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Title

Can two established information models explain the information behaviour of visually impaired people seeking health and social care information?

Short title

The information behaviour of visually impaired people

Abstract

Background and purpose: Although several studies have been conducted on the generic information needs of visually impaired people, Williamson *et al.* (2000) found that no study had examined the information needs and information behaviour of people with visual impairment. The purpose of this study was to determine the extent to which two existing models of information behaviour could explain the information behaviour of visually impaired people seeking health and social care information.

Design/ methodology/ approach: The research was conducted within a constructivist paradigm. Twenty-eight semi-structured interviews (face-to-face or telephone) with 31 visually impaired people were conducted. Framework analysis was used to analyse the results.

Findings: Moore's (2002) model of social information need provided a useful framework for analysing the results of this study. However, the theoretical basis for this model is unclear and it failed to take into account all aspects of information behaviour, focusing predominantly on information needs. Wilson's (1999) revised model could be used to explain, at least in part, the information behaviour of people with a visual impairment seeking health and social care information. However, an additional ‘intervening variable’ was identified relating to the individuals’ health characteristics (type, degree and length or visual impairment and presence of other health conditions and disabilities).

Originality/ value: This study provides a new and valuable insight into the information behaviour of visually impaired people, as well as tests the applicability of a specific and generic information model to the information behaviour of visually impaired people seeking health and social care information.

[251 words]

Keywords

- Information behaviour
- Visually impaired people
- Qualitative research
- Interview study
- Health needs

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- Research paper

Introduction

There are an estimated 161 million visually impaired people worldwide (Resnikoff *et al.*, 2004), including one million people in the United Kingdom (1.8% of the population) (European Blind Union, 2002). Although several studies have been conducted on the generic information needs of visually impaired people (*e.g.* Astbrink, 1996; Oppenheim & Selby, 1999; Williamson & Schauder, 1999), Williamson *et al.* (2000) identified "*no major study of the information needs and information seeking behaviour of this group of people (sight impaired citizens*)". The aims of this study, therefore, were to examine the information behaviour of visually impaired people, and to test the applicability of two existing information models to the information behaviour of visually impaired people seeking health and social care information.

Visual impairment

Numerous formal definitions of visual impairment exist (*e.g.* Bruce & Baker, 2001; European Blind Union 2002); these cover a broad spectrum of people, ranging from people who are partially sighted to people who are completely blind. There are also many different types and causes of visual impairment (Ghafour, 1983), for example, macular degeneration, glaucoma, cataracts, and diabetic retinopathy. Visual impairment is frequently experienced along with another permanent disability or illness, such as arthritis, heart conditions, mobility problems, diabetes and hearing impairment (Bruce *et al.*, 1991). People with a visual impairment are, therefore, often regular users of health and social care services, either because of their visual impairment, or because of associated co-morbidities.

Information and visually impaired people

Information has an important role in helping support and improve people's health and social care (NHS Executive, 1998). However, it is evident that information is not always accessible to, or appropriately 'packaged' for, visually impaired people. For example, information may not be provided in an appropriate format, at the right time, or in sufficient detail (Beverley *et al.*, 2004).

The importance of making information accessible for visually impaired people is highlighted in recent UK legislation, such as *The Disability Discrimination Act* (HMSO, 1995). Service providers now have to make "reasonable adjustments" for disabled people (RNIB, 2003). For visually impaired people, information should be made available in 'alternative formats', such as large print, Braille, Moon, computer disk, audio tape, telephone services, spoken or verbal announcements, accessible Web sites, tactile maps, *etc.* (Bruce *et al.*, 1991; Gregory, 1996). Recent advances in ICT, in particular assistive technologies, such as screen magnification software, screen synthesisers, screen readers, large screen monitors, closed circuit television (CCTV), Braille embossers, character recognition software and speech inputters, have the potential to provide information in more accessible formats to visually impaired people (Gregory, 1996; Wales Council for the Blind, 2002).

Although guidance exists on the information that health and social care providers should provide to visually impaired people (*e.g.* the *National Standards of Social Care for Visually Impaired People* - Association of Directors of Social Services, 2002), this has not been widely adopted in practice or based on research evidence.

Very little literature has been published specifically on the health and social care ‘information behaviour’ (Case, 2002), *i.e.*, the information needs, information sources and information seeking behaviour, of people with a visual impairment. A recent systematic and critical review of the health information needs of visually impaired people reported that the focus of existing research has been on alternative formats for visually impaired people, rather than their explicit needs relating to other aspects of information provision (*e.g.* content, timing, *etc.*) (Beverley *et al.*, 2004).

In this paper we examine the information behaviours, with particular reference to information seeking, of visually impaired people in relation to two existing models, that of Moore (2002) and of Wilson (1999). This is part of a larger ongoing study to fill the gap in the literature identified through a systematic review (Beverley *et al.*, 2004) and is designed to identify the information needs and information behaviours of visually impaired people.

Models of information behaviour

Wilson (2000) defined information behaviour as,

> “*the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given*.”
> (Wilson, 2000, p. 49).

Human information behaviour, therefore, relates to the study of human behaviours in relation to information seeking, foraging, retrieving, organizing and use (Spink & Cole, 2004).

Many of the established information models (*e.g.,* Wilson, 1981; Dervin, 1983; Krikelas, 1983; Ellis, 1989; Kuhlthau, 1991; Ellis *et al.*, 1993; Johnson, 1997; Leckie *et al.*, 1996; Wilson, 1996) have been applied to information seeking in the context of health and social care (*e.g.,* Miller, 1987; Buckland & Dawson, 1989; Johnson & Meischke, 1993). More recently, Spink and Cole (2006) examined three interdisciplinary approaches to how people seek information: information seeking-sense-making (Savolainen, 1995), information foraging (Pirolli & Card, 1999), and problem-solution perspective on information seeking. In response to this review, they proposed a fourth information approach based on information use theory, as well as devised an initial integrated model of these different approaches.

Each approach to studying information behaviour has its strengths and weaknesses in terms of its ability to conceptualize the wide range of specific dimensions or aspects of human information behaviour (Spink & Cole, 2006) and, no one approach completely explains information behaviours. In order to study the information behavious of people with a visual impairment, it is first necessary to examine these different information models in parallel with a consideration of people with a visual impairment themselves and their needs and behaviours.

