greatly enhance short-term compliance' but 'gaining cooperation with long-term treatment is much more difficult'.

### **2.3.4 Environmental Factors**

The social situation in which the patient is situated impacts upon compliance, from the influence of family and friends to the place the individual occupies in society.

Ley(21) assessed studies about factors influencing compliance and found that the influence of family and friends recorded the highest score with 19 studies stating a positive association with compliance. The influence of social networks, and behavioural norms established within the groups in which the patient is located, have also been recorded by DiMatteo and DiNicola:

The patient does not relinquish control and decision-making power to the physician; rather, he or she maintains control through self-determination and through contact with outside social and lay referral networks (which are comprised of individuals who either directly or by means of social norms influence the patient's behaviour at least as much as the physician does). (22)

In the study conducted by Lorenc and Branthwaite into the affect of age on compliance with treatment, they found that age did not impact on compliance,

but living conditions, which are age-related, did. They concluded that 'having someone living with the patient affected compliance'(23).

The need for cultural and social supports is perhaps the major factor in enhancing compliant behaviour but barriers to compliance can also be created by the cost of treatment and poor access to medical care. Low-income families find it difficult to comply with recommended life-style and dietary changes, such as eating more fresh fruit and vegetables, as they cannot afford it. Behavioural norms within the social class structure also relate to this. Recently the rise of consumerism has been accompanied by a heightened awareness of environmental issues. Alternative therapies have become fashionable as some how more 'natural' than traditional medicines. However, the costs of such alternative therapies means that the middle classes dominate as consumers. A study(24) of why people seek treatment by alternative medicines found patients were well informed, using the media and friends as major sources of such information. The movement away from traditional medicine has been established by shifting cultural norms and peer group approval.

### **2.3.5 Health Beliefs**

The majority of illness is treated by self-care. A number of psychological and social factors influence whether the incident of illness will be ignored, tolerated, self-medicated or brought to the attention of health professionals. The influence of psychological factors does not diminish when patients are receiving treatment and such attitudes motivate behaviour.

Such factors have been stated in The Health Belief Model, a theoretical framework, which

hypothesizes that people seek and comply with health-care regimens only under certain specific conditions.(25)

The psychological factors that influence compliance with treatment have been summarised as:

- vulnerability to the disease;
- seriousness/severity of the disease;
- effectiveness of the treatment (that something can be done);
- self-efficacy (one's own ability to deal with the problem);
- the cost of treatment- in terms of fear, time, money, energy, interest, embarrassment.(26, 27)

An individual's locus of control also affects compliance with treatment. If the locus of control is internal then the individual tends towards believing that they are responsible for, and determine, their own autonomous actions. Whereas an external locus of control focuses on determinism and fate; the individual believes that his or her actions are determined by some overall scheme and not by their own decisions. Such patients would tend to display non-compliance.

Smith et al.(28) investigated the relationship between health beliefs, satisfaction and compliance. They found that Health Belief Model variables were significantly correlated to compliance, but they did not predict compliance in the future; whereas patient satisfaction measures did. The provision of health information contributes to greater patient satisfaction. However, there is evidence that patients with different coping styles benefit in

Improvements in patient understanding may lead them to refuse prescribed drugs from health professionals which they know have risk factors or side effects(32).

different ways from information provision. Bolton and Brittain suggest that 'patients require information tailored to their own individual requirements'(29).

## **2.4 Compliance and Health Information**

The impact of health information on compliance with treatment seems to be indirect, in that its provision increases patient satisfaction, which has been defined as correlated to compliance. Carr(30) has suggested nine ways in which patient compliance can be improved, from the perspective of the medical practitioner, and the communication of information plays a significant part in the process:

- clarify how much information patients would like about their condition
- offer an explanation of the patient's condition and the rationale for treatment
- present the treatment regimen and the rationale upon which it is based in language that patients can understand and which allows them to remember what has been said.

Ley(31) has reviewed studies concerning the effects of the provision of written health information and found that 32 studies found it increased patient knowledge and 25 studies found it increased compliance with treatment. Knowledge about a treatment regimen and compliance are connected and he concludes that there is 'an overall beneficial effect from the provision of written health information about medication'. However, written health information has to be read by its intended audience and needs to be at a suitable level so they understand it. A literature search has found no research into whether written health information prompts non-compliance with recommended treatments.

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### **3. OSTEOPOROSIS**

#### **3.1 Background**

Osteoporosis means thin bones. It is a disease characterised by a loss of bone mass and an increased risk of fracture, particularly in the hip, spine and wrist. Compston(1) has stated that 'it affects one in four women and one in twelve men over the age of 60 years'. She goes on to estimate that 60,000 people suffer hip fractures each year in the UK. In England in 1985, 37,600 people aged 65 years and over fractured a hip, with on average 3170 acute hospital beds a day committed to such patients(2). Spine fractures are even more common. Not only does the disease cause considerable personal suffering and disability due to pain, height loss and spinal deformity, but there is also a financial cost. Osteoporosis costs the health services approximately £740 million a year(3).

The disease is associated with loss of bone mineral density, which is essentially the mass of calcium salts per unit volume(4). As bone is a living tissue, it is constantly being destroyed and regenerated throughout life. Bones grow rapidly during childhood and adolescence, with bone mass reaching its peak in the mid-30s. Around the age of 40, bone loss begins in both men and women. Sex hormones, such as oestrogen and testosterone, play an important role in the 'bone remodelling process'(5) which maintains healthy bones. Compston has summarised why the disease is more prevalent in women than in men:

When women reach the menopause, their natural supply of oestrogen begins to dry up as the ovaries effectively start to shut down. This leads to an increasing rate of bone loss which, together

with women's smaller skeletons and greater life expectancy, makes osteoporosis more common in women than in men.(6)

So the most important factor in the development of osteoporosis, at least in women, is oestrogen deficiency associated with the decline of ovarian function at the menopause(7, 8). However, there are a range of factors which influence susceptibility to the disease.

### **3.2 Risk Factors**

It has been suggested that 'the ability to predict the occurrence of osteoporosis is all important for selecting patients for preventive treatment'(9). Ogden(10) has reported support in the medical profession for screening post-menopausal women who are at risk, via bone densitometry checks. The risk of developing osteoporosis depends on the peak bone mass attained in early adult life, and on the subsequent rate of bone loss(11). Although oestrogen deficiency dramatically increases the rate of bone loss, there are other factors associated with lifestyle and diet which influence both bone loss and peak bone mass attained before it commences.

#### **3.2.1 Low Calcium Intake**

A study conducted by Murphy(12) found that frequent milk consumption before the age of 25 was associated with higher hip bone mineral density in middle aged and elderly women. The study was based on the assumption that an assessment of milk consumption may be used as a reasonable proxy for calcium intake early in life, as about 40-60% of children's calcium intake comes from milk. It confirmed the benefit of a high calcium intake on bone

mineral density and recommended that milk consumption should be encouraged during childhood and adolescence. Prior to this study, Nordin and Heaney had suggested that 'in preventing fractures the evidence for a calcium effect is strong'(13). They supported the use of calcium supplements and recommended that 'all postmenopausal women should be advised to ingest more calcium than they ingested before the menopause'. This evidence suggests that a low calcium intake increases the risk of osteoporosis.

### **3.2.2 Vitamin D Deficiency**

A study by Compston(14) indicated that blood levels of vitamin D around, and after, the menopause are positively related to bone mass in the hip and spine. Vitamin D is mainly derived from sunlight and is 'an essential factor in whole body calcium homeostasis'(15). It is necessary for the absorption of calcium, a vital bone-building mineral. This suggests that improving the levels of vitamin D in middle-aged women 'might have beneficial effects on bone density and so reduce the risk of fracture'(16). Fraser advises that for those displaying a deficiency 'vitamin D should be obtained from the environment by careful exposure of the skin to solar ultraviolet light rather than from the artificial source of dietary supplements'(17).

### **3.2.3 Heavy Caffeine Consumption**

It has been suggested in a study conducted by Kiel that 'caffeine intake equivalent to more than two cups of coffee per day is associated with an increase of 53% in the risk of hip fracture in the subsequent two years'(18). This is because caffeine increases urinary calcium output and, thus, is implicated as a risk factor for osteoporosis. However, Barrett-Connor suggests that this is significant only when the diet does not contain milk. Her conclusion

is 'lifetime caffeinated coffee intake equivalent to two cups per day is associated with decreased bone density in older women who do not drink milk on a daily basis'(19).

#### **3.2.4 Low Body Weight**

A lower than appropriate body weight, particularly during childhood and adolescence, can reduce the peak bone mass achieved during early adult life. The curtailing of the optimum peak bone mass which could have been achieved, due to excessive dieting as a teenager for instance, is particularly serious for women, whose bone mass continues to decline after the menopause. The situation is clearly delineated by Stevenson:

A woman with a low bone density who is losing bone slowly may be at greater risk than a fast bone loser with a high bone density...those with a low bone density are at greatest risk of developing the disease irrespective of rate of bone loss.(20)

A study by Rico recommends that 'it is important that women maintain an optimal weight to maximize peak bone mass as a measure to protect against postmenopausal osteoporosis'(21).

#### **3.2.5 Heavy Alcohol Consumption**

Felson concluded that 'alcohol consumption, especially if long-term and heavy, increases the risk of hip fracture'(22). Stevenson asserts that 'alcohol intake clearly has a deleterious effect on bone density in young women, which has hitherto been unrecognised'(23) while Law states 'there is an increased risk of hip fracture of about 30% associated with moderate alcohol

consumption, but this need not imply an effect on bone density'(24). As a toxin, heavy consumption of alcohol is damaging to overall health.

### **3.2.6 Cigarette Smoking**

Research(25, 26) has shown that women who smoke one pack of cigarettes a day throughout their adult life are at much greater risk of osteoporosis and bone fracture than women who do not smoke. One reason suggested for the loss of bone density in female smokers was the reduction in oestrogen production caused by toxins in tobacco. Law(27) recommends that stopping smoking is important, as changing this aspect of a woman's lifestyle before the menopause will reduce her risk of osteoporosis by about a quarter. Stevenson has also noted 'a significant negative effect of smoking on bone density in the vertebrae'(28)

### **3.2.7 Lack of Exercise**

Exercise is important for a healthy lifestyle. Lindsay(29) notes that recommendations for exercise to prevent osteoporosis are variable. Weight-bearing exercises are thought to be important, whereas some doctors simply recommend an increase in walking and aerobic activity. A study by Hamdy(30) found that 'healthy young males, reporting a history of intensive weight-lifting exercises had significantly greater bone mass in upper limb bones than those reporting a history of nonweight-lifting exercises'. Lindsay notes that the impact of this debate is negligible and goes on to make an astute observation:

A more important, but largely ignored, benefit of increasing the level of daily activity, especially among elderly people, is that the consequent improved strength, increased stability, and better balance will reduce the frequency of falls and the risk of associated injury.(31)

### **3.2.8 Other Factors**

A high intake of salt(32) and animal protein(33) in the diet has been found to increase the rate of urinary calcium excretion. Decreasing salt and animal protein intake should benefit the skeletons of women susceptible to osteoporosis. It has been identified that malnutrition is particularly evident in patients admitted to hospital with proximal femoral fractures(34). An adequate dietary intake of vitamin K has been identified as important 'both to early skeletal development and to the maintenance of healthy mature bone'(35). The best sources are green leafy vegetables, certain legumes, and some vegetable oils such as rapeseed and soyabean oils. It has been demonstrated that osteoporosis associated with pernicious anemia may be markedly improved by vitamin B<sup>12</sup> replacement(36).

### **3.3 Intervention Strategies**

There are two stages of intervention, as defined by Lindsay(37). The first stage consists of behaviour modification, and the second of pharmacological methods. He suggests that the weight given to any single group of risk factors is far from clear, but the elimination of such factors often carries more benefits than mere reduction in the risk of fracture. Behaviour modification is usually associated with preventive strategies, although implementing changes in an individual's lifestyle and diet can be used in conjunction with pharmacological methods to treat osteoporosis. Scanning postmenopausal women, who are most at risk from osteoporosis, via bone densitometry checks, can identify those individuals with low bone mineral density who require treatment, and

those with normal bone mineral density for whom preventive strategies are most suitable. This is supported by Law who believes:

Strategies aimed at preventing low bone density in old age should be directed particularly at women and should begin at the time of the menopause because of the rapid and largely irreversible bone loss thereafter.(38)

### **3.3.1 Preventive Strategies**

The prevention of osteoporosis is aimed at addressing risk factors associated with the disease. Changing behaviour as regards lifestyle and diet are the most important elements.

#### **Lifestyle:**

- Stop smoking
- Reduce alcohol consumption
- Take regular exercise
- Avoid crash dieting
- Maintain an appropriate body weight
- Try to get out in the sun for vitamin D

#### **Diet:**

- Ensure an adequate calcium intake through dietary sources (cheese, milk, leafy green vegetables) or supplements
- Reduce intake of salt, animal protein and caffeine
- Have a well balanced diet, encompassing the range of vitamins



### **3.3.2 Treatment**

As oestrogen deficiency associated with the menopause is the most important factor in the development of osteoporosis, then prescribed treatment aims to address this.

