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# **Exploring the Online Health Information Seeking Experiences of Older Adults**

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## Abstract

In this article we explore how the experience of searching for Online Health Information (OHI) becomes a meaningful activity in the lives of older adults living with chronic health conditions. A descriptive phenomenological approach was adopted to contribute to the overall understanding of individuals' lived experiences of OHI-seeking through an exploration of the consciousness of the experiencer. This article provides rich experiential descriptions that have the potential to make a contribution toward healthcare practice within the UK by providing healthcare professionals with an understanding of patient experience that can help them identify patients' needs and make improvements to care in terms of the quality of empathy and understanding for older adults with chronic health conditions. The findings also provide rich stories of older adults actively engaging in this form of health information seeking, data that could be used to challenge pre-conceptions that age is a barrier to using the Internet for this purpose.

The prevalence of long-term or chronic health conditions is increasing. According to the United Kingdom's (UK) Department of Health (2004), 60% of adults in the household population of the UK live with a chronic condition, and many of those individuals live with multiple conditions. In addition, estimates suggest that the UK's 65 years and older population will increase from 35 million in 2000, to 53 million in 2020 (Bodenheimer, Lorig, Holman, & Grumbach, 2002). This would represent a dramatic increase in the size of the age group with the most increased prevalence of chronic health conditions. This predicted expansion in the incidence of chronic health conditions could present huge challenges for patients and health services. Although patients with chronic conditions place great strain on global health systems, healthcare professionals may only interact with patients living with chronic health conditions for a few hours every year. For most of the year, patients are left to manage their own conditions (Department of Health, 2004). This form of condition management or 'self-care' can be defined as the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

In order to self-care effectively patients need access to high quality, and relevant health care information. Research suggests that patients are increasingly turning to the Internet to seek information to fulfill their healthcare needs. In order to provide a simple typology of online health information (OHI) the key sources of OHI can be divided into four main categories: traditional static websites, collaborative sources, person to person communication and mobile application software. Traditional static websites include public, private and voluntary sector sources as well as websites formed independently that focus on one way dissemination of information. Collaborative sources include discussion boards, social networking sites and groups, forums, blogs, wikis and podcasts or vodcasts. In all of these sources, the emphasis is placed on content creation by lay-individuals. Person to person communication refers to the dissemination of health information via email and mailing groups. Finally, the term mobile application software refers to applications that can be downloaded by consumers from the Internet to their mobile devices. OHI sources are increasingly using a combination of these forms of health information dissemination to meet consumer's needs; for example, static websites linking to a blog or discussion board.

Internet usage statistics suggest that online methods of health information dissemination are increasingly popular within the UK and internationally. Recent national statistics suggest that around 39% of UK adults who had accessed the Internet in the three months prior to the survey had sought information relating to their health online (Office of National Statistics, 2010). This figure has grown significantly since 2007, when comparable statistics showed that only 27% of adult Internet users had used the Internet for this purpose (Office of National Statistics, 2007). This increasingly popular form of health information communication has great potential to educate and empower individuals by providing information on aspects of general health and available services as well as supporting self-management and patient choice (Murray, Burns, See Tai, Lai, & Nazareth, 2005; Powell, Darvell, & Gray, 2003). The prospects are especially good for older adults who are more likely to be home bound, have a disability that prevents them from travelling, or live in remote areas, as it might be a challenge for them to access health information using more traditional means (Becker, 2004).

Despite the Internet's potential as a health information tool for older adults, little is known about the everyday experiences of older adults using the Internet to self-manage chronic health conditions. The need to explore such experiences is critical given recent research results that suggest that the OHI seeking experience of older adults is significantly different from that of their younger counterparts (Mayoh, Bond, & Todres, 2011). The quantitative findings from the study by Mayoh et al. (2011) demonstrated that older adults are less likely than younger individuals to experience the potential benefits of OHI seeking, such as confidence when discussing their health with professionals, and confidence in decision making regarding their health. In addition, physiological issues such as vision, cognition, and physical impairments are more likely to affect older adults (Becker, 2004) and these issues can have a direct impact on web usability and the OHI seeking experience. These physiological issues could also be exacerbated by chronic health conditions, creating an additional obstacle for older

adults, who arguably have the greatest need for health information.

In addition to functional issues that could impede older adults' use of OHI, research has also suggested that attitudinal issues might influence the OHI seeking experience for older populations. Negative thoughts associated with older adults, such as a lack of perceived relevance and usability (Olphert, Damodaran, & May, 2005) and a pessimistic orientation toward the future (Blit-Cohen & Litwin, 2004), might affect their motivation to learn new skills associated with OHI seeking. The attitudinal theme of perceiving the self as being 'too old' for computers is also frequently cited within the existing literature (Gustafson et al., 1998; Stanley, 2003; Turner, Turner, & Van de Walle, 2007). Specifically, research suggests that older adults perceive their age as potentially rendering them incapable of learning how to use new technology (Stanley, 2003).