Savolainen (1995) and others have examined the situational aspect of information seeking-sense-making in everyday life information seeking. Spink and Cole (2006) summarised the relative value attributed to information from insiders (*i.e.*, people from the small world in which the individual lives) and outsiders (*i.e.*, people from the larger world, or society). It is possible to consider people with a visual impairment as having contact with insiders, such as other visually impaired people (*e.g.*, groups of people who have been blind since birth), as well as outsiders, such as health care professionals or social care service providers. However, the diversity of visual impairments makes it difficult to determine whether different sources or providers of information are insiders, outsiders, or neither of these, and, therefore, whether it is appropriate to consider the world of people with a visual impairment as separate from society.

Pirolli and Card's (1999) model of information foraging proposed that human information foragers assess the potential value of an information source in relation to other possible sources using “information scent”. The forager sniffing for information based on this scent may lead the forager to pursue that information source with a stronger scent at the expense of others. Superficially this model is potentially attractive in trying to understand the information behaviours of people with a visual impairment, in that it uses scent and the sense of smell as a metaphor for information seeking and people with an impairment in one sense may develop heightened awareness in their other senses. However, the idea of information foraging was developed in relation to Web searching and is likely, at least to some extent, to be dependent on visual cues which may not be readily available or accessible to people with a visual impairment.

Wilson’s problem-solving perspective on information seeking (1999), discussed in greater detail below, is based on the premise that information seeking commences with a perceived need for information by the user, and that the user identifies and then defines this need, before seeking information to meet the need and solve the problem. It is possible to imagine a person with a visual impairment, who has either been blind since birth or has experienced impaired vision in later life, having information gaps, which they try to resolve through information seeking. Wilson’s model is, therefore, likely to be helpful in understanding the information behaviour of visually impaired people.

Very few information models have been specifically applied to the information seeking behaviour of people with a visual impairment. Williamson and Schauder (1999), for example, used Williamson’s (1995, 1998) model as the basis of a conceptual framework for a study of information seeking by visually impaired people in Australia. This model takes into account Dervin’s sense making theory (Dervin, 1983), Wilson’s information seeking behaviour (Wilson, 1996) and the ecological theory of aging (Birren & Birren, 1990).

However, Moore’s model of social information need (Moore, 2002) appears to be the model most applicable to the information behaviour of visually impaired people, mainly because it was developed directly in response to a literature review of the information needs of visually impaired people. For the reasons outlined above, it was decided to analyse the data and interpret the findings using Wilson’s revised model (Wilson, 1999) in order to establish the extent to which this *generic* model could be applied *specifically* to the information behaviour of visually impaired people. Each of these models is, therefore, considered in more detail below.

Moore's model of social information need

Moore's (2002) model of social information need was developed to provide a framework for analysing the results of over 75 reports of research relating to the information needs of visually impaired people. It has also been used by the Royal National Institute for the Blind (RNIB) as a tool for analy*s*ing information provision (Moore, 2002). The model has also been advocated for use in analy*s*ing and identifying the scope and nature of the social information needs of other groups of people.

In essence, Moore (2002) described social information as having six different dimensions:

1. Function (why do people need information?)
2. Form (what kind of information do people need?)
3. Clusters (what do people need information about?)
4. Agents (who initiates the information activity?)
5. Users (how do needs differ between different groups of people?)
6. Mechanisms (which mechanisms can be used to meet information needs?).

According to Moore (2002), people need social information to support them in two roles they play as members of society: as <u>citizens</u> and as <u>consumers</u>. The same can be said of health information and this is indeed advocated in *Information for*

*Health (*NHS Executive, 1998), the information strategy for the National Health Service (NHS) in the UK.

Moore reported that people need information to help them build up an understanding of the world in which they live (‘environmental scanning’) which means that people need to be able to get answers to specific questions that bother them (‘answers to questions’). However, Moore acknowledged that information alone was not always enough to trigger action and that, in an ideal world, there would be a continuum of information provision ranging from information through advice to advocacy (Moore, 2002). Moore’s model focused on three different initiators of the information activity: information ‘seekers’, information ‘providers’ and information ‘processors’.

Moore (2002) described two different approaches to considering information needs. The first was based on different levels of need; for example, Maslow (1968) identified five levels: physiological needs (*e.g.,* food, water, warmth and protection); safety needs; love, affection and belongingness needs; esteem needs; and self-actuali*s*ation needs (the additional benefits that accrue to self-esteem through doing something that the individual feels to be worthwhile). The second approach was based on Tester (1992)’s assumption that information needs were associated with major life events.

Moore (2000) found, however, that it was not possible to identify the actual hierarchy of information needs that were experienced by visually impaired people. Instead, he identified eight main clusters of need: the condition, its treatment and likely outcome; benefits and money; general health; aids and equipment; housing and accommodation; mobility; services and facilities; employment, education and training.

Moore's model provides important insights into the social information needs and behaviour of people with a visual impairment. However, it was based on an analysis of research reporting these needs and not on primary research into these needs. It was, therefore, deemed valuable to verify the applicability of Moore's model in a separate sample of visually impaired people.

Wilson's revised model of information behaviour

Wilson has developed a series of macro-models and models of gross information seeking behaviour which attempt to integrate various information models (Wilson, 1981, Wilson, 1994, Wilson 1997, Wilson, 1999). Unlike Moore's model, Wilson's models were not specifically developed with the information needs of visually impaired people in mind but were based on generic needs in general situations.

Wilson's models were based on two main propositions: first, that information need is not a primary need, but a secondary need that arises out of needs of a more basic kind; and, second, that in the effort to discover information to satisfy a need, the enquirer is likely to meet with barriers of different kinds (Wilson, 1981). The revised Wilson (1999) model (shown in Figure 1) embodied a set of questions about information behaviour: why some need prompt information seeking more so than others ('stress/ coping theory'); why some sources of information are used more than others ('risk/ reward theory'); and why people may, or may not, pursue a goal successfully, based on their perceptions of their own efficacy ('social learning theory'). In addition, Wilson identified a number of 'intervening variables' which may be involved in an individual's information behaviour. Wilson's revised model also recognised that there are different types of active and passive search behaviours. The study described here sought to determine the extent to which Wilson's generic model could be applied to a specific group of people with potentially unique information needs and information behaviours.