Hormone replacement therapy(HRT) replenishes the natural supply of oestrogen lost at the menopause, preventing bone loss and reducing the risk of fracture at the hip, wrist and spine(39). Lindsay(40) states that oestrogen use is associated with a reduction of about 50% in the risk of hip fracture and suggests that efficacy seems to depend on the amount of oestrogen delivered and not on the route of administration.

Although HRT offers the benefit of protecting against coronary heart disease and stroke(41, 42), there are other risk factors and side effects associated with such treatment. There is an increased risk of breast cancer(43) associated with longer-term therapy. Due to this, treatment is usually limited to between five and ten years. Side effects include breast tenderness, weight increase, bloating, heavy withdrawal bleeds and irregular bleeding(44).

### **3.4 Debate Within The Medical Profession**

Although there are general guidelines for best practice in the prevention and treatment of osteoporosis, debate still exists amongst medical professionals as to the efficacy, benefits and risks of such strategies. Patients opening a medical journal for the first time may be shocked by how much uncertainty there is. Equally, patients may be disconcerted to find evidence denouncing a treatment or preventive measure prescribed by their own GP.

### **3.4.1 Calcium Intake**

Studies(45, 46) have shown that increasing calcium intake is beneficial, in terms of reducing bone loss and preventing fractures. However, there are dissenting voices. In 1991, Law(47) suggested that, although calcium supplementation must offer some protection against hip fracture because it reduces postmenopausal bone loss, 'the degree of protection is likely to be small'. In 1994, an editorial in the *British Medical Journal* expressed impatience with such views:

Suggestions for an increase in intake of milk or alternative sources of calcium during youth to maximise skeletal potential should not be the subject of controversy.(48)

Straight away Seppa(49) replied, suggesting other factors should be considered before recommending milk, such as fat intake. He recommended that all possible factors, not just osteoporosis, should be taken into account before such advice is given.

### **3.4.2 Exercise**

A study conducted by Law concluded that 'exercise programmes increased bone density, reversing the normal postmenopausal loss of bone seen in women who did not exercise'(50). However, Stevenson and Marsh responded by asserting that, whilst physical activity should always be encouraged, 'exercise does not prevent or reverse bone loss due to oestrogen deficiency and should not be proposed as an alternative to hormone replacement therapy'(51)

### **3.4.3 Hormone Replacement Therapy(HRT)**

Despite the success of HRT, there are a number of issues which remain unresolved(52). These include:

- How much HRT protects against fractures
- How long therapy should last
- The frequency of other side-effects unrelated to bone density or strength

When Law stated that HRT is likely to have an impact 'only if it is continued indefinitely after the menopause'(53), Compston(54) disagreed, quoting other evidence that suggested even temporary HRT would have a lasting beneficial effect on bone mass. Compston's letter finishes by saying 'nobody would argue against the need for more accurate guidelines on the duration of treatment'. Lindsay assesses the risk of breast cancer with longer-term therapy as a vital factor in determining compliance with HRT.

Although the overall benefit/risk equation seems to favour the use of oestrogens in most individuals, many patients may be deterred by this possibility from embarking on hormone replacement therapy.(55)

He urges doctors to enter into discussions with patients so that informed decisions can be made. Such decisions will impact greatly on compliance with treatment.

### **3.5 Compliance Issues**

Access to health information has been identified as a positive factor in influencing patient compliance with the prevention and treatment of osteoporosis.

#### **3.5.1 Preventive Strategies**

MacLennan(56) focused on the need to provide adequate health information to patients when he suggested guidelines for running a menopause clinic. He recommended that patients view an educational video, prior to their first visit, which would give 'a basic understanding of the physiology of the menopause, the pros and cons of hormone replacement therapy, and lifestyle factors'. He thought the general practice setting was best suited for a menopause clinic. His conclusion stressed 'the importance of giving adequate information and education through combined video, written and verbal information'.

A study by Coope and Roberts(57) compared compliance with preventive treatment between attenders and non-attenders at a menopause clinic. Information provision was a key factor in the clinic protocol including: a five minute informal talk by the doctor to explain the meaning of osteoporosis and how it could be prevented; discussion with the practice nurse; dissemination of educational leaflets; and a video about osteoporosis. A postal questionnaire was sent to 180 clinic attenders and 282 non-attenders, designed to ascertain smoking habits, calcium intake and present hormone use. After one year 14% of clinic attenders were smoking as opposed to 27% of non-attenders. Average calcium intake among attenders was 791mg daily as opposed to 676mg in non-attenders, and 38% of attenders were using hormone replacement therapy as opposed to 13% of non-attenders. Compliance with

preventive strategies was higher among patients attending the menopause clinic, and a significant differentiating factor was the provision of health information.

Ley(58) has stated the 'patient satisfaction is an important determinant of patients' compliance with advice'. Roberts compared the satisfaction between menopause clinic attenders and non-attenders. Her conclusion supports the hypothesis that the provision of health information positively affects compliance with treatment:

Sufficient and understandable information is a prerequisite for patient satisfaction and clinic attenders were more likely than the other group to be satisfied with the information they received about the menopause, their treatment and possible side effects of treatment.(59)

### **3.5.2 Hormone Replacement Therapy(HRT)**

Despite the benefits of HRT in reducing osteoporosis-related fractures, there seems to be a low level of compliance with prescribed HRT(60).

However, not all studies support this finding. McCleery and Gebbie(61) aimed to determine the level of compliance with HRT prescribed at a specialist menopause clinic. They found that, of 135 women surveyed, 79% were continuing to use HRT nine months or longer after discharge from the clinic. They identified that information about the benefits of HRT is not being made available to potential users, quoting a study in which only 27% of non-users knew that lack of oestrogen was a significant factor in causing osteoporosis, compared with 89% of users. They also suggest that many patients perceive using HRT as so inconvenient or unpleasant that this outweighs the advantages. They conclude that information has a major impact on

compliance and that its provision in the menopause clinic they studied contributed to the high incidence of compliance:

It seems likely that specialist menopause services providing up-to-date information on the risks and benefits of HRT and on the preparations which could be used to minimise side effects might achieve higher compliance rates than primary care.(62)

An earlier study by Draper and Roland(63) in 1990 found a high rate of interest in HRT among women in the UK, but this was accompanied by a widespread wish for more information. Of 84 respondents to a questionnaire asking about interest in taking HRT to prevent osteoporosis, 57 said that they would like more information. 64 women thought it was very important to prevent osteoporosis, but 51 said that they would worry about the side effects of HRT if recommended to take it. 15 women specifically detailed a lack of information about the hormones and their side effects, worries about cancer, and whether the benefits of such treatment outweighed the risks. The study's conclusion focused on information as pivotal in influencing patient compliance with HRT:

The results showed that when women are given a modest amount of information on the prevention of osteoporosis by taking hormone replacement therapy they show considerable interest in obtaining further information and treatment.(64)

Other studies(65, 66) support the positive influence of information on patients' willingness to take HRT. Nachtigall has concluded that 'patients who understand why hormone therapy is prescribed are the most compliant'(67). In her study(68), withdrawal bleeding, irregular bleeding, breast tenderness and fluid retention were significant factors in determining non-compliance with HRT. However, the impact of such factors can be influenced by health information, which can dispell misconceptions and misinformation. She

suggests that patient/doctor discussion and the provision of books, booklets and videos enhances patient compliance.

Ryan(69) found 74% of patients were using HRT in his study and this increased usage occurred in those women with low bone mineral density. However, 40% of women advised to start HRT were not taking treatment an average of eight months following screening, mostly due to side effects like withdrawal bleeding and weight gain. Among the reasons for not starting HRT, lack of information was given, as well as concerns over side effects, breast cancer and the fact that it was a controversial therapy. A study by Ravnkar(70) also recorded high rates of non-compliance due to side effects and a study conducted by Kadri(71) found 57% of women anxious about such effects. The provision of information has been shown to reduce anxiety and thus improve compliance(72). Although information improves compliance with HRT, each patient is different and,

what is both needed and appreciated is an individual approach to each woman's particular risks, problems and concerns.(73)

### **3.6 Access to Health Information**

There is an awareness that women have access to other sources of health information other than their doctor. However, a literature search has found no studies which investigate the types of information sources that women use about the prevention and treatment of osteoporosis. There are statements which hint at the number of information sources which women use, and the influence that such sources have on their decision-making, but they fizzle out

into mere opinion because they are not supported by reference to hard evidence.

Nachtigall suggests that the media, friends and family are all sources of information used by women. She asserts that:

Hormone therapy has caught the attention of the media recently, and their reports constitute a large part of women's education about hormone therapy.(74)

There is no reference to the source which provides this evidence that the media (the term presumably encapsulates TV, radio, newspapers and magazines) is the major information source for women outside of the doctor's surgery.

The study by Draper and Roland(75) concluded that there was considerable awareness and interest among perimenopausal women about HRT, but there was an unmet information need. Kaufert is disdainful of the idea that non-compliance with HRT can be 'solved by education, better package design, and even by setting up an information phone line'(76). In the light of the evidence, it is difficult to understand her scepticism about the positive impact of information provision on compliance. Maslow believes women require health information 'if they are to make informed decisions about various treatment options, including hormone therapy, other medications, and non-pharmacological approaches such as nutrition and exercise'(77). However, she goes on to make a completely unsubstantiated claim:

Increasingly, women are eager to obtain information that may affect their health. They listen to the news. They buy magazines and newspapers that report the latest findings. Some women trust their physician and other health professionals to provide good advice about treatments, but others are suspicious and trust the media



reports instead. Some women are particularly suspicious of pharmacological treatments and strongly prefer non-pharmacological approaches.(78)

This radical claim is plucked out of the sky. It is not supported by reference to any research. Maslow suggests that other sources of health information, particularly the media, are prompting non-compliance in some women. She believes that advice and treatment issued by GPs is being forsaken for different approaches recommended in health columns, or abandoned due to contradictory evidence provided in the media. This is an interesting hypothesis; but it is merely speculation as she provides no evidence to substantiate her claim.

A recent article(79) in the *Daily Mail* focused on new evidence that osteoporosis is caused by genetic factors. Although the article states that 'the genetic check will enable doctors to advise young women on how to minimise their chances of developing the disease and provide early treatment to control it', some women may misinterpret this information to mean that they have no control over the disease. In Maslow's opinion, this could prompt non-compliance. *The Change* by Greer is widely available in public libraries as a source of information on the menopause. Greer has a negative view about HRT and sets herself against, what she terms, the 'evangelicalism' of the medical profession:

In fact no preventive effect of HRT on the development of osteoporosis has actually been demonstrated, because the longitudinal cohort studies have simply not been done.(80)

Again, Maslow suggests that access to such information may prompt non-compliance in some women. It is a hypothesis that the research undertaken in this study aims to investigate.

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## **4. RESEARCH METHODOLOGY**

### **4.1 Background**

The three month study was undertaken as a joint venture with Dr M. G. Kirby of The Surgery, Nevells Road, Letchworth from April - June 1995. The study took place using a stratified sample which was selected by Dr Kirby, who defined the patient group to be assessed. A collaborative decision was taken to obtain data via a questionnaire survey, followed up with individual interviews.

### **4.2 Sample Population**

The study took place using a sample population of 70 women between the ages of 40 and 65 who were attending a menopause clinic in a Letchworth general practice. The total sample population of 70 women was divided into two categories:

#### *First category:*

35 women who had undergone bone scans, but who had not been diagnosed as having osteoporosis. They had normal bone mineral density (Normal BMD). They had been issued with information by the general practitioner and menopause clinic nurse on preventive measures relating to changes in diet and life-style (exercise, smoking and alcohol consumption) as they remained in the "at risk" category.

### *Second category:*

35 women who had undergone bone scans and who had been identified as having osteoporosis. They had low bone mineral density (Low BMD) and were issued with information relating to changes in diet and life-style. They had also been prescribed hormone replacement therapy (HRT) and received information from the general practitioner and menopause clinic nurse about the treatment they were undertaking.

### **4.3 Survey Questionnaire**

All 70 women were sent a questionnaire accompanied by a covering letter and a stamped addressed envelope. The questionnaires were issued by post on 16 May 1995 with a deadline for return of 31 May 1995. A reminder letter was issued to non-respondents on 1 June 1995, with the final deadline for return being 9 June 1995.

The questionnaire (see appendix I) consisted of 11 closed questions in order to ease collection and analysis of data, as well as reducing the possibility of ambiguous answers. Of the 11 closed questions, 5 had the option of an "Other" category, which allowed the addition of answers not anticipated when the list of possible responses was compiled. Question 10 asked respondents to identify the formal educational qualifications which they possessed. Question 11 asked whether respondents would be willing to attend an interview in order to provide qualitative data for the study.

A letter from Dr Kirby accompanied each questionnaire (see appendix II). This explained the purpose of the survey, indicating what would be done with the



information provided and reassuring the respondents of their anonymity and the confidentiality of their replies. It introduced the person undertaking the research project.