Research also suggests that attitudinal issues relating to preferences in terms of level of health care responsibility may be related to age. Levinson, Kao, Kuby, and Thisted (2005) found that preferences for taking active responsibility for health increased with age up to 45 years, but then declined significantly, thus suggesting that older adults may be less likely to engage in self-management behaviour than their younger counterparts.

Despite recent reports suggesting that older adults are increasingly using the Internet both in the UK and internationally (Becker, 2004; Fox, 2001; Office of National Statistics, 2009), research also suggests that this population remains less likely than their younger counterparts to seek information online (Mayoh et al., 2011; Office of National Statistics, 2010). These findings demonstrate that the potential of this health information source for the older population is not being actualized.

These findings demonstrate the need for additional indepth experiential research to provide rich descriptions of the OHI seeking experiences of older adults with chronic health conditions in order to understand the challenges and complexities that they face. This form of exploratory research would allow for the dissemination of rich stories from individuals actively engaged in the process of OHI seeking and would also help present any aspects of the experience that may relate specifically to age. With this in mind, the aim of this study was to explore, in a detailed manner, how the experience of searching for OHI became a meaningful activity for older adults living with chronic illness through the provision of rich experiential descriptions.

In line with experiential research tradition, it was

necessary to orientate to the phenomenon prior to formulating the phenomenological question (Van Manen, 1990). As part of this orientation process the researcher focuses carefully on the question of what possible human experience is to be made topical for phenomenological research and ensures that there is a specific focus for descriptive experiential research. Within the current study, orientation was achieved through reflection on existing literature, as well as through the conducting of a pilot stage that explored the breadth of OHI seeking and OHI sharing experiences (Mayoh et al., 2011). Through the orientation process four experiential themes were identified as related to the broader experience of OHI seeking (an additional theme was identified in relation to information sharing). These four themes are analyzed and discussed within the current paper.

The current article describes the examination of the structures and constituents of the following four experiential themes within the broader experience of OHI seeking for older adults with chronic health conditions:

- 1. Being unable to find OHI;
- 2. Finding poor quality OHI;
- 3. OHI helping increase understanding; and
- 4. OHI increasing confidence.

It was hoped that more focused experiential descriptions of these facets of the broader OHI seeking experience for older adults with chronic health conditions would help provide insight into the essential structure of these lived experiences. A better understanding of these experiences could potentially inform health professionals, caregivers and loved one's of older adults with chronic health conditions. It would also lead to a wider understanding of the phenomenon. In addition to these clear benefits, supplementary in-depth experiential description can facilitate the design of informed interventions that may assist older adults in engaging in OHI seeking in the future, thus contributing to the prevention of a digital health divide within contemporary society.

# Method

### Methodological Approach

Phenomenology as a philosophy seeks to understand anything at all that can be experienced through the consciousness one has of whatever is 'given' – whether it be an object, a person, or a complex state of affairs – from the perspective of the conscious person undergoing the experience. (Giorgi, 2009, p. 4)

The main emphasis of descriptive phenomenological

research is the description of human experience as lived by the experiencer in a way that can be utilized as a source of in-depth qualitative evidence (Todres & Holloway, 2006). Through the development of an understanding of the commonalities and variances in features of the experience of seeking OHI for older adults with chronic health conditions, crucial information is presented that has the potential to inform and enlighten health professionals in understanding the nature of the lived experiences of their existing and potential patients.

#### Sample

Six individuals agreed to be involved in the research as participants. These individuals were purposefully sampled using fixed inclusion criteria designed to maximise the possibility of gaining in-depth descriptions of the four lived experiences outlined above. The inclusion criteria for participants were that they had to be more than 60 years old, that they selfreported being clinically diagnosed as having a chronic health condition, and could share personal experiences of seeking information relating to their health online. In order to access the sample seven different condition specific support groups dealing with many different chronic health conditions were approached, including groups for people who had suffered strokes, haematological cancers, diabetes, myalgic encephalomyelitis (ME), multiple sclerosis (MS), general cancer, and osteoporosis. All the groups were located on the south coast of England throughout the counties of Dorset and Hampshire. Participants were invited to contribute to the research provided that they met the inclusion criteria. This purposive recruitment strategy was adopted as it was felt that adults actively engaging in support for an ongoing chronic health condition would probably be able to provide information rich descriptions of the lived experience of this form of health information seeking. In keeping with the tradition of phenomenological research design, we believed that the final sample of six participants would provide adequate opportunity to study the lived experiences, and yield interesting insights into the commonalities and variations in how these experiences were lived within a variety of circumstances. According to Todres and Galvin (2005), if the aim of a study is to obtain phenomenological depth then even "single-case studies can yield findings that are attuned to focusing on very specific and highly textured details within their unique context" (p. 2). Using this rationale, we argue that in the pursuit of phenomenological breadth a sample size of six is more than adequate for this form of research.