Insert Figure 1 here.

Research aim and questions

The aim of this particular part of the study was, therefore, to build on the existing literature and to investigate the extent to which Moore's (2002) and Wilson's (1999) models could explain the information behaviour of two groups of visually impaired people (people with an age-related visual impairment and people with a visual impairment since birth or early childhood) seeking health and social care information. As indicated above, the study forms part of a larger scale research investigation which is examining the following research questions:

1. What are the health and social care information needs of people with a visual impairment?
2. What information sources are used by people seeking health and social care information?
3. Are there differences in the information behaviours of people with different visual impairments?
4. Can new developments in information provision (*e.g.* NHS Direct and the Internet) help to meet the needs of visually impaired people?

Research design

The research was conducted within a constructivist paradigm. Constructivism views the world as a constantly changing place where individuals have varying perceptions of a given situation (Dootson, 1995). Constructivism is synonymous with naturalistic research conducted within a holistic-inductive framework (Patton, 2002) and is, therefore, usually associated with qualitative research (Davis, 2000).

Data collection

Semi-structured interviews (face-to-face or telephone) with two groups of visually impaired people: people with an **a**ge-related visual impairment (Group **A**) and people with a visual impairment since **b**irth or early childhood (Group **B**).

This approach was adopted in response to the findings of a detailed literature review (*e.g.* Duckett & Pratt, 2001), a consultation exercise with visually impaired people at three local visual impairment support groups, and suggestions made by five visually impaired advisors to this study (Beverley, in preparation). In addition, several authors (*e.g.* Wilson, 1981, 1994; Nicholas, 2000) have advocated the use of qualitative research methods to undertake studies of information behaviour.

In order to recruit an adequate number of participants, several recruitment routes were employed, including placing an advert in a local talking newspaper and newsletter for visually impaired people, as well as via local visual impairment support groups and via referrals from the local society for the blind. Participants were given a choice of the type of interview (*i.e.*, face-to-face or telephone) and of venue for face-to-face interviews (in their own home, at the University or at the local society for the blind). An information sheet was sent to all participants in their preferred format (*i.e.,* large print, audio tape or email). Verbal consent was obtained from the participants at the start of the interview.

A topic guide (Figure 2) was used to structure the interviews. This was piloted with two of the visually impaired advisors to this study and revised in response to their feedback. The interviews covered the information participants had received, sought or acquired in connection with their visual impairment and/or other aspects of their health and social care. Interviewees were also given an opportunity to suggest ways in which the existing provision of health and social care information could be improved for people with a visual impairment.

Insert Figure 2 here.

Data analysis

Within four weeks of each interview, the tape recorded interview data were transcribed verbatim into *Microsoft Word* 2002. The demographic data collected for each participant were entered into the *Statistical Package for the Social Sciences* (*SPSS*) version 11.0.1. The transcripts were analysed manually using framework analysis (Ritchie & Spencer, 1994). Framework analysis follows a well-defined procedure (Miles & Hubermann, 1994; Ritchie & Spencer, 1994) and provides a systematic, transparent, accessible and robust approach to qualitative data analysis (Lacey & Luff, 2001). Framework analysis involves five distinct, though highly interconnected, stages: familiarisation (*i.e.* reading and familiarisation of the transcripts); identifying a thematic framework (which is initially heavily rooted in *a priori* issues); indexing (application of the thematic framework to the data); charting (*i.e.* creating charts of the data); and mapping and interpretation (*i.e.* searching for patterns, associations, concepts, and explanations in the data) (Ritchie & Spencer, 1994).

Initially all the interviews were read carefully so that the researcher (CB) became familiar with the data and acquired an overview of the richness, depth and diversity of the data (Ritchie & Spencer, 1994). An initial thematic framework was developed based on the interview topic guide and familiarisation with the data. This framework was tested and modified in response to a detailed analysis of two interviews covering both interview groups.

In response to this exercise, it was decided that it was appropriate to develop a single index across the two interview groups, but for any differences to be highlighted. Quotations elicited from interviews with people with a visual impairment since birth or early childhood were recorded in a different colour font (blue) in *Microsoft Word* 2002 to enable the easy identification of similarities and differences between the two interview groups. This procedure was repeated until half the interviews (n=14) had been analysed. This sample included eight interviews with people from Group A and six interviews with people from Group B, *i.e.,* in proportion to the total number of people interviewed in each group. Although minor changes were made to the framework during the first set of 14 interviews, a major revision of the framework was undertaken at this half-way stage. The remaining interviews were subsequently analysed and minor modifications were made to the thematic framework. Analysis of this framework revealed that the point of data saturation was reached after 24 interviews. At this point, the thematic framework was revisited and finali*s*ed with the participants, the visually impaired advisors to this study, and the research supervisors (PB and RB).

Results and Discussion

Participant details

Twenty-eight interviews were conducted in total between September 2003 and March 2004. This equated to 31 people, because three visually impaired couples requested to be interviewed together. Sixteen of the interviews (17 people) were conducted with people from Group A and 12 interviews (14 people) were conducted with people from Group B. Twenty-three interviewees chose to have a face-to-face interview in their own home, one interviewee opted for a face-to-face interview at the University, while seven expressed a preference for a telephone interview. All of the people opting for a telephone interview came from Group B. The mean interview duration was 45.5 minutes (range: 18-131 minutes); the duration being longer for Group A participants (50.6 minutes, compared with 38.8 minutes for Group B participants).

The mean interviewee age was 62.4 years (range: 19-91 years), with Group A participants having a greater mean age (80.2 years, compared with 40.8 years for Group B participants). In total, 15 men and 16 women were interviewed. However, this was not equally distributed across the two interview groups. The majority of participants were white-British. Approximately one third of participants lived alone; this figure being higher amongst people from Group A.