The questionnaires were coded numerically to allow anonymous analysis, and the two patient categories were differentiated by questionnaire paper colour. Non-respondents were identified by this system, and a reminder letter (see appendix III) was sent to these women.

The survey technique of postal questionnaire was chosen to gather the initial quantitative data because it allowed 'the collection of large amounts of data in a short period of time'(1). The short timescale of the study meant that this factor was paramount. It also allowed respondents to give anonymous answers, which they could complete in their own time. The scope for bias was reduced and a consistent format could be achieved. It also enabled the group of 70 women, dispersed at geographical distance, to be contacted at minimal cost. Interest in being interviewed could be indicated on the questionnaire and this saved time, money and inconvenience to patients by identifying those willing to take part in follow-up interviews.

#### **4.4 Analysis of Questionnaires**

The data from the questionnaires was collated manually using summary sheets and the results were presented using a spreadsheet package, Excel 3.

#### 4.5 Standardised Open-Ended Interview

From the questionnaire responses, 30 women indicated that they would be willing to take part in a follow-up interview. 19 women were interviewed in total, with 11 women responding that they were not available to be interviewed for various reasons when contacted by telephone.

12 interviews were conducted by Andrew Hampson on Thursday 15 June 1995 in a consultation room at The Surgery, Nevells Road, Letchworth. A further 7 interviews were conducted by the practice nurse between 15-30 June 1995, at times convenient to the patients involved.

The interview structure and format was established using guidelines suggested by Patton, who defines the standardised open-ended interview as consisting of

a set of questions carefully worded and arranged with the intention of taking each respondent through the same sequence and asking each respondent the same questions with essentially the same words.(2)

The interviews consisted of an opening explanatory statement based on guidelines set out by Patton(3). It was followed by seven questions which were asked of all 19 women in the same order. Questions 6 and 7 were the only questions in which respondents did not express their understanding or opinions in their own terms. Question 6 consisted of 10 statements with which respondents were asked to agree or disagree and Question 7 required a "Yes" or "No" response. Answers were recorded separately on a standard interview sheet (see appendix IV).

Interviews were of 20 minutes duration. Care was taken to ask the questions in a consistent manner and tone, so that bias responses prompted by the influence of the interviewer were reduced. The interview sheets were coded numerically to allow anonymous analysis.

The reason for following up the questionnaire survey with interviews was to provide qualitative data to confirm, support or contradict the results of the questionnaire survey. Qualitative interviewing enables patients to express their opinions in their own language. The interview can capture their judgements and gain insight into 'the complexities of their individual perceptions and experiences'(4). Only 19 women were interviewed. However, the small size of the sample provides valid data. This is emphasised by Patton:

The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytic capabilities of the researcher than with sample sizes.(5)

The reasons for using the standardised open-ended interview were(6):

- The exact instrument used in the study is available for inspection
- Variations among interviews can be minimised where a number of different interviewers must be used
- The interview is highly focused so that interviewee time is carefully used

#### **4.6 Analysis of Interviews**

The quantitative data collected from Questions 6 and 7 was analysed using summary sheets and was then organised, along with the qualitative data collected, into four categories reflecting the main themes which emerged:

- Knowledge and Understanding
- Sources of Health Information
- Affects of Health Information
- Health Beliefs

#### **4.7 Limitations of the Study**

The sample population was taken from one general practice in Letchworth and was not a random sample, nor representative of the population as a whole. The study undertaken attempted to provide a "snap-shot" of a sample population in a specific geographical location, focusing on postmenopausal womens' compliance with preventive measures and prescribed treatments for osteoporosis. The study does not attempt to make generalisations for other health situations.

Compliance is a difficult factor to measure. The nature of the questionnaire survey relied upon patients to state how their behaviour had changed as a result of health information. There was no way of checking if this was valid.

The standardised open-ended interview technique adopted for the follow-up interviews did not permit the interviewer to pursue topics or issues that were not anticipated when the interview was written. It imposed constraints on lines

of questioning which could be adopted with different people, based on their unique experiences, and therefore reduced the extent to which individual differences and circumstances could be explained. However, this approach reduced individual interviewer effects, particularly necessary as two people were undertaking the interviews, and also facilitated data analysis.

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## 5. RESULTS

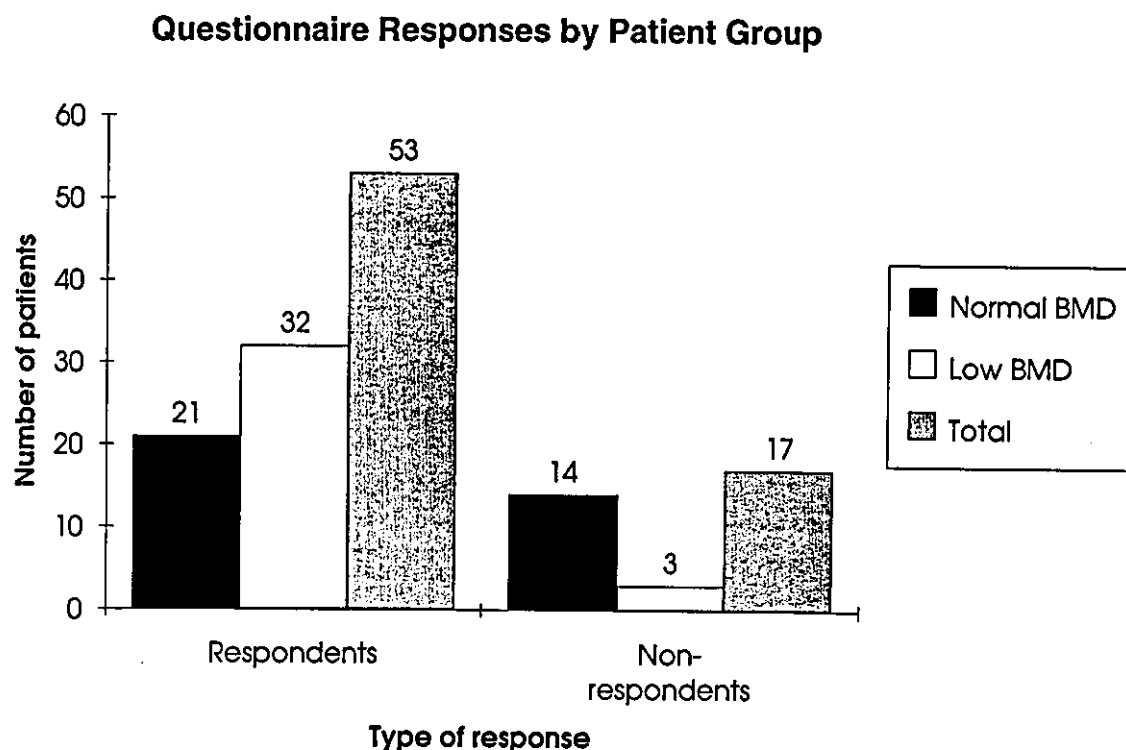
### 5.1 The Impact of Health Information Survey

#### 5.1.1 Problems Encountered in Analysing the Questionnaires

The only problem which appeared when analysing the data from the questionnaires was when a respondent had either left a question unanswered, or ticked more than one answer on certain questions. Question 9, which asked respondents to identify the single health information source most influential in affecting their compliance with treatment, was problematic as respondents ticked multiple sources. In these events, the data was categorised as "unclassified" for that particular question.

#### 5.1.2 Questionnaire Responses

Questionnaires were sent to 70 women of whom 53 (76%) returned completed questionnaires. The total sample population consisted of two patient groups: 35 women with Normal Bone Mass Density (Normal BMD) and 35 women with Low Bone Mass Density (Low BMD). Figure 1 shows the breakdown of returned questionnaires by the two patient groups. There is a significant difference in questionnaire response-rates between the two patient groups with the Normal BMD patient group recording 60% response-rate, whereas the Low BMD patient group has 91% response-rate.



**Figure 1**

This difference in response rate can be attributed to the different health situations faced by the two groups of patients. The Normal BMD patient group have been issued with advice on life-style changes. These are preventive measures as they do not have osteoporosis. However, the Low BMD patient group have osteoporosis and are undertaking prescribed HRT as well as implementing preventive measures. They are likely to take their health situation more seriously than those with Normal BMD.

This is directly related to The Health Belief Model which Ley(1) had identified as being a major factor in compliance. He suggests that patient perceptions of the following affect compliance with recommended treatments:



- perceived vulnerability
- seriousness of illness
- effectiveness of treatment
- costs and barriers of treatment

The levels of perceived vulnerability and seriousness of the illness will be higher in the Low BMD patient group and this is possibly reflected in their questionnaire response-rate.

### **5.1.3 Coverage of Health Information Topics**

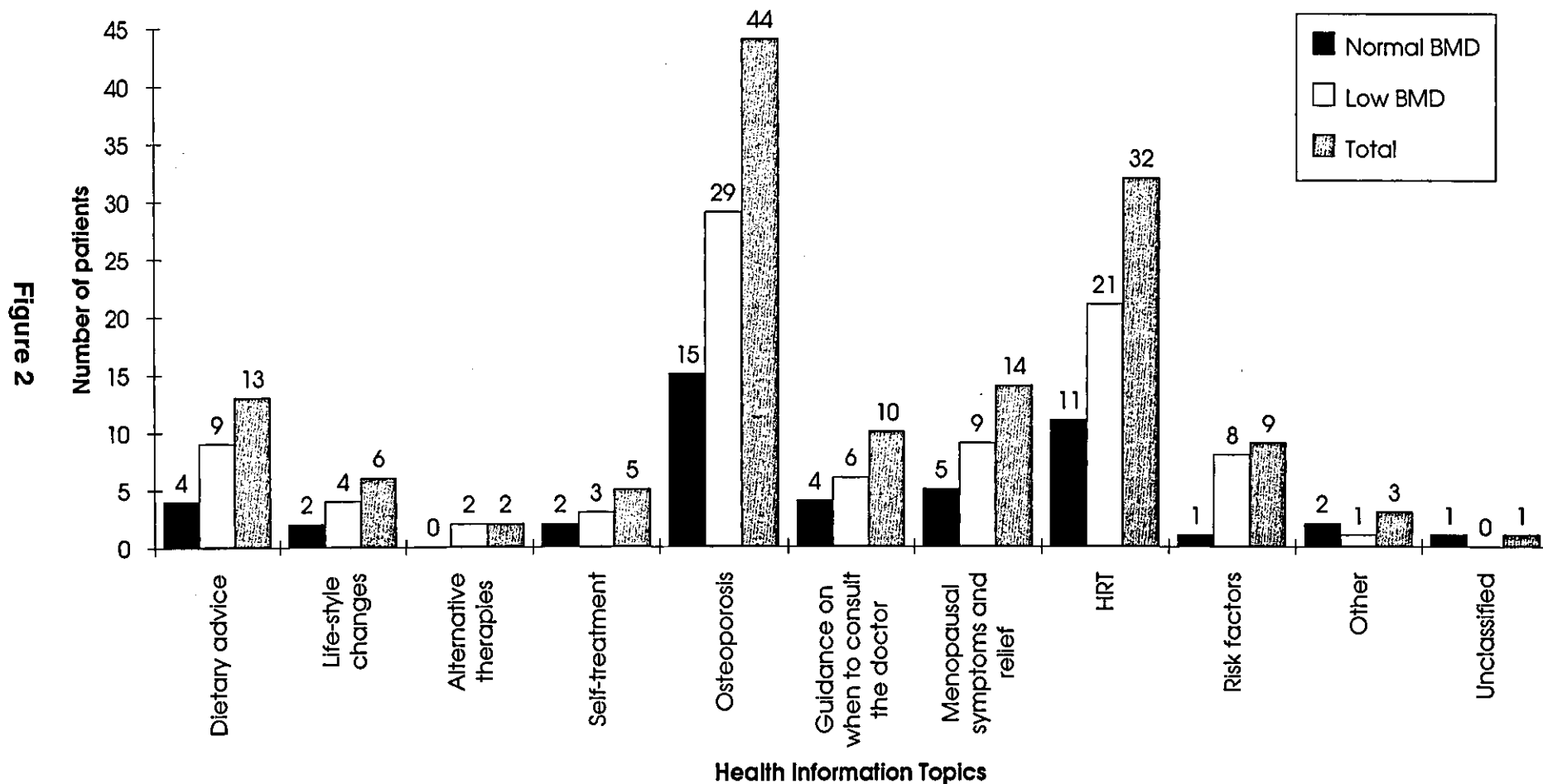
Patients were asked to recall what health topics have been covered in the general practice setting. Figure 2 shows that osteoporosis, hormone replacement therapy(HRT), menopausal symptoms and relief and dietary advice were the four most prominent health topics that patients thought had been covered.

Table 1 shows that information relating to osteoporosis was perceived to be covered by 71% of Normal BMD patients and 91% of Low BMD patients. 52% of Normal BMD patients, compared to 66% of Low BMD patients, thought that information on HRT had been provided. However, there is a large gap to the next topic with 24% of Normal BMD patients and 28% of Low BMD patients stating that information on menopausal symptoms and relief had been provided.