The final six participants whose experiences were used in the analysis were recruited from support groups for the following chronic conditions: Multiple

Sclerosis (1 participant); Cancer (1); Diabetes (2); Osteoporosis (1) and Stroke (1). Four of the participants were female, and their ages ranged from 64 to 79 years.

#### Ethics

Ethical approval for the research was sought from the internal University Research Ethics Committee (UREC). Approval was sought from this committee rather than from the National Health Service (NHS) because the research was conducted within the context of social research and was seen as broader NHS research because it dealt with social issues such as self-management and social support. It was therefore deemed appropriate to seek ethical approval through the university in order to ensure consistency between the research and its procedures. In order to ensure the participants' anonymity pseudonyms are used throughout this article

#### **Procedure**

Semi-structured interviews were conducted with a phenomenological focus in accordance with Giorgi's descriptive phenomenological approach (Giorgi, 1985, 2009; Giorgi & Giorgi, 2004). Interviews were either conducted in a private room at the local university campus or (in the case of two participants) in private rooms at the support group centers they regularly attended. The two participants who were interviewed at the support group centers had functional concerns that prevented them from comfortably travelling to the university campus. This necessitated the seeking of an amendment to the study's ethical approval in order to ensure flexibility in terms of the interview location. The length of each interview varied depending on the length and depth of responses provided by the interviewees. However, all the interviews lasted between 90 and 120 minutes in total. To gain in-depth descriptions of each of the specific experiences within broader OHI seeking experience for older adults with chronic health conditions, a life-world evoking question was initially asked in accordance with the four specific experiential themes (Todres & Holloway, 2004; Todres & Galvin, 2006). These questions acted as explicit requests for concrete descriptions of the lived experiences outlined above. For example, the interview theme 'The lived experience of being unable to find OHI' was translated into the initial lifeworld evoking question: 'Could you please talk me through a time when you were unable to find the health information that you needed online?' Once these questions had been formulated, they were collated to form the basis of the interview guide:

The inclusion of this specific form of phenomenological questioning helped focus the

interview and guide the participants towards providing a description of a specific lived experience in their own words as opposed to talking generally about the research area. Once the relevant life-world evoking question had been asked the participant was encouraged to continue the description, although the interviewer took care to avoid influencing the participant's account in order to ensure that the data was as true to the participant's stream of consciousness as possible. If clarification was required regarding specific aspects of the participant's account, the interviewer made an appropriate request for clarification.

#### Analysis

Giorgi (2009) provides a discussion of the systematic steps involved in conducting a descriptive phenomenological analysis. These steps are:

- 1. Obtain rich life-world descriptions.
- 2. Read transcriptions thoughtfully to get a narrative sense of the text as a whole.
- 3. Divide the descriptions up into units, signifying changes in meaning 'meaning units'.
- 4. Express the sense of each meaning unit generally.
- 5. Develop a 'structure' that integrates the common meanings.
- 6. Open out the structure and elaborate on the common themes from within 'constituents' by using original participant data to develop the richness of the analysis.

Rich life-world descriptions were audio-recorded during the phenomenological interviewing process. The data was subsequently transcribed and read for a sense of the whole. It was then possible for the final four stages of Giorgi's descriptive phenomenological method to be applied to the data to ascertain the essential structures of each the themes under investigation. These fundamental stages of analysis involved backwards and forwards movement between the general structure of the experience and the explicit nature of the actual experience in order to develop the final structure and constituents for descriptive presentation. The development of the expression of the essential structure involves the researcher using a process of imaginative variation in order to determine the most invariant elements of the experience (Giorgi, 2009). The term imaginative variation describes an exercise whereby the researcher uses his or her imagination to make alterations to aspects by either subtracting or adding elements. For example, in this study the researchers asked imaginative questions such as: "Is the experience of searching for online health information still this experience if the experience has no information requirement?" This

process of imaginative variation allows the researcher to discover the aspects and/or qualities that make a phenomenon uniquely what it is and without which it would be something else (Van Manen, 1990). This experimentation thus leaves the researcher with the 'essence' or 'bare bones' of what constitutes the phenomena and this can then be articulated as the structure (Holloway & Todres, 2003). Once these general structures had been finalized it was then possible to discuss them in a more holistic manner in order to provide a more comprehensive structure for the broader experience of OHI seeking for older adults with chronic health conditions.