The type of visual impairment experienced by participants varied considerably between the two groups. The majority of Group A interviewees had a diagnosis of age-related macular degeneration (AMD), with or without cataracts. Most interviewees had had a visual impairment for more than 12 months and were registered blind or partially sighted. Over three quarters of participants experienced other health conditions (*e.g.*, breathing difficulties, arthritis, heart problems, hearing impairment); this figure being higher amongst Group A participants.

Interview themes

The final interview framework consisted of the following four major themes:

1. Health and social care information needs.
2. Sources of health and social care information.
3. Possible improvements in the provision of health and social care information.
4. ‘Intervening variables’.

These themes and related sub-themes are discussed in detail elsewhere (Beverley, in preparation; Beverley *et al.*, submitted for publication). The purpose of this article is to focus on the results relating to Moore’s (2002) and Wilson’s (1999) models. Illustrative quotes are used where appropriate. These are denoted by a letter (A or B, which relates to the group the participant came from), and a number relating to the individual participant.

Moore's model of social information need (Moore, 2002)

Moore's (2002) six dimensions of social information formed the basis of the analysis of the interview data: function, form, clusters, agents, users and mechanisms.

Function

Visually impaired people in this study reported needing sufficient information at critical decision points, such as deciding whether or not to go ahead with laser surgery for AMD:

> *"No, … the specialist … he said to me … your eyesight may last for 2 days … may last two weeks … it may last two months … err … and then told me exactly the pros and cons of laser treatment … that it has a 50% chance of succeeding and a 50% chance of it not returning. So a 25% chance of it working overall.*" (A17, lines 155-159)

This corresponds with Moore's (2002) suggestion that people need social information to support them as citizens and as consumers, *i.e.,* people with a visual impairment need to be adequately informed about the range of different treatment options to which they are entitled and that are available to them ('information for citizenship') and the pros and cons of each of them ('information for consumption').

Form

It was also clear from the interviews that participants sought, processed and absorbed many different kinds of information ('environmental scanning'). Moore (2002) acknowledged that information alone was not always enough to trigger action. This was supported by this study in that some participants reported feeling overwhelmed with the amount of information provided at the time of diagnosis, as well as the various ‘intervening variables’ (similar to Moore’s ‘attitudinal barriers’) which either inhibited or encouraged people from seeking health and social care information. For example,

> “*No, I’m not bothered. What I don’t know can’t … harm me. I suppose … in some ways I’d rather not know*.” (A11, line 71-72)

Other authors have found a similar pattern; for example, Miller (1987) discovered that some people do not want information about their health condition, but instead choose to avoid, or even ‘blunt’, such information.

In addition, participants identified a series of questions relating to their visual impairment which they subsequently asked during their medical consultations (similar to Moore’s ‘answers to questions’). For example, the following participant emphasised the importance of this approach in order to elicit information:

> “*Well when I went to the hospital … of course I’ve already stated that one … erm ... what I find is you’ve not got to be … timid … or namby pamby about it … you have got to ASK … and you’ve got to stick to your guns … and you’ve got to really know what you want … and … get the information by asking the relevant questions*” (B12, lines 198-201)

While this determined approach to obtaining information might be of use to other groups of health care consumers, it may be that this approach is particularly important to visually impaired people, who may view an appointment with health care professionals as an important opportunity to obtain information that is not so readily accessible at other times because their impairment is visual, *e.g.*, reading books, magazines.

Clusters

As noted previously, Moore (2002) described two different approaches to considering information needs: ‘hierarchies of need’ and ‘life events’. Moore (2000) identified eight main clusters of need (the condition, its treatment and likely outcome; benefits and money; general health; aids and equipment; housing and accommodation; mobility; services and facilities; and employment, education and training), but he was unable to identify the actual hierarchy of information needs that were experienced by visually impaired people. The findings from this study have enabled this idea to be progressed further by revising these cluster names and proposing a hierarchy of information needs for the visually impaired people taking part in this research. The clusters identified in this study, in order of importance to the participants, therefore, were:

1. The eye condition (including diagnosis, prognosis, treatment options and causes).
2. Health and social care services and facilities (including reading general correspondence and filing forms in).
3. Aids, adaptations and equipment (*e.g.,* low vision aids, talking books, talking watches, liquid level indicators, *etc.*).
4. General health care (*e.g.,* techniques for administering medications, such as eye drops and tablets, and reading medical information, such as appointment letters, prescriptions, medicine labels, hospital notices and signs, *etc.*).

5. Benefits and money (including knowledge about financial benefits, coin recognition and use of cash machines)
6. Mobility (including using public transport, shopping, eating out, going on holiday, *etc.*).
7. Housing and accommodation (including performing household chores, such as cooking and cleaning).
8. Employment, education and training.

Participants received, acquired and/or sought considerable information about their eye condition. This included information about diagnosis, prognosis (*i.e.*, the anticipated outcome of their visual impairment) and treatment options. For example,

> "*I was told it developed from the age of 8 … and was expected to sort of level out by the age of 18 … err … which is pretty much what happened …*" (B6, lines 73-75)

> "*… err … I did hear on a radio programme over in the United States that they had done an operation on one person … and … they could see … what 10 feet in front of them … and 8 feet to the side … err … and … but they could only see black on white or white on black … and that was back in 1997* ..." (B7, lines 40-44)

In addition, participants expressed a need for information about the cause(s) of their visual impairment. For example, one person thought that she may have inherited her eye condition:

> “*This macular thing, off the record, I think it must be hereditary thing, because I had two uncles and an aunt who went blind on m’ Dad’s side of the family …*” (A2, lines 227-228)

Most participants were also informed about the health and social care services that were available to them. This mainly consisted of information about visual aids (*e.g.,* magnifiers), available from the hospital low vision clinic and local opticians. However, participants also received information about social care services, such as mobility training provided by Social Services, the Guide Dogs for the Blind Society, and benefits advice from the local society for the blind. In addition, participants received information about a range of aids, adaptations and equipment available to them (*e.g.* white canes, talking books, talking watches, liquid level indicators and coin holders). However, it was clear that many participants found out about different social care services, in particular advice about financial benefits, through friends, family members, support groups and talking newspapers. For example,