Interestingly, Table 1 shows that only 19% of Normal BMD patients stated that they had received information on dietary advice and only 10% of that group thought they had received information on life-style changes. This is surprising

as the Normal BMD patient group had been provided with information on such preventive measures. 25% of Low BMD patients perceived that information about risk factors associated with treatment has been covered in the general practice setting, whereas only 5% of Normal BMD patients thought that they had been informed of such risks. This difference is to be expected as prescribed treatment in the form of HRT was given to patients with Low BMD. It is notable that only a quarter of Low BMD patients thought they had received information on risk factors associated with their treatment, considering the uncertainties surrounding HRT.

## Health Information Topics Covered at The Surgery by Patient Group



**Table 1: Health Information Topics Covered at The Surgery by Patient Group**

<b>Health Information Topic</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n=32)</b>
Osteoporosis	71% (15)	91% (29)
Hormone replacement therapy(HRT)	52% (11)	66% (21)
Menopausal symptoms and relief	24% (5)	28% (9)
Dietary advice	19% (4)	28% (9)
Guidance on when to consult the doctor	19% (4)	19% (6)
Risk factors	5% (1)	25% (8)
Life-style changes	10% (2)	13% (4)
Self-treatment	10% (2)	9% (3)
Other	10% (2)	3% (1)
Alternative therapies	--	6% (2)
Unclassified	5% (1)	--

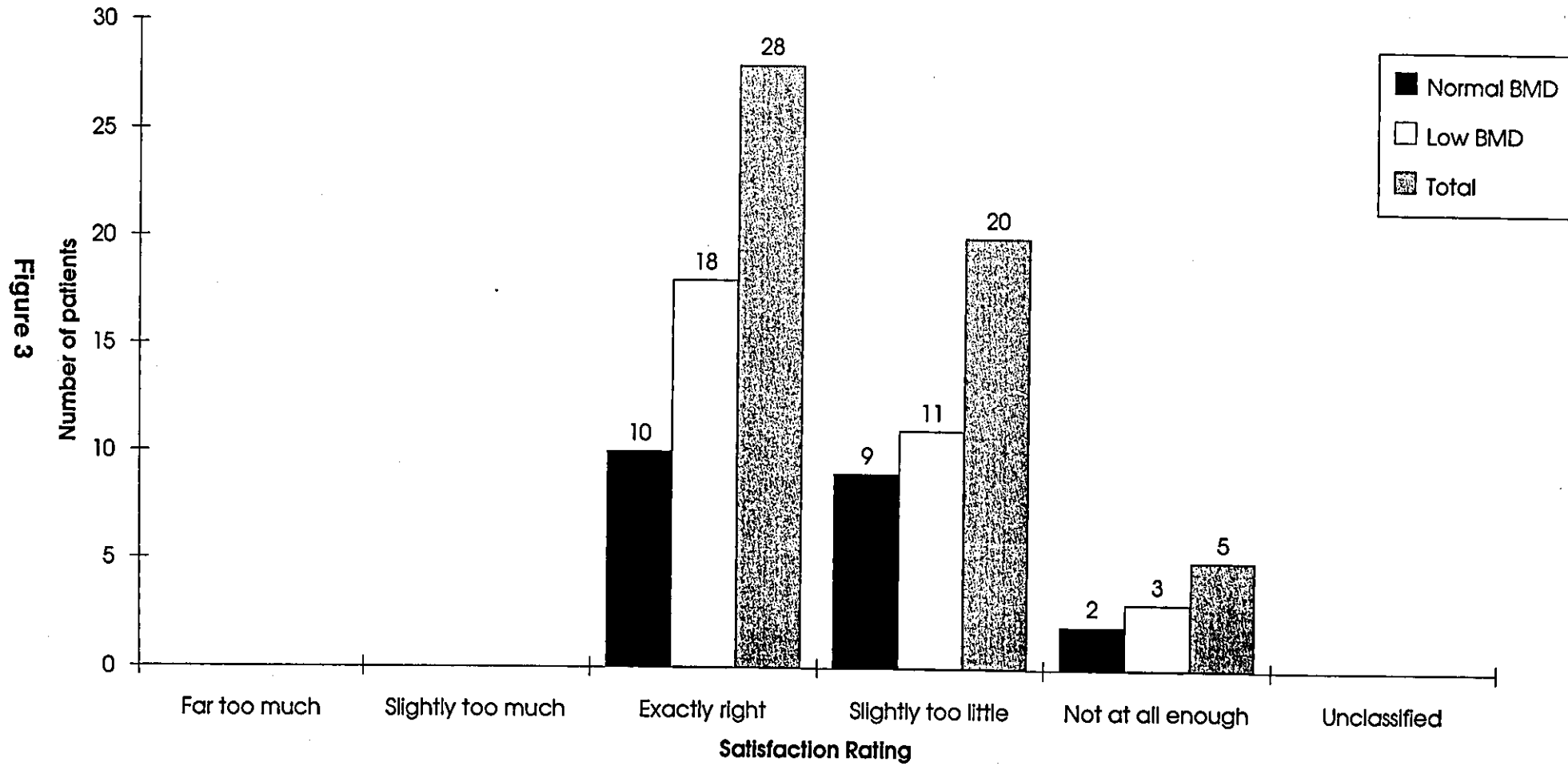
**5.1.4 Satisfaction with the Provision of Health Information**

**Table 2: Satisfaction with the Amount of Health Information  
Provided at The Surgery by Patient Group**

<b>Satisfaction rating</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>	<b>Total (n= 53)</b>
Far too much	--	--	--
Slightly too much	--	--	--
Exactly right	48% (10)	56% (18)	53% (28)
Slightly too little	43% (9)	35% (11)	38% (20)
Not at all enough	9% (2)	9% (3)	9% (5)
Unclassified	--	--	--

As can be seen from Table 2, 53% of patients thought that the amount of health information provided in the general practice setting was exactly right. However, 38% rated the amount of information provided as slightly too little and 9% stated there was not at all enough. 43% of Normal BMD patients thought there was slightly too little information provided, as opposed to 35% of Low BMD patients. This suggests that although the Normal BMD patients do not have osteoporosis, they still want health information.

Satisfaction with the Amount of Health Information Provided at The Surgery by Patient Group



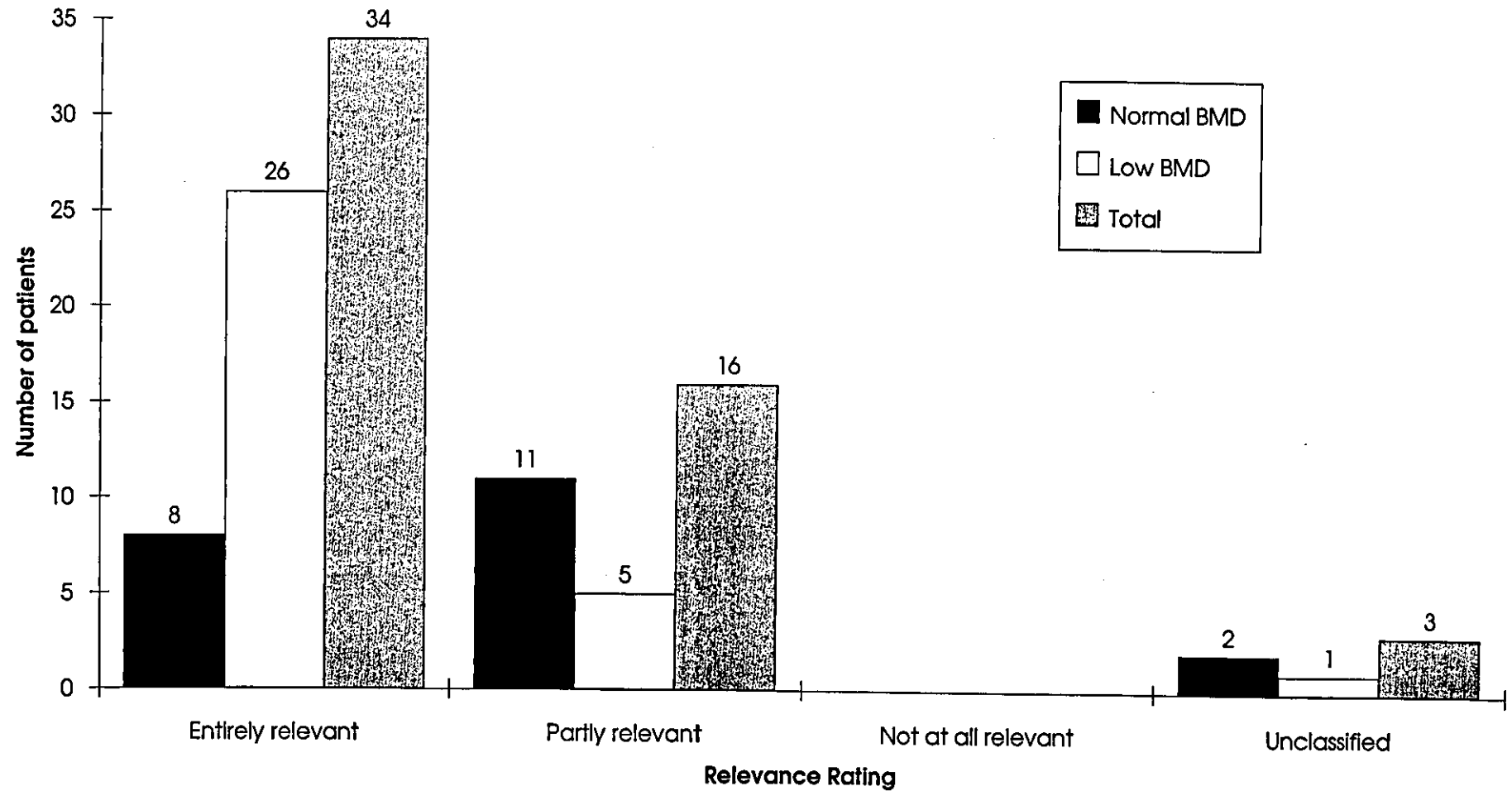
**5.1.5 Perceived Relevance of Health Information**

Table 3 shows that 64% of patients found the health information they received in the general practice setting entirely relevant to their situation; but within the patient groups there is a discrepancy. Only 38% of Normal BMD patients found the information entirely relevant, as opposed to 81% of Low BMD patients. 52% of Normal BMD patients rated the health information they received as partly relevant to their situation. This could be connected to their health beliefs about their individual situation.

**Table 3: Perceived Relevance of Health Information Provided at The Surgery by Patient Group**

<b>Relevance rating</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>	<b>Total (n= 53)</b>
Entirely relevant	38% (8)	81% (26)	64% (34)
Partly relevant	52% (11)	16% (5)	30% (16)
Not at all relevant	--	--	--
Unclassified	10% (2)	3% (1)	6% (3)

Perceived Relevance of Health Information Provided at The Surgery by Patient Group





### 5.1.6 Suitability of Level of Health Information

Measuring patients' perceptions about the level of health information given to them is significant in that a barrier to information can be created if it is too difficult, and equally, if it is too basic then this can force patients to look at other health information sources. As can be seen from Figure 5, 34 patients found the level of health information to be exactly right for their needs.

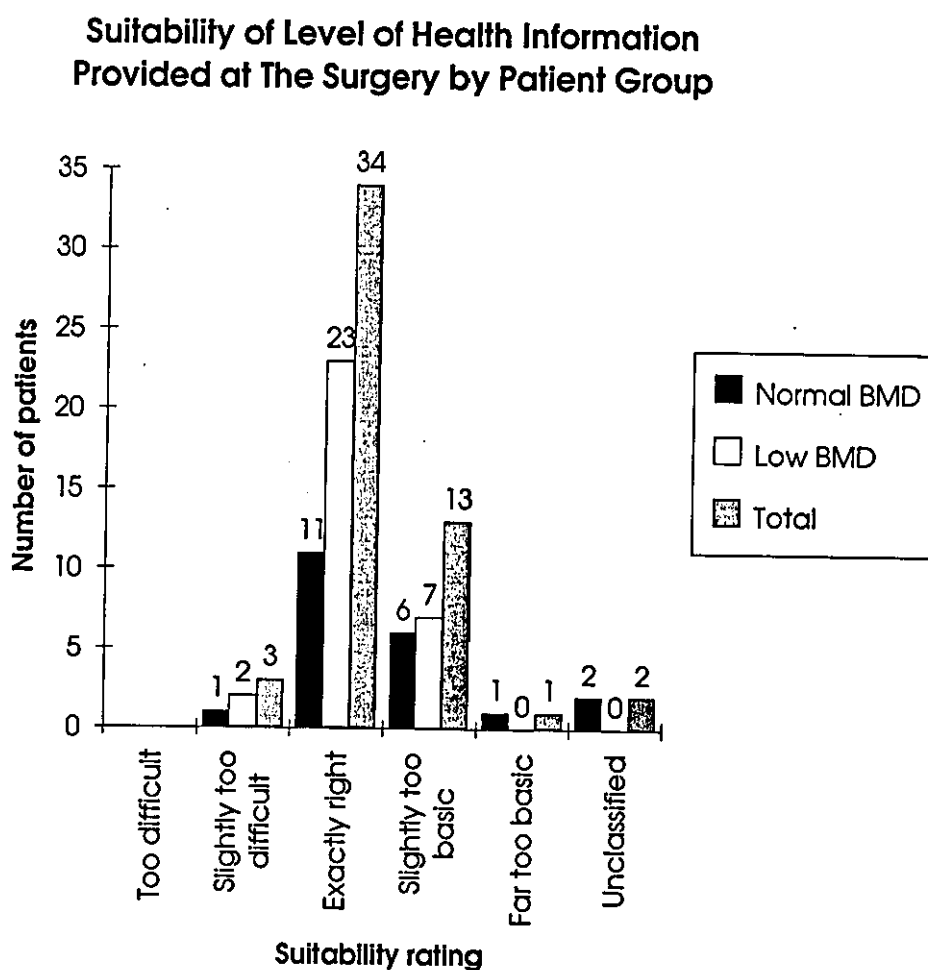


Figure 5

Table 4 shows that 64% of patients found the level of health information to be exactly right, with 25% perceiving it to be slightly too basic. There is no discrepancy between the views of the two patient groups, except to say that 20% more Low BMD patients found the level of health information to be exactly right.