It is important to note that the final two stages of the methodological procedure, involving the development of an essential structure and opening it out to elaborate on the constituents, were far from a straightforward linear exercise. According to Todres (2005), in order to effectively synthesize the typical themes from the descriptions within the life-world and develop the elements of an experience the researcher must retain a sense of the whole and remain aware of the transformed data contained within the individual constituents or insights. In other words, prior to the articulation of the structure of experience and the constituents of that structure, the researcher has to enter into a process of moving between the transformed data, invariant themes (structure) and the textual constituents. This process helps ensure that the elements of the structure are mindful and developed in relation to their roles within the whole (Gurwitsch, 1964) and that the whole is constructed in a way that is dependent on the individual parts. Therefore, the transformation, structure and constituents are deeply interrelated and reliant on each other to provide a holistic presentation of the experience.

## The Structure and Constituents

# Presentation

Once the experiential data had been analyzed and a general structure for each experience had been produced, it became clear that all the lived experiences shared two common characteristics. Therefore, in order to meet the communicative concern of the research a general structure for all OHI seeking experiences for older adults with chronic health conditions is presented prior to the discussion of the structures for the four more specific phenomenological experiences.

# The Structure of the Experience of Searching for Health Information Online

Older adults with chronic health conditions' experience of OHI seeking occurs in response to the

identification of a gap in healthcare knowledge. This can relate either to personal knowledge or to the knowledge of an individual within their social circle. The experiencers perceive this gap in health information in a negative manner and wish to relieve themselves/another of it by becoming more informed. The experiencers feel that it is, to a certain extent, their responsibility to ensure that they become more informed. A desire emerges to seek information concerning their health and to demonstrate ownership of their bodies and/or the bodies of those for whom they feel responsible.

## Identifying an Information Requirement

The first central constituent for all of the OHI seeking experiences was the identification of a perceived health information requirement. The specific nature of information requirement varied between participants. For some of the participants the health information deficit took the form of a need for general information about a recently diagnosed chronic condition, whereas other participants had more precise information needs regarding a specific treatment or medication. Participants implied that they perceived having a health information deficit as a negative thing and therefore attempted to rectify the situation. However, the manner in which this negativity was experienced by individuals varied between the lived experiences. Specifically, Claire stated that she felt dissatisfied with the lack of information, whereas Denise described being worried about an information deficit regarding a drug that she was taking "you're very worried about, you know, you're thinking this drug is going into my body and what's it going to do?"

## Taking Responsibility

The next unifying characteristic of the general and more specific experiences was that all participants described taking responsibility for either their own health or for the health of another person for whom they felt personally responsible, such as a dependent or life partner. Most of the participants described a desire to take control of their own health and wellbeing, and showed a sense of routine ownership over their own health. Participants did not specifically justify this experience but instead described it as part of a natural process. This appeared to be something they perceived doing without conscious awareness. In some cases, participants described taking initial and complete responsibility for becoming more informed about their health care. However, most descriptions also demonstrated a perception of sharing the responsibility for the management of their chronic health conditions with their health professionals. Specifically, a number of the lived experiences indicated that the participants felt personally

responsible for filling in the gaps in their healthcare knowledge that remained after their interactions with healthcare professionals. In this way, the participants acknowledged the role of a partnership approach between patient and practitioner in order to ensure that the patient is fully informed.

In the following sections the analysis of four specific experiences of seeking OHI is presented. The aim of this presentation is to articulate important components of the overall experience and to uncover the varying themes concerning different seeking experiences. The common themes of 'Identifying an Information Requirement' and 'Taking Responsibility' have already been discussed and the subsequent sections will therefore concentrate on the unique constituents of the experiences.

# Experience 1: The Experience of Not Being Able to Find Health Information Online

## **Unfulfilled Expectations**

During this lived experience the participants described having a specific idea regarding the information required and then finding that the information they located failed to meet this expectation. In this regard, Denise described a time when she was unable to locate OHI regarding a potential medication, while Fiona specifically described a time when she failed to locate information regarding a specific side-effect of her condition:

... there is nothing there that describes what is a hypo and what is a hyper, it talks about hypo and a hyper but it didn't actually tell you what might happen at that point in time...when I actually looked it up, it talked about people having a hypo and having low blood sugar, but it didn't talk about the effect that would be. (Fiona)

Participants described experiencing high levels of self-assurance in their abilities to distinguish and recognize the information that they required to self-manage their conditions. They thus had confidence in their ability to take responsibility for their own health. Participants had a specific idea about the information that they required but often found information that they felt was too descriptive and was unable to assist them in being fully informed. In other words, participants had unfulfilled expectations in terms of the OHI that they located.