> “*Saw an advert again in Sheffield Talking News … there was a telephone number to ring … and it were the … I don’t know it’s full title … but it’s tied up with the pensions* ...” (A5, lines 312-315)

Interestingly, participants did not tend to receive information about the remaining five clusters of information (general health care, benefits and money, mobility, housing and accommodation, and employment, education and training), but instead acquired, sought or had outstanding information needs relating to these areas. Several participants, for example, described the difficulties they encountered in terms of medical information, such as reading appointment letters, prescriptions, medicine labels, hospital notices and signs. For example:

> "… *like for our medical appointments … things of that nature … err … they don't call and tell us … they send us print notes through the door … and, if it's … err … you know … within a week of the delivery of the note … and we don't know it … then we miss our appointment* …" (B8, lines 15-18)

In general, information needs relating to benefits and money, mobility, housing and accommodation, and employment, education and training were more person specific. For example, most participants in this study, particularly those in Group A, were not concerned with employment, education and training information because they were now retired.

Agents

Moore's model (2002) focused on three different initiators of the information activity: information 'seekers', information 'providers' and information 'processors'. In this study not only were information 'seekers' and information 'providers' identified, but it was also evident that organisations, such as the local society for the blind, were acting as information processors, *i.e.,* processing and digesting information on behalf of users.

Some visually impaired people, actively sought information to meet their needs, as the quotation from participant B12 above and the following quotation illustrate:

> "*Well, the thing is … you do not get information either from your GP or the hospital unless you ask … and sometimes they think it's an impertinence to do this …*" (A2, lines 181-183)

In contrast, other participants were unclear about their actual needs, and were dependent on the information that they either received from information providers or which they acquired passively:

> "*No. To be honest, I don't know what I'd want anyway*." (A14, line 71)

In line with Moore's 'trust and authority' theme, several participants expressed concern about the quality of the information they had either received, sought or acquired. For example the following person expressed reservations about information obtained from the Internet:

> "*I'm overly cautious of what people put out there. And … I know it's got some wonderful facilities on there … but I know it's also full of … lots of … err … nonsense*." (B10, 184-186)

While caution about the quality of information available on the Internet is widespread, and a particular concern in relation to health and social care information (Silberg *et al.*,1997; Eysenbach and Diepgen, 1998), it is possible that people who have been blind since birth, such as the above participant, have additional concerns, because they are less able to visuali*s*e and evaluate this source of information, and are, therefore, more willing to trust more traditional sources.

Users

This study has started to identify some of the similarities and differences between the information needs of two groups of visually impaired people, namely people with an age-related visual impairment and people with a visual impairment since birth or early childhood. In doing so, it has also added support to the hypothesis that visually impaired people cannot be regarded as a homogeneous group. This is illustrated by the following quotation:

> "*Well, that's a difficult one isn't it … because … you see … everybody's different … and we all need it in different ways* …" (A12, lines 967-968)

Moore (2000) specifically identified eight different groups of people that could be thought of as having a common core of information needs according to: the degree of their visual impairment, whether they were newly visually impaired people, older people, children, people with multiple disabilities, people with ethnic minorities, carers and professionals. This study included participants who were from several of these groups, *i.e.*, the participants with AMD were, by definition, older people, and included participants who had been diagnosed in the last 12 months and had co-morbidities. However, the study did not include professionals, and although information on the needs of carers may have been gleaned in the interviews of three visually impaired couples, when one person may have act as a carer for the other person as well as being visually impaired themselves, it was not an aim of the study to identify carers' needs explicitly. It is possible, therefore, that the needs of these groups, identified by Moore (2000, 2002) may extend beyond those of people within this study.

This study identified several factors ('intervening variables') that may affect a visually impaired person's information behaviour. These related to the presence of other health conditions or disabilities, participants' understanding of the word 'information', their interactions with information providers, their degree of independence, the support they received from friends and family, their acceptance of their own visual impairment, as well as their awareness of other visual impairments, their registration status and their willingness and ability to pay for aids, adaptations and equipment. Some of these factors are considered in more detail below.

Participants in this study experienced one or more co-morbidities, *i.e.*, other health conditions or disabilities, such as arthritis and hearing impairments, in addition to their visual impairment. It was evident that, for many participants, these additional conditions and disabilities further hindered their lifestyle:

> "*And … so … I've been cut off secondly ... with my arthritis …*" (A1, lines 85)
>
> "*Erm … so … I-I tend to lump the two handicaps together because one hinders the other ...*" (B12, lines 40-41)

Visually impaired people with co-morbid conditions are, therefore, at a particular disadvantage, in that their visual impairment acts as a barrier to information about the impairment *<u>and</u>* the associated condition.

Participants' understanding of the word 'information' ultimately affected their responses. Most participants found it difficult to express this in words, with several people highlighting the complexities associated with the concept 'information'. For example:

> “*Well, it can mean different things depending on what you’re talking about …*” (A14, line 8)

Of those participants who were able to provide a definition, some people viewed information solely in terms of the information that they received:

> “*Well, it’s telling people about what things are about, isn’t it*?” (A6, line 5)

whereas several participants stressed the ‘advice’ facet of information:

> “*Information … erm … guidance … really … err … and advice … on anything*.” (B6, lines 68)

and others emphasised the two-way flow of information:

> “*Well, information … is … err … getting communication, more than anything else, I suppose, communication between those who are providing a service and those who are wanting a service …*” (A17, lines 74-76)

Finally, a few participants illustrated their awareness of a wide range of information sources:

> “*Erm … it means organisations, bodies, trying to put over what services they might have. It might be err … on the street … it might be on radio, TV, through the media. It might be written … it might be email*.” (B10, lines 48-50)

Many participants found it difficult to explain their understanding of the phrase ‘health and social care information’. A few people pointed out that this meant different things to different people; for example:

> "*I think it really depends on the individual person … and what their particular needs are*." (B10, lines 55-56)

Several participants focused on their understanding of social care information by expanding on the definition provided in the original information sheet sent to all participants prior to the interviews:

> "*I would answer that by saying not social care … well, I suppose it is social care really … the whole gamut of social interaction, erm, you know, how can I manage shopping, doing this that and the other … going out … getting around … walking around … etcetera … etcetera …*" (A17, line 100-103)