**Table 4: Suitability of Level of Health Information Provided at The Surgery by Patient Group**

Suitability rating	Normal BMD (n= 21)	Low BMD (n= 32)	Total (n= 53)
Too difficult	--	--	--
Slightly too difficult	5% (1)	6% (2)	6% (3)
Exactly right	52% (11)	72% (23)	64% (34)
Slightly too basic	29% (6)	22% (7)	25% (13)
Far too basic	5% (1)	--	2% (1)
Unclassified	10% (2)	--	4% (2)

Question 10 asked respondents to indicate the type of formal educational qualification they possessed. The results from this question were cross-tabulated to patients' assessment of the level of health information provided in order to see if there was any significance (Table 5).

**Table 5: Suitability of Level of Health Information Provided at The Surgery by Educational Qualification Obtained**

<b>Educational Qualification</b>	<b>Too difficult</b>	<b>Slightly too difficult</b>	<b>Exactly right</b>	<b>Slightly too basic</b>	<b>Far too basic</b>	<b>Unclassified</b>
None	--	--	15	1	1	--
O' Levels	--	2	10	3	--	--
A' Levels	--	--	3	7	--	--
Higher education/ degree	--	--	5	2	--	2
Unclassified	--	1	1	--	--	--
Total	--	3	34	13	1	2

In order to obtain the average satisfaction rating for each type of educational qualification, the rating categories were given the following values: Too difficult= 1, Slightly too difficult= 2, Exactly right= 3, Slightly too basic= 4, Far too basic= 5. The average scores for each educational qualification are shown in Table 6.

**Table 6: Average Score for Satisfaction Rating by Educational Qualification**

<b>Educational Qualification</b>	<b>Average Score</b>
None	3.2
O' Levels	3.1
A' Levels	3.7
Higher education/degree	3.2

The hypothesis that those with no formal educational qualifications will rate the health information as too difficult can be dismissed as the average score is 3.2. The hypothesis that those with a high level of formal education will rate the health information as too basic is partly substantiated by the figures, as those patients with A' Levels have an average score of 3.7 which tends towards the slightly too basic satisfaction rating. However, those patients with a degree have an average score of 3.2 which is equal to that for those with no formal qualifications and expresses the view that the level of health information provided was exactly right for their individual needs.

**5.1.7 Impact of Health Information**

Overall, 68% of patients handled their situation differently due to the health information provided, as shown in Table 7. However, there is a significant difference between the two patient groups, with only 57% of Normal BMD patients changing their behaviour as opposed to 75% of Low BMD patients. This would be expected as those with Normal BMD do not feel as vulnerable as those with Low BMD.

**Table 7: Impact of Health Information Provided at The Surgery  
by Patient Group**

<b>Impact of health information</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>	<b>Total (n= 53)</b>
Changed behaviour	57% (12)	75% (24)	68% (36)
No change in behaviour	24% (5)	19% (6)	21% (11)
Unclassified	19% (4)	6% (2)	11% (6)

### **5.1.8 Effect of Health Information**

Table 8 shows that for 38% of Normal BMD patients and 53% of Low BMD patients the health information improved their understanding of their condition. It enable 47% of Low BMD patients and 29% of Normal BMD patients to follow instructions for prescribed drugs, and this factor would positively affect their compliance with treatment.

However, 24% of Normal BMD patients used the health information to assess risk factors and this increased to 47% for Low BMD patients, who had been prescribed HRT. This suggests that patients are using the information to make informed decisions about treatments they are prescribed. If risk factors are too great in the individual's opinion, then this will reduce compliance, particularly for prescribed drugs. This suggests that health information could have a negative effect on compliance with treatment. However, 47% of Low BMD patients and 24% of Normal BMD patients were stimulated to ask more questions of health professionals by the information they received. This suggests that as patients become more informed, particularly of risk factors associated with treatment, they turn to health professionals for advice. An awareness of risk factors provided by health information does not necessarily prompt non-compliance with treatment. The figures suggest that patients enter into discussions with health professionals when their concerns have been aroused by access to health information. 38% of Low BMD patients and 29% of Normal BMD patients made choices about treatment as a result of the health information they accessed. This suggests that information has empowered individuals, leaving the decision to comply with treatment in their hands.

**Table 8: Effect of Health Information Accessed by Patient Group**

<b>Effect of health information</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>
Improve understanding of condition	38% (8)	53% (17)
Follow instructions for prescribed drugs	29% (6)	47% (15)
Stimulate more questions to ask GP/nurse	24% (5)	47% (15)
Assess risk factors	24% (5)	47% (15)
Make choices about treatment	29% (6)	38% (12)
Gain reassurance	24% (5)	34% (11)
Assess side effects	19% (4)	31% (10)
Confirm prior knowledge	24% (5)	28% (9)
Improve life-style	24% (5)	16% (5)
Refresh memory of details/facts	19% (4)	19% (6)
Substantiate what GP/nurse had said	5% (1)	19% (6)
Nothing	10% (2)	3% (1)
Unclassified	10% (2)	3% (1)
Other	5% (1)	--

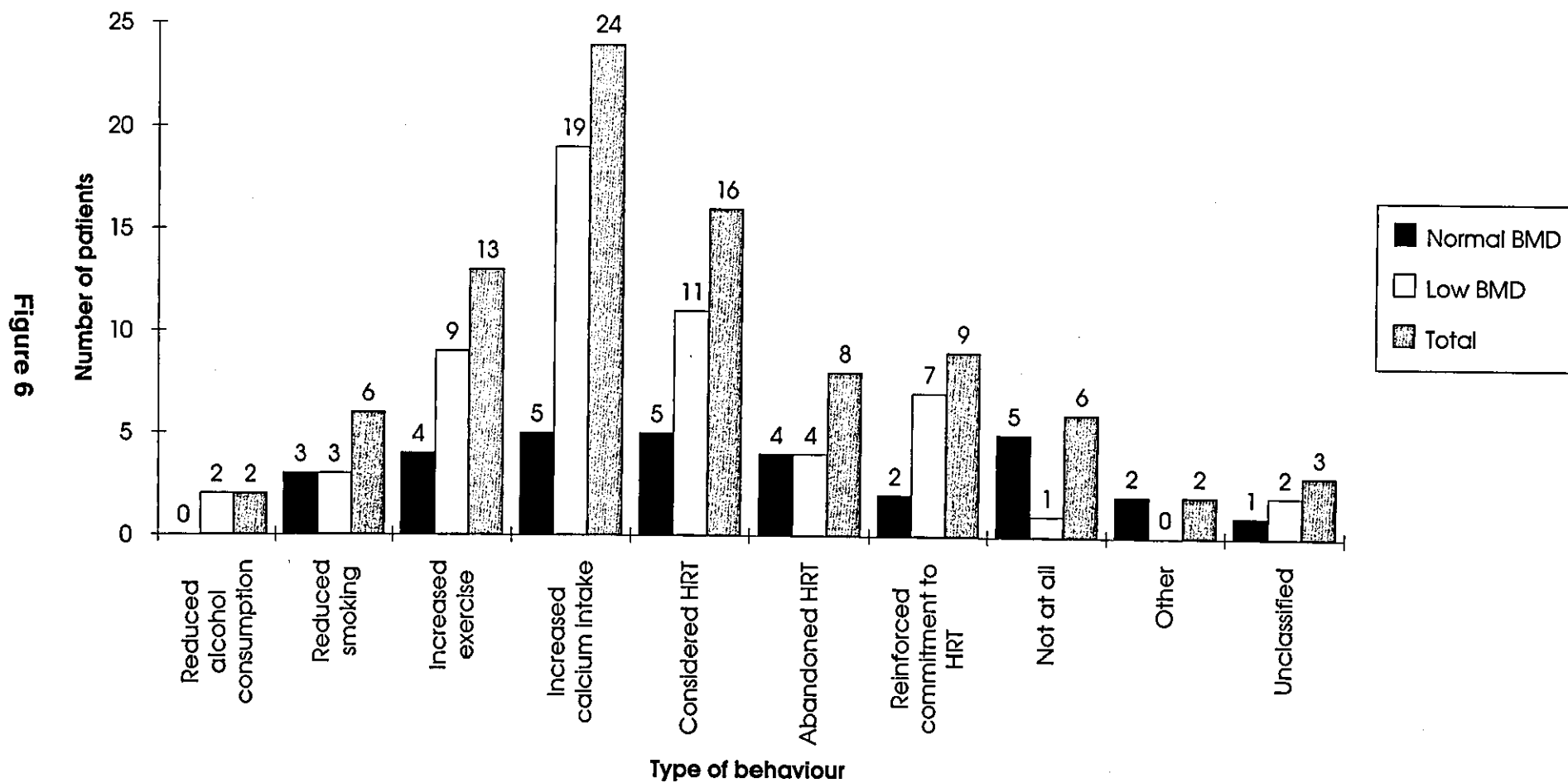
### **5.1.9 Impact of Health Information on Behaviour**

Figure 6 shows that 24 patients in total increased their dietary calcium intake having accessed health information. This type of preventive behaviour was taken by 19 Low BMD patients and 5 Normal BMD patients.

Table 9 shows that 22% of Low BMD patients had become committed to continuing taking HRT and that 34% of this group had considered HRT as a result of accessing health information on the subject. However, 13% of Low BMD patients had abandoned HRT, probably due to an assessment of risk factors or side effects. 24% of Normal BMD had not changed their behaviour at all as opposed to only 3% of Low BMD patients. In the "Other" category, the types of behaviour health information prompted was: to start HRT and to attend homeopathic consultation.