## Being Left in the Dark

Within the broader experience of being unable to locate OHI, the participants described the experience of being 'left in the dark' or 'not knowing' for an

extended time. This experience also included being left without desired reassurance in the form of information with which to effectively manage a chronic condition. Denise experienced being left in the dark when she was unable to find information on the Internet or through other sources to give her reassurance about her chronic condition. Fiona experienced being left in the dark when she knew that there were side-effects for her condition but she did not know what this meant for her. Fiona also provided additional detail regarding the negative implications of being 'left in the dark' and not being fully informed about a condition. In this regard, she stated: "...and that was really difficult, because you're left sitting there knowing that these things could happen, but not knowing what it actually means for you".

These accounts imply that the individuals need to be effectively informed regarding aspects of their health in order to be confident and reassured about their health so as to effectively manage it in the future.

# Experience 2: The Experience of Finding Poor Quality Health Information Online

#### Unfulfilled Quality Expectations

The lived experience of finding poor quality OHI demonstrated that although the experience of being left unfulfilled was overwhelmingly negative, the participants encountered this experience in a variety of different ways. For example, Claire had specifically expected to find information that corroborated other OHI sources, but in reality found that "some of them really contradicted each other". The participants provided a variety of reasons for why they perceived the information that they located to be of poor quality, including lack of corroboration of sources and failure to relieve a specific requirement. However, the common experience for all the participants involved the existence of expectations in terms of what constituted quality OHI.

The participants experienced different consequences as a result of these unfulfilled quality expectations. For Brian, finding information which did not meet his quality expectations made him believe that he had not improved his knowledge. In contrast, Denise found herself overwhelmed by the experience. Finally, for Fiona the experience of being unfulfilled resulted in feelings of concern and powerlessness.

# Confidence and Concern

Some of the participants explicitly stated while others implied that they have confidence in their ability to discern OHI quality. Participants also demonstrated concern regarding other's ability to discern OHI quality. Being unable to identify poor quality health

information was seen as a potential problem for others, demonstrating that the participants' perceived themselves as having advanced ability to navigate OHI effectively. For example, Claire explained that she felt reassured that, although there was poor quality OHI available, she knew which information she should take onboard. In addition, Edward confidently described being able to distinguish between good and poor quality OHI as "a matter of experience, and you think there's somebody trying to flog me something, this makes more sense to me than this one. It's more judgment."

All participants described potential problems associated with locating poor quality OHI, but felt that these problems would not affect them because of the confidence they had in their own abilities. This confidence allowed the participants to feel a sense of immunity from the possible negative implications of finding poor quality OHI. This confidence was further characterised by a perception that others might not be able to operate on the same level. Although Denise and Brian did not explicitly provide information to describe the nature of their confidence, Edward stated that his confidence stemmed from an awareness of his own ability to show judgment, and an awareness of the type of advice that would be provided by a professional. For all the participants this sense of confidence allowed them to step outside of the simple consumer role and instead identify potential hazards for others. This confidence thus provided a sense of immunity as well as perceived advanced ability in relation to judgment and additional knowledge of the situation.

# Experience 3: The Experience of Online Health Information Helping Participants Understand Something Better

## Entering into a Process

During the description of this lived experience, individuals discussed the process of navigating OHI to a greater extent than had been discussed in other experiences. The way in which this process was described was very similar for all participants. Edward described it as the "usual system", thus suggesting that this part of the process was almost routinely accepted as the only manner in which to search for OHI.

This process always begins with the use of a search engine tool to locate the required information. The participants mentioned using Google (no other search engines were named during any of the interviews) to locate information, suggesting high levels of reliance and trust in this specific search engine. Once the participants have entered a search term into a search engine they are faced with multiple pages of OHI that

they have to navigate to locate the required information. Thus, although the participants stated that it was easy to locate some information relating to their query, they were faced with additional challenges in terms of searching and appraising the vast quantity of information available.

Although the participants did not explicitly describe the process of navigation, they stated that they felt able to locate the information that they required after being faced with multiple pages relating to their query. Claire specifically described this experience as one of "perseverance", a concept that is echoed throughout other participants' descriptions. In contrast, Denise provided a much more positive description of navigation and stated that she felt that she was faced with a wealth of useful information and saw navigation as a process that could be used to obtain a greater web of related information instead of as an obstacle that needed to be overcome. Regardless of how the participants perceived the navigation process itself, they all experienced the outcome of the process as positive, leading to the fulfillment of expectations.