It emerged that participants' interactions with the different information providers and their progression through the various different health and social care services affected their information behaviour. For example, many participants commented on their dissatisfaction with the quantity and quality of information they had received, particularly from the ophthalmologist at the time of diagnosis. As noted earlier, several participants expressed concern about how this information was conveyed:

> "... *err … 'Nothing we can do about that'. So … err … you know … 'there's no point you having another appointment' … err … 'unless you get flashing lights and things like that'. So … I said, 'Do you mind me asking, will it get worse?' So they said, 'Well, it all depends. You might go to bed one night and wake up blind in the morning … or you might go for 10 years and you'll not worry very much'. And then he said … to the nurse, 'Next'. [Participant laughs]. So it was a bit of a shock that*." (A3, lines 41-47)

Not only would this participant have liked further information concerning their condition, but the manner in which the lack of available information was communicated appeared to be unsatisfactory. Several other older participants described how they felt they had been spoken to in an inappropriate manner during their consultations with the ophthalmologist:

> "*This is it, you see some of them talk down to elderly people … and think it's all wrong … especially if you're sort of equipped upstairs, you know*." (A2, lines 108-110)

> "… *but anybody who was still reeling from the shock that we all know we felt when we were told that we're … you know … and the favourite sentence … and the one that was repeated by this lady at Birmingham was, 'You will definitely not go blind'. Now they should not do that … they should treat you as though you are an intelligent person and tell you what is wrong … so you can begin to face up to it. That is where I personally find … found a lot of fault … and so did many others*." (A12, lines 220-226)

The diagnosis process was particularly traumatic for some participants:

> "*Many people going into the hospital are frightened and the consultants are frightening*" (A12, lines 1181-1182)

Previous research across a range of conditions has indicated that the information needs of patients at the time of diagnosis can be highly variable, depending on individual need, the condition being diagnosed and other intervening variables. While some patients cannot cope with any additional information at the time of diagnosis, beyond the actual diagnosis, it is clear that these participants expressed that they had clear needs for information at the time of diagnosis, not only in terms of the diagnosis, but also in terms of the prognosis of the condition. This may be because they had perceived a change in their visual capacity and having a diagnosis and prognosis was important for them to come to terms with this change and to plan for the future, as participant A12 indicated above. People who have been blind since birth, however, are probably less likely to have such needs for information at this stage, because diagnosis is at a very early age and because the prognosis is clear. People with other conditions, *e.g.*, a diagnosis of breast cancer, may be less prepared and less willing for information if they had not noticed or had ignored a lump developing.

In addition a few participants felt that they had been treated unfairly by the hospital staff:

> "*… now … I didn't actually see the consultant … I saw one of his team … and I said what does that mean … and he was very officious … he said oh you'll see when you get there … and no cheating. I said, 'You man, at my age you don't cheat'. I said, 'What do you mean by no cheating?' He said, 'well some people do, you know. They think they're blind when they're not.' Well I said, 'I've never heard anything so stupid in my life' …*" (A2, lines 99-104)

The above comments suggest that the interaction between visually impaired people and health and social care professionals can be important in determining the quantity and quality of information received by the person, and their satisfaction with that information and with their overall quality of care.

Other participants found the period between diagnosis and treatment and the lack of information provided during this period difficult:

> *"… and that is a long gap … you know, between, for someone less fortunate than myself … between … you know, the first … erm … becoming aware of the problem and starting treatment and erm … going to the low vision unit …"* (A17, lines 137-140)

> *"You shouldn't have been allowed to have wait a fortnight, because that's really the critical period. You should really have been given some help with regard to laser treatment'.*" (A15, lines 46-48)

These comments reinforce the point made earlier that when people are aware of a problem they may want a diagnosis and prognosis in order to face reality and prepare for the future.

A few participants had to be persistent and ask questions during their consultations in order to obtain the information they required:

> "*When I've always had to ask questions … err … about subjects like that … I've always had to ask them … err … because … especially the current surgeon I'm under … he … err … tends to … err … want to get the appointment over as quickly as possible … err … very dismissive … so I have to ask the questions*." (B3, lines 99-102)

> "*One of the problems is that many of the people at the hospital avoid the issues altogether and just think that it will go away*" (A12, lines 1185-1186)

These comments provide further evidence that the relationship between health and social care professionals and visually impaired people can act as an important intervening variable in determining whether the information needs of patients are met.

Mechanisms

A range of different mechanisms can be used to meet people's information needs. Moore (2000) considered these in terms of 'recording and storage', 'transmission and communication', and 'tailoring and customisation'. Although this interview study has not considered mechanisms in this manner, it has highlighted the importance of providing information in a participants' preferred format, such as on audio tape, on CD ROM, via email and/or on the Internet.

> "*Erm … I think … err … dealing with … err … people with a visual impairment … I think … a wider range of formats should be available … i.e., large print, audio cassette … Internet … mind you, you can't really send letters on Internet … but … maybe emails … floppy disks … erm … Braille … err … just a wider range so that people have got more choice … erm … instead of having a standard print letter that nobody can read*." (B2, lines 151-155)

Wilson's revised model of information behaviour (Wilson, 1999)

Context of information need

As noted earlier, Wilson's models were based on two main propositions: first, that information need is not a primary need, but a secondary need that arises out of needs of a more basic kind; and, second, that in the effort to discover information to satisfy a need, the enquirer is likely to meet with barriers of different kinds (Wilson, 1981). Both of these propositions are reinforced by the findings of this interview study: many participants did not explicitly state their information needs, but described areas of need from which it was possible to determine an information need. Typically participants referred to the difficulties they experienced in various aspects of their life (*e.g.*, taking tablets, cooking, eating out, filling forms out, *etc.*), and rather than acknowledging an information need *per se*, they focused on the actual problems, from which needs for information could be inferred . For example, the following participant described the problems he encountered taking tablets:

> "*You mean, tablets like? I've had no end of problems with them. I don't know what I'm taking. I'm on so many, you see. I'm fine if someone puts them to one side and tells me … but I forget … and my eyes have not been so good lately. When you're on so many different drugs … it's easy to get confused.*"
> (A11, lines 80-83)

Although this participant did not explicitly state that he needed information in relation to taking medications, his description of the problems he faced in taking them indicated that information on each medication, and a means of differentiating between the different medication, was required. Thus, in accordance with Wilson's model, the primary need was to take the medication and the secondary need for information arose from this. Similarly, and as noted above, the visual impairment presented a barrier to gaining that information.