Impact of Health Information on Types of Behavioural Change by Patient Group

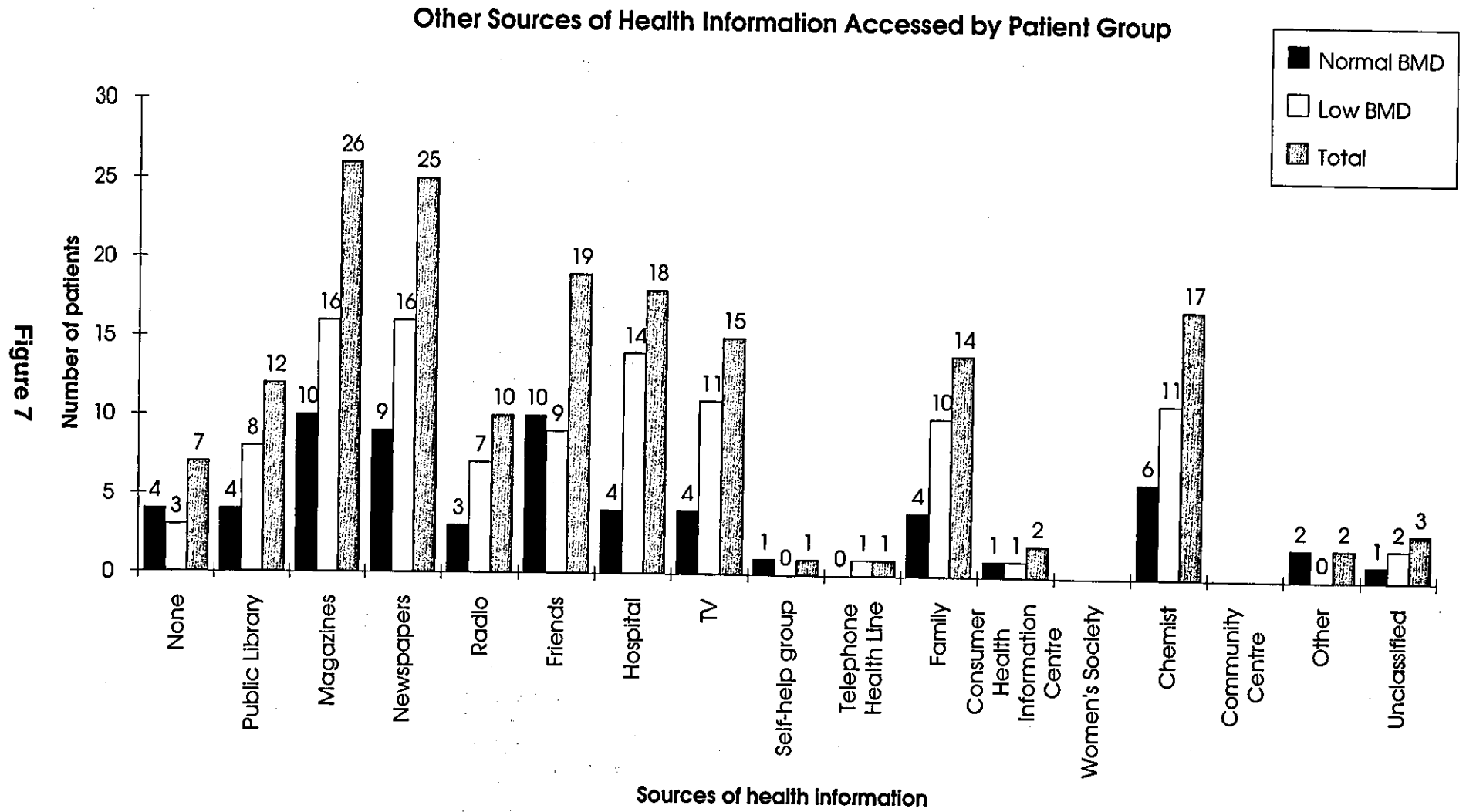


**Table 9: Impact of Health Information on Types of Behavioural Change by Patient Group**

<b>Type of behaviour</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>
Increased calcium intake	24% (5)	59% (19)
Considered HRT	24% (5)	34% (11)
Increased exercise	19% (4)	28% (9)
Reinforced commitment to HRT	10% (2)	22% (7)
Abandoned HRT	19% (4)	13% (4)
Reduced smoking	14% (3)	9% (3)
Not at all	24% (5)	3% (1)
Unclassified	5% (1)	6% (2)
Other	10% (2)	--
Reduced alcohol consumption	--	6% (2)

#### **5.1.10      Sources of Health Information**

Traditional sources of health information were the most used sources of health information outside of the general practice, as shown in Figure 7. It is significant that the newly established sources of health information, like telephone health lines and consumer health information centres, have been accessed by only 3-5% of the sample population, as can be seen in Table 10. Magazines and newspapers are used by just under 50% of the patients. The informal source for health information of friends is used by 48% of Normal BMD patients and 28% of Low BMD patients; a significant difference in patient groups. The hospital is used by 44% of Low BMD patients, as opposed to 19% for Normal BMD patients and this is expected due to the differing health conditions, with hospital referral being more common among Low BMD patients. The chemist is a significant source of health information for both patient groups, as is the public library. 19% of Normal BMD patients accessed no other sources of health information outside of the general practice setting, compared to only 9% of Low BMD patients, indicating a difference in motivation between the two groups probably influenced by health beliefs. The community centre and women's society were not used as sources of health information by any patients within the sample population.



**Table 10: Other Sources of Health Information Accessed by Patient Group**

<b>Sources of health information</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>
Magazines	48% (10)	50% (16)
Newspapers	43% (9)	50% (16)
Friends	48% (10)	28% (9)
Hospital	19% (4)	44% (14)
Chemist	29% (6)	34% (11)
TV	19% (4)	34% (11)
Family	19% (4)	31% (10)
Public Library	19% (4)	25% (8)
Radio	14% (3)	22% (7)
None	19% (4)	9% (3)
Unclassified	5% (1)	6% (2)
Consumer health information centre	5% (1)	3% (1)
Other	10% (2)	--
Self-help group	5% (1)	--
Telephone health line	--	3% (1)

#### **5.1.11      Impact of Health Information Sources**

Table 11 shows that the GP is considered the most influential source of health information in affecting compliance with treatment, with 47% of Low BMD patients stating this, compared to 19% of Normal BMD patients. 29% of Normal BMD patients stated that the menopause clinic nurse was the most influential source of health information in affecting their compliance with treatment. Of the "Other" sources of health information stated, one Normal BMD patient considered the homeopathic centre as the most influential and one Low BMD patient stated that the Patient Information Collection(PIC) in the general practice setting was the most influential source affecting her compliance with treatment. Significantly, 29% of Normal BMD patients identified that no source of information was most influential in affecting their compliance with treatment, whereas only 9% of Low BMD patients responded that this was the case.

Ten health information sources were not considered by the sample population and received zero response rate, namely: radio, friends, TV, self-help group, telephone health line, family, consumer health information centre, women's centre, chemist, health visitor. 9 responses were "unclassified" as more than one information source was identified on the questionnaire survey for this question.

**Table 11: Single Health Information Source Most Influential in Affecting Compliance with Treatment by Patient Group**

<b>Health Information Source</b>	<b>Normal BMD (n= 21)</b>	<b>Low BMD (n= 32)</b>
GP/Doctor	19% (4)	47% (15)
None	29% (6)	9% (3)
Menopause clinic nurse	29% (6)	6% (2)
Unclassified	10% (2)	22% (7)
Newspapers	5% (1)	3% (1)
Hospital	--	6% (2)
Other	5% (1)	3% (1)
Magazines	5% (1)	--
Public Library	--	3% (1)

## **5.2 Standardised Open-Ended Interviews**

### **5.2.1 Problems Encountered in Analysing the Interviews**

There was no way of determining how many women would volunteer to be interviewed, or what proportion from each group would come forward. In total 19 women were interviewed, of which 9 women were in the normal bone mineral density group (Normal BMD) and 10 were from the low bone mineral density group (Low BMD).

A tape recorder was not used during the interviews, as this factor could have inhibited responses to the questions. Answers were therefore written on the interview sheet by the interviewer. There was difficulty in transcribing the words of the patient being interviewed while responding via verbal and non-verbal communication to what was being said. On analysing the written evidence, some answers were illegible and other statements were incomplete. Question 6 required patients to agree or disagree with 10 statements. Some patients replied that they "did not know" and this was recorded as a valid answer on the interview form.

### **5.2.2 Knowledge and Understanding**

Patients were asked to respond to 10 statements in order to gain an insight into their knowledge and understanding of the prevention and treatment of osteoporosis.



**Table 12: Responses to Statements Testing Health Knowledge,  
Understanding and Beliefs by Patient Group**

Statement No.	Normal BMD (n= 9)			Low BMD (n= 10)		
	Agree	Disagree	Don't Know	Agree	Disagree	Don't Know
<b>1</b>	89% (8)	11% (1)	--	90% (9)	10% (1)	--
<b>2</b>	100% (9)	--	--	90% (9)	10% (1)	--
<b>3</b>	89% (8)	11% (1)	--	100% (10)	--	--
<b>4</b>	100% (9)	--	--	100% (10)	--	--
<b>5</b>	56% (5)	33% (3)	11% (1)	80% (8)	10% (1)	10% (1)
<b>6</b>	--	100% (9)	--	30% (3)	70% (7)	--
<b>7</b>	67% (6)	33% (3)	--	60% (6)	30% (3)	10% (1)
<b>8</b>	78% (7)	22% (2)	--	90% (9)	10% (1)	--
<b>9</b>	100% (9)	--	--	100% (10)	--	--
<b>10</b>	--	100% (9)	--	10% (1)	90% (9)	--

**Statements:**

1. Oestrogen deficiency is the most important factor in the development of osteoporosis.
2. Eating and drinking more dietary sources of calcium reduces the risk of bone fractures.
3. Hormone replacement therapy replenishes the natural supply of oestrogen lost at the menopause.
4. Calcium deficiency is an important factor in the development of osteoporosis.
5. Hormone replacement therapy is only prescribed for between five and ten years because of concerns about an increased risk of breast cancer with longer-term therapy.
6. Regular exercise does not improve bone structure.
7. Hormone replacement therapy offers protection against coronary heart disease and stroke.
8. Smoking and excessive alcohol consumption accelerates the rate of postmenopausal bone loss.
9. Written health information enables patients to follow treatment prescribed by their GP.
10. Changing your life-style now makes no difference to your health in the future.

Both Normal BMD patients and Low BMD patients displayed a clear understanding that oestrogen deficiency is central to the development of osteoporosis. As can be seen in Table 12 , 89% of Normal BMD patients and 90% of Low BMD patients agreed with Statement 1, which defines oestrogen deficiency as the most important factor in the development of osteoporosis. The role of hormone replacement therapy(HRT) in replenishing the oestrogen lost at the menopause is acknowledged by both patient groups.

There was unanimous agreement that calcium deficiency is an important factor in the development of osteoporosis. 100% of Normal BMD patients and 90% of Low BMD patients agreed that increasing dietary sources of calcium would reduce the risk of bone fracture. This cognitive understanding of the role of calcium has resulted in behavioural change, as can be substantiated by Figure 6 which shows 24 patients recorded that health information had prompted them to increase their calcium intake.

With reference to Table 12, all 19 patients agreed with Statement 9 that written health information facilitates compliance with treatment. In terms of health beliefs, 18 patients believed that decisions and behaviour implemented in the present have an impact on their future state of health. This suggests that those patients have an internal locus of control.

Statements 5, 6, 7 and 8 caused some confusion for both patient groups. Only 56% of Normal BMD patients were aware of the increased risk of breast cancer associated with long-term HRT, as opposed to 80% of Low BMD patients. However, this would be expected as most Normal BMD patients have not been prescribed HRT. 100% of Normal BMD patients were aware that regular exercise improves bone structure, whereas only 70% of Low BMD patients displayed this understanding. This can be explained by the fact that

Normal BMD patients have been issued with information specifically on preventive measures, like increasing exercise, and the benefits associated with such changes in behaviour. 33% of Normal BMD patients and 40% of Low BMD patients were not aware that HRT offers protection against coronary heart disease and stroke. It is surprising that 4 Low BMD patients were not aware of this benefit, as they have been targeted with information regarding HRT. Most patients understood the negative effects of smoking and alcohol consumption, but 2 Normal BMD patients disagreed with Statement 8 which linked such behaviour to an acceleration in the rate of postmenopausal bone loss.

**Table 13: Responses to Offer of More Information About Osteoporosis by Patient Group**

Patient Group	Yes	No
Normal BMD	44% (4)	55% (5)
Low BMD	70% (7)	30% (3)
Total	58% (11)	42% (8)

Table 13 shows how patients responded to the offer of more information. When asked if they would like more information about osteoporosis, 70% of Low BMD patients confirmed that they would, compared to 44% of Normal BMD patients. This reflects the differing health situations of the two patient groups with the Low BMD patients feeling a closer association, and more vulnerable, to osteoporosis. Despite a clear basic understanding of osteoporosis, 58% of patients interviewed still felt they would like more information about osteoporosis.

### Low BMD Patient Group:

The Low BMD patient group displayed a reasonable understanding of the term 'osteoporosis' and the cause of the disease. All 10 patients from this group associated the disease with "brittle bones" or "thinning of the bones" which leads to increased incidence of breakage and fracture. 5 patients associated osteoporosis with the menopause, although there was some confusion concerning the role of hormones in the development of the disease:

"It's to do with the menopause and not making the right sort of oestrogen."

"Older bones get softer and more spongy because of hormone changes."

"Elderly women are deprived of hormones which causes thinning of the bones and leads to more breakages."

One patient suggested that her brittle bones were caused by having a hysterectomy, although she did not understand the implications of a lack of oestrogen; only that she was glad not to be taking HRT because of the risk of cancer. One patient raised the genetic factor as a cause, but was unsure about this:

"I don't know whether it's hereditary, but I was asked about my family history."

### Normal BMD Patient Group:

The Normal BMD patient group were less well informed about the meaning and cause of osteoporosis, compared to the Low BMD patients. All 9 patients

associated the disease with "brittle bones" but further probing exposed no further understanding among 6 patients. There were exceptions to this however:

"It's brittle bones connected to hormonal change at the menopause."

"It's more common in women and caused by falling hormone levels- yes, lack of oestrogen after menopause in women."

There was an awareness of terms associated with osteoporosis, but a lack of understanding connected with how such terms fitted together into a coherent conceptual framework.

"The bones go fragile and it's just women who get it. I don't know if it's diet or in the genes- and hormones contribute as well."

These patients had been issued with advice on preventive measures. There was a tendency for them to emphasise such factors in their definition of osteoporosis:

"It's the softening and weakening of bones due to lack of calcium and lack of exercise."

"I know it's caused by the menopause, lack of calcium, lack of exercise and it can be inherited."

### 5.2.3 Sources of Health Information

#### Low BMD Patient Group:

All 10 patients confirmed that they had received advice on increasing calcium intake and levels of exercise, as well as information about HRT, in the general practice setting. A verbal explanation was provided by the GP. 8 patients said that this was followed up by written information in leaflet format from the menopause clinic nurse.