#### Fulfilled Expectations

The participants all felt that they located information that met their expectations in terms of OHI. They also demonstrated trust in the information by utilizing it to manage their condition. The participants thus have faith in the quality of the OHI that they locate. Denise went into great detail about the comprehensive information that she found, proclaiming "oh yes, it's all there". For Edward, his trust was based on the fact that he only makes use of studies as opposed to other forms of OHI. Fiona described the information that she located as factual as opposed to just opinions, thus suggesting belief in the reliability of the information. Although most participants did not explicitly state that they trusted the OHI they located, this trust was implied in their behaviour as they used the information for self-care. The participants thus experienced fulfillment in terms of locating OHI that was trusted to the extent that it could be used practically to help self-manage their conditions.

### Empowerment

As a result of this experience, the participants consistently described a sense of empowerment. They were able to utilize the information that fulfilled their expectations to self-manage their chronic health conditions and this resulted in a sense of empowerment. For the participants, increased understanding and knowledge led to a sense of empowerment which allowed them to make decisions about the way they self-managed their conditions. Although the participants used the OHI in different

ways, they all displayed trust in the information and provided evidence of practical examples of them taking responsibility for their health. For example, Brian was empowered to choose a form of cancer treatment because of his increased understanding and Denise was reassured about taking a specific medication:

It gave me relief ... it gave me confidence to think right, I will take this drug. Because I must be honest, I'd had the prescription made up for three months and I hadn't taken the drug. Because that was just fear. (*Denise*)

This experience demonstrates a clear link between knowledge/understanding and confidence/power that serves as a potential benefit to OHI seeking in the management of the individual's condition. The experience of locating OHI thus not only resulted in better understanding, it also resulted in empowerment based on an increase in personal knowledge, a level of confidence in the information, and the individual's perception of the information's usability in assisting self-management. Empowerment is experienced as a result of a successful OHI seeking process. Accessing OHI has a positive effect on the individual as it allows them to fulfill their expectations and become better informed.

# Experience 4: The Experience of Online Health Information Increasing One's Confidence

# Trust and Fulfillment

Individuals who lived this experience reported high levels of trust in the OHI that they located while attempting to fulfill their information deficit. Claire and Denise specifically described the experience of fulfillment as one of reassurance and stated that they had been looking specifically for information that they felt would help them move forward. For Denise this information allowed her to experience a sense of comfort regarding taking a new medication, whereas for Claire the information helped her accept the diagnosis provided by a biopsy. Brian made a direct link between finding the information that he felt he needed and an increase in his confidence. Edward spoke about two different ways of experiencing fulfillment in relation to two different experiences. In Edward's first experience, fulfillment occurred as a result of satisfying a general interest in response to broad OHI seeking. However, in the second experience, fulfillment occurred as a result of finding the information he required to self-diagnose. Although the manner in which fulfillment was experienced varied, the participants demonstrated an overall sense of satisfaction with the health information that they found online. They also noted that locating this trusted information helped them feel

more reassured about the decisions that they had made, thereby increasing their overall confidence.

## Empowerment

Through becoming more informed based on seeking trusted OHI, individuals felt empowered to make decisions about their health and treatment regimens and to self-manage their own health conditions in a similar manner to other positive seeking experiences. For Brian and Denise becoming information-enabled patients gave them the confidence to make decisions about their treatment. Claire felt empowered to "take a more positive view" and to work in partnership with her doctor to ensure she was getting the appropriate treatment for her condition.

For all the participants becoming more informed through locating trusted OHI led to a greater sense of confidence in their ability to self-manage. This also resulted in more substantial notions of control over their health and treatment regimes. There was also a distinct sense that becoming more informed increased participants' perceived ability to work effectively in partnership with health professionals. The participants experienced as sense of empowerment as a result of their increased knowledge, thus reducing the gap in the information power balance between patient and health professional. This resulted in the health professional no longer 'holding all the cards', and the participants experiencing a sense of increased confidence based on the information they accessed. Empowerment was thus experienced as a by-product of increased confidence, and was expressed through the practical application of the information that initially helped to increase the individuals' confidence.

# The Overarching Experience of OHI Seeking

The experience of OHI seeking for older adults with chronic health conditions begins with the individual identifying a health information need and then taking the responsibility for fulfilling that need by going online to seek OHI. During this seeking experience, individuals' expectations in terms of OHI are either fulfilled or unfulfilled.

If the individuals' expectations are left unfulfilled by the OHI seeking experience, then the experience is perceived to be negative. Examples of negative seeking experiences include the experience of not being able to locate OHI and the experience of finding poor quality OHI. These experiences did not result in the OHI being used to self-manage chronic health conditions.