Activating mechanisms

Wilson's (1999) model embodied a set of questions about information behaviour. Examples from this interview study include the different coping strategies exhibited by participants (*e.g.,* some participants chose to ask their ophthalmologist more information about their visual impairment whereas other participants ‘blocked’ any further information) (‘stress/ coping theory’).

> “*Erm … I suppose. I know what I need to know and that’s it … basically*.” (B2, line 63)

> “*No, I’m not bothered. What I don’t know can’t … harm me. I suppose … in some ways I’d rather not know*.” (A11, line 71-72)

These comments reflect the differences between different patients in relation to their information needs and the individualistic nature of these needs, as discussed earlier in relation to Moore’s model.

Participants expressed a preference for health care professionals and the local society for the blind as an information source; this may because the benefits (or ‘rewards’) of doing so were greater than the ‘risks’. In addition, it was clear that ‘social learning theory’ was involved; for example, participants acquired information and knowledge through less formal contacts, *e.g.*, via local support groups and friends and family.

> “*It’s people I know who’ve got problems with their eyes that have told me a lot … a lot of things*.” (A13, lines 68-69)

> “*Sometimes … one hears by word of mouth, of course … Somebody else will say, ‘Oh, have you tried this?’, or ‘Did you know you could get that?’*” (A3, lines 186-188)

The importance of a range of information sources in this study was clear, and while information needs can be highly individualistic, it was clear that the profile of resources that participants drew upon was also dependent on the individual.

Intervening variables

This study has identified a number of Wilson's 'intervening variables' which could potentially act as a barrier (or, in some cases, a facilitator) for visually impaired people. Although the labels identified here are slightly different to those used by Wilson (1999) ('psychological', 'demographic', 'role-related or interpersonal', 'environmental', and 'source characteristics'), a similar range of 'intervening variables' emerged. For example, the demographic background (such as age, gender, ethnic origin), the individual's social role (such as degree of independence, support available from friends and family, involvement with local support groups, *etc.*), the individual's psychological status (*e.g.,* acceptance of having a visual impairment), environmental variables (*e.g.,* registration status, access to the Internet, willingness and ability to pay for aids, adaptations and equipment), and the characteristics of the sources (*e.g.,* availability of information in alternative formats, reliability of the information provided, interactions with different information providers as discussed earlier) may all have affected participants' information behaviour.

However, an interesting finding from this study is that, in addition to Wilson's list of 'intervening' variables, there are further issues that must be taken into account when considering the information behaviour of visually impaired people seeking health and social care information. For example, in this study we have also identified variables relating to the person's visual impairment (*e.g.,* type, degree and length of impairment) and the presence of other health conditions and disabilities, all of which may affect an individual's information behaviour.

Information seeking behaviour

Wilson's revised model also recognised that there were different types of search behaviours: passive attention, passive search, active search and ongoing search and the findings from this study are in accordance with this. In addition to receiving information from a variety of sources ('passive attention'), participants 'acquired' information ('passive search'), as well as actively sought information in order to meet their health and social care information needs. For example,

> "*Well, the thing is … you do not get information either from your GP or the hospital unless you ask …*" (A2, lines 181-182)

The quotations from participants A2 and B12 discussed above in relation to Moore's model also indicate that the visually impaired people in this study were obliged to go to some lengths to obtain the information they required, in addition to receiving information more passively.

Information processing and use

In accordance with Wilson's model it was evident that if participants' information needs were to be satisfied then 'information processing and use' was an essential part of the feedback loop, *i.e.,* participants, having received, acquired or sought the necessary information then had to make sense of this information, as illustrated by the quote from A17 above weighing up the pros and cons of receiving laser treatment for AMD.

To summarise, Wilson’s revised model can be used to explain, at least in part, the information behaviour of people with a visual impairment seeking health and social care information. However, this interview study has identified an additional ‘intervening variable’ category relating to an individual’s health characteristics (type, degree and length or visual impairment and presence of other health conditions and disabilities).

Summary of findings

Moore’s model of social information need and Wilson’s model of information behaviour have been useful in analysing and interpreting the results of this study. The results from this primary research study supported the six dimensions of social information need for people with a visual impairment derived by Moore (2000, 2002) in his review of previous studies. Building upon Moore’s clusters of information needs (Moore, 2000), it was possible to develop these into an ordered hierarchy of importance from the perspective of the visually impaired people in this study. The results also emphasised the importance of the relationship between health and social care providers and people with a visual impairment and the effect that this can have on the communication process and people’s access to information. However, Moore’s model does not account for all the “intervening variables” in Wilson’s model which appear to be important in determining information behaviour among people with a visual impairment.

This study also demonstrated that Wilson’s model of information behaviour, developed with more general information situations in mind, can be applied, although modified slightly in terms of the individual's health characteristics, to a specific group of people. This indicates that Wilson's model can make a valuable contribution to our understanding of information needs in the context of other groups, diseases and conditions.

Research limitations

It is helpful to highlight briefly some of the potential limitations of this research study.

- The findings and implications were derived from a relatively small sample size that is not likely to be representative of the general population of people with a visual impairment and these findings cannot necessarily be generalised to the wider group, or indeed to the two groups of people who have been blind since birth or who have AMD. Data saturation was, however, reached after 24 interviews and qualitative research does not aim to be generalisable (Lincoln & Guba, 1985), but attempts to develop findings that can be applied to similar groups.
- For practical reasons, a convenient self-selecting sampling frame was used. It is, therefore, possible, that the people who volunteered to be interviewed were more confident and active in seeking out information than non-responders or groups of visually impaired people who were not included in the sample.
- The majority of participants were white-British; had had a visual impairment for more than twelve months and were registered blind or partially sighted and were, therefore, already in contact with relevant services. It is not clear if the findings could be applied to people who have been more recently diagnosed and/or people from other ethnic groups, many of whom have an additional language barrier. It is also possible that participants in this study were more likely to be in

contact with services and facilities (*e.g.*, in receipt of the local talking newspaper, or a member of a local visual impairment support group) and that the barriers to information and unmet information needs of people not in contact with these services could be greater than those in this sample.