"I first of all went for a bone scan which showed deficiencies in the spine which was beginning to thin. I was on HRT for four months to rebuild the bones and help my heart and I took calcium tablets. I had no written information but got a verbal explanation. I was sent a leaflet that I had to read and sign."

Significantly, 3 patients had contacted the Osteoporosis Society for more information. They had found its address in prescription leaflets and in leaflets issued by the menopause clinic nurse:

"I received leaflets from the menopause clinic nurse which were easy to understand and useful. It was nice to have the name of a society to contact. If I felt worried I knew I had a back up to write to independently."

The Patient Information Collection (PIC) located within the general practice setting was used as an information source by 4 patients who stated that they took out books and articles on osteoporosis. Magazines, newspapers, TV and radio were used by 8 patients:

"There's a lot in the women's magazines about osteoporosis. I read *Choice*- a monthly publication."

One patient stated that information from the media was "more readily available" than any other information source. *This Morning* was cited by one patient as a TV programme through which she had obtained information on osteoporosis. However, she stated that such TV programmes could be,

"a little bit alarmist at times which can be unhelpful."

The hospital and friends were quoted as other information sources. 3 patients had used their public library. One patient said that she had read about a Consumer Health Information Line in a newspaper and consequently rang up to obtain information on osteoporosis:

"They were very helpful. I received a batch of information in four days of ringing up."

Normal BMD Patient Group:

All 9 patients said that they had received information from the menopause clinic nurse about preventive measures concerned with diet and lifestyle, with 5 patients confirming that they had been informed about HRT from the general practice setting. However, no Normal BMD patients specified that they had used the Patient Information Collection(PIC) in the general practice, with 3 patients responding that they were not aware of its existence when probed by the interviewer.

All 9 patients had used magazines and newspapers as an information source on osteoporosis. Other media, such as radio and TV, were also noted but the lack of interaction was specified by one patient:

"It's interesting and sometimes helpful, but you can't ask the TV a question."

One patient had used the homeopathic centre she attended and another patient had listened to a talk about the side-effects associated with HRT organised by a women's society she was a member of. The hospital was cited as an information source by one Normal BMD patient.

5 patients said that they used the public library. 7 patients responded that they entered into discussions with friends, exchanging the knowledge they had obtained in an informal setting.

"I've got most of my information from the library and magazines. I cut out relevant articles. I don't rely on other people to get things done, I refer to information."

"One of my friends has started taking HRT and she's developed a lump on her breast. Others say it's wonderful. I think they're rather anti-HRT at this surgery. It's meant to prevent heart disease and brittle bones. (How did you find out about that?) Oh, I read it somewhere. I read a lot in magazines and newspapers and use the public library."

"A friend of mine got osteoporosis and she told me about what was happening to her."

#### **5.2.4 Effects of Health Information**

##### **Low BMD Patient Group:**

All 10 Low BMD patients suggested that health information they had accessed increased their awareness of osteoporosis. 8 patients recorded 100% compliance with taking HRT, and all patients said that they were actively



pursuing preventive measures which included increasing calcium intake and maintaining exercise levels.

"I increased my exercise levels and continued with my previous fairly healthy diet. I'm more aware of the reasons for keeping bones healthy now."

6 patients noted that the health information they had accessed improved their understanding of their health situation:

"It answers unanswered questions."

"It does help you understand what's going on."

"I've built up a memory bank of knowledge."

There were differing views about whether changing behaviour could affect their health situation. Two patients asserted that patients had to be active and that health information enabled them to participate in their own health care:

"It's common sense- the patient has to do their part as well."

"A lot of people don't like taking a drug over a period of time. I think you should assess side effects yourself- but I have faith in my doctor."

However, there was a passive attitude amongst some patients:

"The help came too late."

"The information makes you think. As far as I understand it, there's not a lot I can do. I didn't receive any information about prevention. I think you can prevent it when you are young."

8 patients found that the information they received within the general practice setting was not contradicted by information they accessed from other information sources. They responded that the information from all sources supported each other:

"It supported information from The Surgery."

"I took magazine articles away from The Surgery. They confirmed what had been said by the GP and nurse. It was nice to take home and confirm a few things. It is more about other people's experiences. I started taking HRT. It was recommended by the doctor."

"I've found no contradictions. The information I got from The Surgery was backed up by what the official Osteoporosis Society leaflet said- though it did give me a few more ideas, like types of exercise, and not to do aerobics."

"Information from the hospital supported information given at The Surgery."

However, 2 patients voiced confusion at the range of sources of health information available and the different messages that they conveyed.

"You know, you sit down in The Surgery and things are thrown at you. At least it's getting more preventive now. I find it confusing- there's too much information and it's often contradictory."

Identifying the information source which was most influential in affecting their compliance with treatment, all 10 patients stressed that health professionals in the general practice setting were the most important and influential sources of health information. 3 patients responded that the time constraints and pressure in the consultation room meant that other information sources were necessary and useful. However, patients stressed that they needed to discuss

the implications of the health information they had accessed with health professionals. They wanted to check with their doctor whether they should apply the knowledge they had acquired to their individual situation.

"There's a lot in the women's magazines about osteoporosis and I listen to Jimmy Young on the radio, but I've nobody to discuss it with afterwards. Magazine articles are clearly written and easy to understand. It gives you the opportunity of digesting information at your leisure because when you're with the doctor, no matter what anyone says, you're hyped up and can't take things in."

"All the things I want to say to the GP go out of my mind. I don't like to hold him up. I suppose I should read up, but I suppose I'm just lazy. If anything, it's usually the newspaper and TV programmes- they're never long enough, you can't get much in half an hour."

"I took a book from the collection here at The Surgery. Sometimes the only information I've had is what I've read. I asked for HRT fifteen years ago, but they told me I didn't need it. Nowadays they treat you as people who have a part to play in disease prevention."

7 patients responded that information from sources other than the general practice were useful, but that they would always return to health professionals to discuss the information they had accessed before implementing changes in their behaviour:

"The media provokes interest but is often misleading as it tends to take the sensational aspects of health."

"Information from magazines, newspapers, radio and TV is more readily available than the GP. It explains to you about diet and exercise. You have to pick out the bits that are relevant. It's not more influential than the GP though."

"I tend to think that what the doctor tells me is right, rather than rely on another source."

"I prefer to take vitamins through diet rather than vitamin supplements because you can overdose on vitamin A and E. I got that from an article in the *Daily Mail*. But I wouldn't go off on a tangent on my own after reading something like that, not without asking the doctor."

Normal BMD Patient Group:

6 Normal BMD patients reported that health information had enabled them to comply with preventive measures associated with increasing calcium intake and exercise levels. 2 patients had started HRT, but one had abandoned the treatment after 6-8 months on doctor's advice. Health information had facilitated compliance and increased understanding:

"I'm more aware of bones and the importance of healthy bones."

"The information I received made adherence to treatment easier."

"I think it has changed my attitude in some ways- it helped me quite a bit."

All patients read newspapers and magazines and they were seen as a reliable source of health information by 3 patients:

"Most magazines contain information about osteoporosis. I read *Woman* and *Eva*- I think they offer up to date information."

"I trust the magazine articles. After all, most of them are in-depth studies by doctors and nurses, aren't they?"

However, as with Low BMD patients, all those interviewed stressed that they would always return to health professionals to discuss the information they had accessed before implementing behavioural changes:

"All the magazines and TV said not to go on HRT, so I had a discussion with the practice nurse."

"I decided not to take HRT after advice from the practice nurse."

"Magazine articles have an impact enough to make me question other people, those who know about it- the health professionals, I mean. I also discuss with friends."

8 patients said that information they had accessed from other sources had reinforced and supported the information issued within the general practice setting. One patient found that external information sources she had accessed contradicted the information issued at The Surgery:

"There was some conflict on dietary matters. I've been told to increase calcium intake, but other articles tell you to watch your fat intake."

There was unanimous agreement among Normal BMD patients that health information from external sources increased their understanding, but they would always take the knowledge they had gained back to their GP in order to share it and check its validity before changing behaviour or deciding not to comply with treatment.

"You can't ask the TV a question- it doesn't answer back."

"I wouldn't take as gospel what I read. I'd always use these people (health professionals) and get information if I wanted it. The major influence has been the Well Woman Clinic. I'm lippy enough to ask the doctor if I want to know anything."

"I cut out clippings to ask the doctor."

"I take more notice of advice from the doctor than from outside sources."

### 5.2.5 Health Beliefs

#### Low BMD Patient Group:

All 10 patients agreed that decisions taken about diet, exercise and life-style affected their health in the present and in the future. This indicates that they have an internal locus of control which positively influences compliance with treatment.

"Your health is the most important thing."

"Your decisions matter enormously."

"It does affect your health, definitely."

"It does matter. We can do things ourselves."

"A healthy lifestyle is very important for continued independence."

#### Normal BMD Patient Group:

All 9 patients agreed that their decisions concerning diet, exercise and life-style affected their health, noting that they were active agents in controlling their environment. It was significant that 3 patients from this group focused on the importance of making the right decisions.

"Your diet and life-style does matter, but you don't always know if your making the right decisions."

"Yes, as long as you take the right decisions, otherwise it could be detrimental."

"It does matter. I think about it when I cough in the morning."

"It matters to keep active and watch your diet."

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## **6. CONCLUSION**

### **6.1 Sources of Health Information**

#### **6.1.1 General Practice Setting**

The general practice setting provided information on osteoporosis and hormone replacement therapy(HRT) to over half of the sample population, but other topics such as dietary advice, life-style changes and risk factors were less well covered. Patients with normal bone mineral density(Normal BMD), who were targeted with preventive advice, perceived that information on dietary advice and life-style changes was rarely covered. Only a quarter of low bone mineral density(Low BMD) patients perceived that they had received information on risk factors associated with treatment. As the majority of this patient group have been administered with HRT, about which there is much debate surrounding risk factors, then this indicates an unmet information need.

Half of the sample population indicated that the amount of health information provided in the general practice setting was exactly right. Although over 60% of patients perceived such information to be entirely relevant to their individual situation, there was a marked disparity in patient groups with over half of the Normal BMD patients indicating that it was partly relevant. This rating could be influenced by health beliefs and the low vulnerability to osteoporosis such a group associates with its health situation. Over 60% of patients found the level of health information provided in the general practice setting to be exactly right and the level of formal education attained by each patient did not influence their rating. This indicates a high level of satisfaction with the



amount, relevance and level of health information provided within the general practice setting.

However, not all the information resources within the general practice setting are being exploited by patients. The Patient Information Collection(PIC), based in the general practice, was not used by over two thirds of those patients interviewed and many were unaware of its existence. This suggests that such resources need to be better promoted and more accessible within the general practice setting.

#### **6.1.2 Other Sources**

The newly established sources of health information, such as telephone health lines and consumer health information centres, are hardly used at all. By far the most popular sources of health information outside of the general practice setting are the traditional sources. Half of the sample population accessed information from magazines and newspapers with other media sources, such as TV and radio figuring prominently. This supports Nachtigall's assessment that the media is a significant source of health information for postmenopausal women.

Hormone therapy has caught the attention of the media recently, and their reports constitute a large part of women's education about hormone therapy.(1)

The informal interpersonal networks of family and friends are heavily used as sources of health information, but with a significant difference in patient groups. Half of the Normal BMD patients used friends, compared to 28% of Low BMD patients. This trend is reversed for the family as a source of health information with significantly more Low BMD patients using this as a source.

Normal BMD patients use the informal network of friends as they do not have as much contact with health professionals. Over half of Low BMD patients used the hospital as an information source. The chemist and public library were also used.

Other sources of health information were explored by a majority of patients, with under 20% of the sample population accessing no other sources of health information outside of the general practice setting. The range of such sources was wide. Patients felt they were encouraged to explore other sources of health information. The majority were satisfied with the amount of information they were given and had access to.

## **6.2 Impact on Patient Compliance**

Three quarters of the sample population had changed their behaviour as a result of the health information provided in the general practice setting. It prompted over half of the sample population to increase their calcium intake and exercise levels. It informed patients about HRT and a significant proportion of patients either considered such therapy, or reinforced their commitment to it. However, almost a quarter of patients abandoned HRT, but only after detailed discussions with health professionals.

Overall, health information positively affected patients' compliance with treatment. It enabled patients to improve their understanding of their condition and to follow instructions for prescribed drugs. However, half of the Low BMD patients, who had been prescribed HRT, used the health information to assess risk factors. If risk factors are too great in the individual's opinion, then this will reduce compliance, particularly for prescribed drugs. This suggests

that health information could have a negative effect on compliance with treatment. Patients are using information to make informed decisions about treatments they are prescribed. The ability to make such choices suggests that information has empowered individuals, leaving the decision to comply with treatment in their hands.

Patients understanding of osteoporosis and associated treatments was generally good, except there was some confusion surrounding risk factors and benefits associated with HRT. Only one quarter of those prescribed HRT perceived that they had received information about risk factors within the general practice setting. This might entail that such information could be obtained from other information sources, prompting non-compliance with treatment. However, this study concludes that this is not the case.