If the individuals' expectations are fulfilled by the OHI seeking experience, then the experience is

perceived to be positive. Examples of positive seeking experiences include the experience of OHI helping individuals understand something better and the experience of OHI increasing individuals' confidence. Positive experiences ultimately resulted in the experiencers believing that they were empowered by the OHI. The participants then used the OHI to self-manage chronic health conditions. Positive experiences also gave older adults with chronic health conditions the confidence to engage in discussions with healthcare professionals and make decisions regarding their health.

#### Discussion

The presentation of the results demonstrates the emergence of numerous key findings pertinent to the experience of older adults seeking OHI. The discussion that follows focuses on the three key themes that emerged in relation to the aims of the research and existing literature:

### Responsibility

The lived experiences described by older adults with chronic health conditions demonstrated that participants felt the need to take responsibility for their health or for the health of a loved one. In accordance with the findings of previous studies (Spiers, 1997) participants demonstrated a sense of bodily ownership and assumed this responsibility almost automatically and without justification. Furthermore, the lived experiences demonstrated that individuals felt an intention to share responsibility with health professionals and to engage in a partnership relationship to ensure positive health outcomes in line with UK health policy. This theme is extremely important as it fails to reflect findings from previous survey research that suggest that older adults are less inclined to take responsibility for their health than their younger counterparts (Levinson et al., 2005). This paper demonstrates that the older adults with chronic health conditions included in this sample automatically and autonomously felt responsible for their own health care. In addition, the paper provides rich descriptions of these adults' behaviour in relation to this responsibility. However, it is important to note that the aim of the current study was to achieve depth as opposed to experimental breadth, and the findings therefore lack generalizability owing to the sampling technique and size adopted. Although the study is unable to quantify the extent to which older adults take responsibility for their health, it does provide a rich description of 'how, where and why' older adults engage in OHI seeking. While this study provides rich descriptions of this experience for older adults within the UK, there is a need to explore the experience within other countries with different healthcare systems. For example, future research could explore whether the nature of this responsibility is different in countries with private healthcare systems.

#### **Expectations**

A recurring theme within the structures of seeking experiences was patient expectations. The participants experienced a specific set of expectations regarding OHI. When these expectations were fulfilled this led to positive evaluative perceptions of the experience. This finding is in keeping with the findings of previous research, which suggest a specific link more between the fulfillment of patient broadly expectations and satisfaction (Kravitz, 2001; Sitza & Wood, 1998). When these expectations were observed more closely through the descriptive phenomenological analysis it was clear that the participants experienced different forms expectations. These expectations could be classified as general expectations, formed from long-term experience and unconsciously ingrained in their minds, and query-specific expectations, which were short term and based on their specific needs at that precise moment.

Examples of general expectations include quality expectations such as a lack of financial motivation, an acceptable standard of writing, simplicity and clarity. These expectations are based on the individual's longterm experiences and are deeply rooted in the minds of the individuals. Participants also had query-specific expectations. For example, Fiona expected the OHI to discuss the effect of hypoglycemia (hypos). Queryspecific expectations are short-term and are formed based on the individual's specific situation and specific reasons for seeking OHI at that time. Both general expectations and query-specific expectations vary between individuals. Thus, they are experienced differently by different participants and individual experiences vary depending on the participant's particular situation.

The experience of the expectations articulated by the older adults in the current study demonstrated that the participants engaged in a rigorous level of information appraisal prior to adopting OHI to assist with self-care. This depiction of older adults as critical appraisers of online information contradicts previous research findings which suggest that age could prevent or be perceived to prevent internet usability (Olphert et al., 2005; Stanley, 2003). This study provides strong examples of older adults adapting general information comprehension skills to OHI.

### Confidence and Concern

The participants' confidence in their ability to discern the quality of OHI was a key feature of their OHI seeking experience, as was their concern regarding other's ability to discern the quality of OHI. These experiences suggested that the participants are aware of the large volume of poor quality OHI available online and also believe themselves to be able to ascertain the quality of the OHI they access. If this confidence is appropriate then this constituent of the OHI seeking experience has potential implications in terms of the quality debate that exists within the field of consumer health informatics (Cline & Haynes, 2001, Eysenbach, Powell, Kuss, & Sa, 2002). Furthermore, participants demonstrated a form of internal review of OHI, where only OHI which met their specific expectations was utilized for selfmanagement of chronic health conditions. As with the previous theme, this finding is extremely pertinent as previous research has suggested that older adults may not have the same levels of confidence in their OHI seeking skills as their younger counterparts (Mayoh et al., 2001; Olphert et al., 2005; Stanley, 2003). Although the purposeful sampling techniques used in this study specifically selected participants who were actively engaged in the OHI seeking process, therefore effecting generalizability, these stories provide texture to existing quantitative research that depicts older adults as lacking confidence in their OHI seeking skills by demonstrating that some older adults are actively engaging with this form of selfcare and have confidence in their own abilities to search and appraise information.