However, despite these limitations, a number of useful conclusions can be drawn from this study.

Conclusions

Both Moore's (2002) model of social information need and Wilson's (1999) revised model of information behaviour provide a useful basis for examining the information behaviour of visually impaired people seeking health and social care information. The findings reported here are broadly in accordance with Moore's larger scale analysis of the literature in this field. However, Moore's model focused predominantly on information needs and did not formally take into account the broader aspects of information behaviour, such as 'intervening variables' which have been identified here as an important facet of the information behaviour of visually impaired people.

In contrast, the theoretical basis for Wilson's revised model of information behaviour is well established, and this model helps to explain the information behaviour of people with a visual impairment seeking health and social care information. An additional 'intervening variable' category has, however, been identified relating to the individuals' health characteristics (type, degree and length or visual impairment and presence of other health conditions and disabilities).

Implications for future research

The generalisability of these findings will need to be tested by undertaking a large-scale quantitative study of the information behaviour of visually impaired people. It will also be useful to examine Wilson's revised model in more detail in the context of other health information research, for example, to see if the additional 'intervening variable' relating to the individuals' health characteristics exists for other conditions and disabilities. As noted earlier, an initial integrated human information behaviour model (Spink & Cole, 2006) has been published since this study was undertaken. It will be interesting to use this model as a template for examining these research findings in more detail.

Implications for practice

It is clear that both Moore's (2002) and Wilson's (1999) models provide a useful framework for analysing and understanding the information needs and information behaviour of visually impaired people in relation to health and social care information. Health and social care professionals and information professionals/ providers for people with visual impairments need to take account of the individualistic nature of information needs and to be aware that these needs can be affected by a variety of factors. This study has also demonstrated the problems of poor communication between professionals and visually impaired people and the impact of these on people being able to access information. It emphasises the importance of encouraging an open and trusting environment and of fostering a relationship in which people feel empowered to seek and obtain the information they need.

[9,244 words]

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TABLES AND FIGURES

***Figure 1.* A revised general model of information behaviour (adapted from Wilson, 1999; explained in Wilson, 1997)**

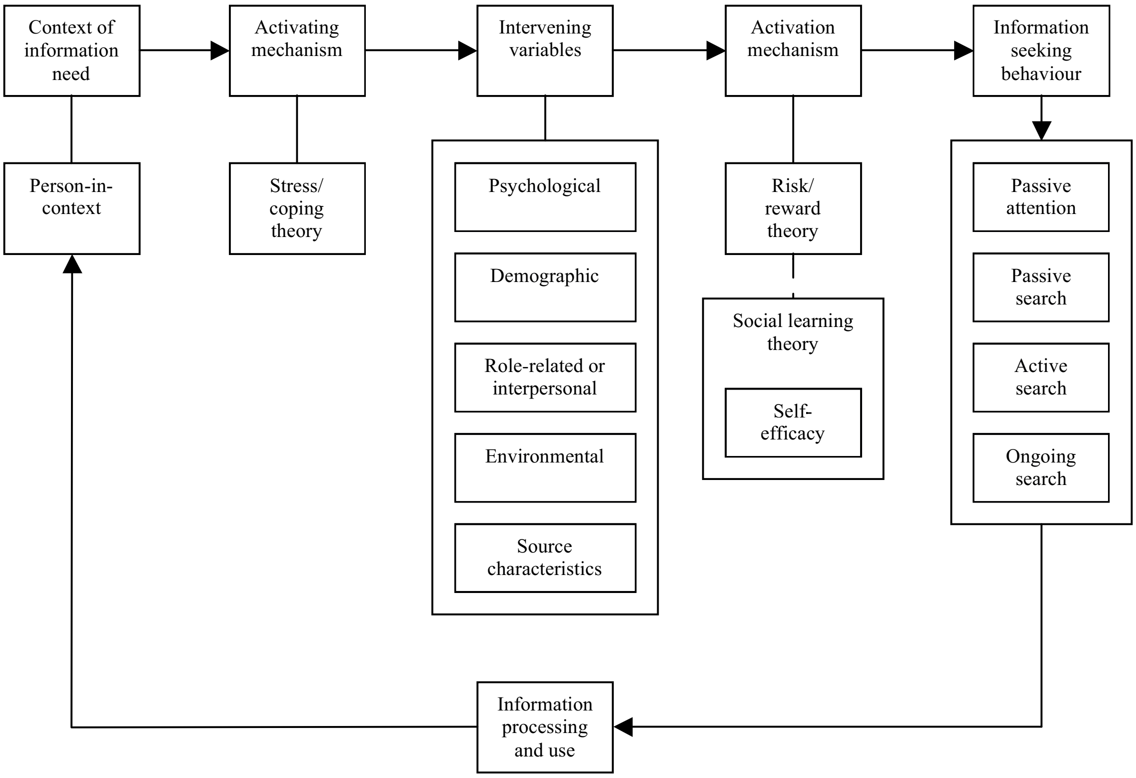

***Figure 2.** Interview topic guide*

Checks:

- Information sheet
- Outline of study
- Tape recorder
- Consent

1. Background to visual impairment
    - Including other health conditions

2. Meaning of health and social care information

3. Contact with different agencies (*e.g.* hospital, Social Services, local societies, *etc.*)

4. Information relating to visual impairment
    - Received
    - Sought
    - Acquired
    - Outstanding information needs

5. Information relating to other aspects of health and social care
    - Received
    - Sought

- Acquired
- Outstanding information needs

6. Newer sources of information
    - Telephone helplines (e.g. NHS Direct)
    - Internet
    - Touch screens

7. Possible improvements to the provision of health and social care information

8. Demographic information
    - Sex
    - Age
    - Ethnic origin
    - Marital status
    - Co-habitation
    - Employment status
    - Socio-economic status