Health information from sources beyond the general practice setting does not prompt non-compliance, even when it contradicts information disseminated in the general practice. Maslow suggests that some women trust information from magazines articles and newspapers more than information provided in the general practice setting.

Some women trust their physician and other health care professionals to provide good advice about treatments, but others are suspicious and trust the media reports instead.(2)

This study provides evidence that this does not occur. A significant number of patients were stimulated to ask more questions of health professionals by the information they received and accessed. This suggests that as patients become more informed, particularly of risk factors associated with treatments, they turn to health professionals for advice. An awareness of risk factors provided by health information does not necessarily prompt non-compliance

with treatment. Rather patients enter into discussions with health professionals when their concerns have been aroused by access to health information.

Health professionals located within the general practice setting were identified as the most influential sources of health information in affecting compliance with treatment. The general practitioner was identified by the majority of Low BMD patients as the most influential source, whereas Normal BMD patients identified the menopause clinic nurse as the most influential. This reflects the health professional the different patient groups saw the most in the general practice setting. When patients accessed health information from beyond the general practice setting, they stressed the need to discuss the implications of the health information they had accessed with health professionals. Patients wanted to check with their doctors whether they should apply the knowledge they had acquired to their individual situation.

Patients stated in interviews that they would bring health information, often in the physical format of books or newspaper cuttings, to the consultation room. They would discuss it with health professionals, thereby supplementing and enforcing the knowledge of health professionals. Knight(3) has quoted Osmond in defining the basis of authority in the doctor/patient relationship. It is sapiental, in that doctors must know or appear to know more about medicine than their patients, and also charismatic, 'which comes close to magical powers in that patients often do not understand what the treatment is doing to them, only that they are hopefully being healed'. That patients bring health information to the consultation room adds to the sapiental basis of the doctor's authority. Patients contribute to the doctor's knowledge, and reinforce their belief in his/her seemingly magical powers: it is a mutually enforced, cyclical process in which both patients and their doctors are embroiled.

### **6.3    Health Beliefs**

The significant impact of health beliefs on patients' compliance with treatment was identified in the responses of the two patient groups. Those with Normal BMD reported significantly reduced compliance to treatment compared to the Low BMD patient group. This can be attributed to the different levels of vulnerability to osteoporosis perceived by the two patient groups. Low BMD patients investigated a wider range of health information sources outside of the general practice setting compared to Normal BMD patients, which suggests that their motivation was higher due to their perception of high vulnerability to osteoporosis.

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## APPENDICES

## APPENDIX I



The Surgery, Nevells Road, Letchworth

# Health information impact survey

All your answers and comments will be dealt with in the strictest confidence.

Please tick all the boxes that apply

- What subjects have been covered in the health information you have been provided with at The Surgery?

Dietary advice	<input type="checkbox"/>	Guidance on when to consult the doctor	<input type="checkbox"/>
Life-style changes	<input type="checkbox"/>	Menopausal symptoms and relief	<input type="checkbox"/>
Alternative therapies	<input type="checkbox"/>	Hormone replacement therapy (HRT)	<input type="checkbox"/>
Self-treatment	<input type="checkbox"/>	Risk-factors in treatment	<input type="checkbox"/>
Osteoporosis	<input type="checkbox"/>	Other (please specify)	<input type="checkbox"/>

.....

Please tick *one box only*

- How satisfied are you with the amount of information given to you at The Surgery?

Far too much	Slightly too much	Exactly right	Slightly too little	Not at all enough
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tick *one box only*

- How relevant was the information to your situation?

Entirely relevant	Partly relevant	Not at all relevant
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tick *one box only*

- How suitable was the level of information given to you?

Too difficult to understand	Slightly too difficult	Exactly right	Slightly too basic	Far too basic
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you handle your situation differently as a result of the health information provided?

Yes ☐

No ☐

*Please tick all the boxes that apply*

6. What did the health information enable you to do?

- |  |                          |
|--|--------------------------|
| Follow instructions for prescribed drugs | <input type="checkbox"/> |
| Stimulate more questions to ask GP/nurse | <input type="checkbox"/> |
| Refresh memory of details/facts          | <input type="checkbox"/> |
| Substantiate what GP/nurse had said      | <input type="checkbox"/> |
| Make choices about treatment             | <input type="checkbox"/> |
| Assess risk-factors                      | <input type="checkbox"/> |
| Improve understanding of condition       | <input type="checkbox"/> |
| Nothing                                  | <input type="checkbox"/> |
| Assess side-effects                      | <input type="checkbox"/> |
| Confirm prior knowledge                  | <input type="checkbox"/> |
| Gain reassurance                         | <input type="checkbox"/> |
| Improve lifestyle                        | <input type="checkbox"/> |
| Other (please specify)                   | <input type="checkbox"/> |

.....

*Please tick all the boxes that apply*

7. In what ways has the health information changed your behaviour?

- |                              |                          |
|------------------------------|--------------------------|
| Reduced alcohol consumption  | <input type="checkbox"/> |
| Given up/reduced smoking     | <input type="checkbox"/> |
| Increased level of exercise  | <input type="checkbox"/> |
| Increased calcium intake     | <input type="checkbox"/> |
| Considered the option of HRT | <input type="checkbox"/> |
| Abandoned HRT                | <input type="checkbox"/> |
| Reinforced commitment to HRT | <input type="checkbox"/> |
| Not at all                   | <input type="checkbox"/> |
| Other (please specify)       | <input type="checkbox"/> |

.....

*Please tick all the boxes that apply*

**8. What other sources of health information have you used?**

- |                |                          |                                    |                          |
|----------------|--------------------------|------------------------------------|--------------------------|
| None           | <input type="checkbox"/> | Self-help group                    | <input type="checkbox"/> |
| Public library | <input type="checkbox"/> | Telephone health line              | <input type="checkbox"/> |
| Magazines      | <input type="checkbox"/> | Family                             | <input type="checkbox"/> |
| Newspapers     | <input type="checkbox"/> | Consumer health information centre | <input type="checkbox"/> |
| Radio          | <input type="checkbox"/> | Women's society                    | <input type="checkbox"/> |
| Friends        | <input type="checkbox"/> | Chemist                            | <input type="checkbox"/> |
| Hospital       | <input type="checkbox"/> | Community centre                   | <input type="checkbox"/> |
| TV             | <input type="checkbox"/> | Other (please specify)             | <input type="checkbox"/> |
- .....

*Please tick one box only*

**9. What single health information source has been most influential in affecting changes in your life-style and compliance with treatment?**

- |                |                          |                                    |                          |
|----------------|--------------------------|------------------------------------|--------------------------|
| None           | <input type="checkbox"/> | Self-help group                    | <input type="checkbox"/> |
| Public library | <input type="checkbox"/> | Telephone health line              | <input type="checkbox"/> |
| Magazines      | <input type="checkbox"/> | Family                             | <input type="checkbox"/> |
| Newspapers     | <input type="checkbox"/> | Consumer health information centre | <input type="checkbox"/> |
| Radio          | <input type="checkbox"/> | Women's centre/club                | <input type="checkbox"/> |
| GP/Doctor      | <input type="checkbox"/> | Menopause clinic nurse             | <input type="checkbox"/> |
| Friends        | <input type="checkbox"/> | Chemist                            | <input type="checkbox"/> |
| Hospital       | <input type="checkbox"/> | Health visitor                     | <input type="checkbox"/> |
| TV             | <input type="checkbox"/> | Other (please specify)             | <input type="checkbox"/> |
- .....

*Please tick one box only*

**10. What formal qualifications do you possess?**

- |                           |                          |                           |                          |
|---------------------------|--------------------------|---------------------------|--------------------------|
| None                      | <input type="checkbox"/> | A' Levels (or equivalent) | <input type="checkbox"/> |
| O' Levels (or equivalent) | <input type="checkbox"/> | Higher education degree   | <input type="checkbox"/> |

**11. Would you be willing to be interviewed?**

Yes ☐ No ☐

*If Yes, please include a contact phone number (plus area code) in the space below:*

\_\_\_\_\_

**THANK YOU FOR YOUR HELP**

**Please return this questionnaire by 31 May 1995 in the envelope provided.**

## APPENDIX II

The Surgery  
Nevels Road  
Letchworth  
Herts SG6 4TS

16 May 1995

Dear

**Impact of Health Information Survey**

As part of our assessment into your satisfaction with the medical care we provide, we are keen to get feedback about the health information you have received. Your views would be greatly appreciated.

Andrew Hampson, a postgraduate at Loughborough University, is undertaking this survey as part of his Master's degree in Information and Library Studies. He will treat the answers and comments you provide in the strictest of confidence.

The final question of the survey asks whether you would be willing to attend a 15 minute interview at The Surgery, to take place between 11 - 18 June. This would be conducted by Andrew Hampson in order to obtain a deeper understanding of your information needs. If you are willing to take part in the interview, you are asked to leave your phone number so that he can arrange a mutually convenient time.

The enclosed questionnaire should take approximately 5 minutes to complete. Please return it in the envelope provided by Wednesday 31 May 1995.

Yours sincerely

**Dr M Kirby**

### APPENDIX III

The John Phillips Court  
Loughborough University of Technology  
Garendon Road  
Loughborough  
LE11 OQB

1 June 1995

Dear

**Impact of Health Information Survey**

I am undertaking a study, on behalf of Dr Kirby, concerning your satisfaction with the health information you have received at The Surgery in Nevells Road, Letchworth.

A questionnaire was sent to you, requesting that you return the completed form in the pre-paid envelope provided by Wednesday 31 May 1995.

I would be grateful if you could return the questionnaire by Friday 9 June 1995. Your views are important to us in providing a more complete picture of satisfaction with the service offered. Your contribution would be greatly appreciated.

Yours sincerely

**Andrew Hampson**

## APPENDIX IV



## **Impact of Health Information Interview**

This statement is to be read out by Andrew Hampson at the beginning of each interview:

### **OPENING STATEMENT**

The purpose of this interview is to find out how the health information you have received has helped you in taking action to prevent and/or treat osteoporosis (**Prompt:** crumbling bones). The interview is about your experiences of how health information has affected you. The answers from all the people I interview, and I'm interviewing about 20, will be combined for a report. Nothing you say will be identified with you personally. Any questions about why I'm asking something, feel free to ask. This will take about 15 minutes to complete.

**Impact of Health Information Interview**

The first **two** questions are concerned with the health information you have received here at The Surgery.

1. (a) What is your understanding of the term 'osteoporosis'?  
What is it's cause?
- (b) What health information have you received about the prevention and treatment of osteoporosis here at The Surgery?

**2. How has that health information affected you?**

Life-style changes:

Attitude changes:

Adherence to prescribed treatment:

3. Do you think the decisions you take about diet/exercise/life-style affect your health, or do you think it doesn't matter?

4. Other than from your GP and the Practice Nurse here at The Surgery, where else have you got information about the prevention and treatment of osteoporosis from?

Prompts:	Public Library <input type="checkbox"/>	Magazines/Newspapers <input type="checkbox"/>	Friends <input type="checkbox"/>
	Self-help group <input type="checkbox"/>	Community centre <input type="checkbox"/>	Radio <input type="checkbox"/>
	Hospital <input type="checkbox"/>	Women's society <input type="checkbox"/>	TV <input type="checkbox"/>
	Chemist <input type="checkbox"/>	Health line (phone-in) <input type="checkbox"/>	Family <input type="checkbox"/>
	Consumer Health Information Centre <input type="checkbox"/>		

**5. How did that health information affect you?**

**Prompt:** Did it support the information you'd been provided with at The Surgery, or contradict it? Have you explored alternative therapies?

Life-style changes:

Attitude changes:

Adherence to prescribed treatment:

To finish with I'm going to ask you ten questions that require one word answers. This isn't a test and there are no right or wrong answers, so don't worry.

**6. Do you agree or disagree with the following statements?**

- a) Oestrogen deficiency is the most important factor in the development of osteoporosis.

AGREE

DISAGREE

- b) Eating and drinking more dietary sources of calcium reduces the risk of bone fractures.

AGREE

DISAGREE

- c) Hormone replacement therapy replenishes the natural supply of oestrogen lost at the menopause.

AGREE

DISAGREE

- d) Calcium deficiency is an important factor in the development of osteoporosis.

AGREE

DISAGREE

- e) Hormone replacement therapy is only prescribed for between five and ten years because of concerns about an increased risk of breast cancer with longer-term therapy.

AGREE

DISAGREE

- f) Regular exercise does not improve bone structure.

AGREE

DISAGREE

- g) Hormone replacement therapy offers protection against coronary heart disease and stroke.

AGREE

DISAGREE

- h) Smoking and excessive alcohol consumption accelerates the rate of postmenopausal bone loss.

AGREE

DISAGREE

- i) Written health information enables patients to follow treatment prescribed by their GP.

AGREE

DISAGREE

- j) Changing your life-style now makes no difference to your health in the future.

AGREE

DISAGREE

7. Would you like more information about osteoporosis?

Yes

☐

No

☐

***Provide thanks for taking part in the interview.***

**Additional Information:**

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