More specifically, the analysis provides examples of OHI resulting in older adults experiencing increased confidence to engage in discussions with health care professionals regarding their health, and make informed decisions regarding their health and treatment regimes. This finding contrasts with the pilot findings, which suggested that older adults were less likely than their younger counterparts to experience these positive outcomes of OHI seeking (Mayoh et al., 2011).

## **Implications and Contributions of the Findings**

In line with the aims of the current study, the findings provide rich descriptions of human experience that allow for exploration regarding how searching for OHI becomes a meaningful activity for older adults with chronic health conditions. Specifically, the findings show that this behaviour is performed in response to an individual taking responsibility for their health and treatment regimes, activities that are not always associated with the older population (Levinson et al., 2005).

The research also uncovered rich descriptions regarding the nature of appraisal of OHI by older adults with chronic health conditions. The participants had great confidence in their ability to appraise OHI,

a finding that contrasts with quantitative findings that suggest that older adults lack confidence in this area (Mayoh et al., Olphert, 2005; Stanley, 2003). This theme is also topically relevant as there is currently debate within the field of consumer health informatics regarding the extent of the quality issue in terms of OHI, and the effect this has on individuals globally. Numerous research studies support the belief that the quality of OHI needs to improve (Berland et al., 2001; Impicciatore, Pandolfini, Casella, & Bonati, 1997). However, research also suggests that that the overwhelming majority of OHI seekers believe that the health information they obtain via the Internet is reliable (Harris Interactive, 2008). The results from this research demonstrate that despite being aware of the high volumes of poor quality OHI, the older adults had confidence in their ability to discern the quality of the OHI they accessed. However, a drawback of these findings is that they rely entirely on individuals' perceptions of their own search and appraisal skills as opposed to objectively measuring their effectiveness. Future research projects should therefore focus on patients' quality assessment criteria in practice to determine the actual effectiveness of these strategies. Similar work has been undertaken in Germany (Eysenbach & Kohler, 2002) using naturalistic observation, questionnaires, interviews and focus groups to ascertain how people assess OHI quality.

Although the current study focused on the experiences of older adults with chronic health conditions, age was not a central theme in the findings. Specifically, the participants did not mention any physical or attitudinal issues associated with older adults using the Internet. This is somewhat surprising as previous research findings have suggested that age plays an important role in the OHI seeking experience of older adults (Gustafson et al., 1998; Mayoh et al., 2011; Olphert et al., 2005; Stanley, 2003; Turner et al., 2007). However, as previously stated, the purposive sampling strategy adopted by the study does prevent comparisons between the sample and the general population. Despite this lack of generalizability, the depth of data provides rich stories of older adults actively engaging in this form of health information seeking. This data can be used to challenge pre-conceptions that age is a barrier to using the Internet (Gustafson et al., 1998; Olphert et al., 2005; Stanley, 2003; Turner, et al., 2007).

Further descriptive phenomenological research concerning the experience of younger groups seeking OHI could be beneficial for the current study as these results would provide a structural comparison that could help uncover the elements of the experience that are unique and central to older adults. Additional research looking at the OHI seeking experience for

those with acute as opposed to chronic health conditions would also help build the analysis and discussion of the current study's findings. This would help further discussion regarding the role of age and different health conditions as a part of the experience of OHI seeking becoming a meaningful activity. Finally, although this research has international implications as it describes experiences of using the Internet to search for health information, there is a need for comparable research from other countries. This research would help to describe the nature of the

experience for older adults with chronic health conditions from different geographical locations. This is especially important as older adults with chronic health conditions are a strain on health services both in the UK and internationally. This form of self-management behaviour could potentially help prevent and relieve some of this strain by empowering people to take responsibility for their own health and treatment regimes.

### **Referencing Format**

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Les Todres, PhD, is a clinical psychologist and Professor of Qualitative Research at the School of Health and Social Care, Bournemouth University, UK. Since the early 1970s he has been interested in the relationship between phenomenology, existentialism and hermeneutics. His 2007 book, *Embodied Enquiry: Phenomenological touchstones for research, psychotherapy and spirituality* (Palgrave Macmillan) reflects a particular interest in the lived body as a way of knowing and being. Drawing particularly on the works of Merleau-Ponty and Gendlin, Les took qualitative research methodologies towards a more aesthetic emphasis, considered how psychotherapy addresses meanings

carried in the body, and reflected on an embodied spirituality where the felt sense of a 'supportive mystery' is met in palpable way. Together with his colleague, Kate Galvin, he is taking forward a research programme that includes a conceptual framework for humanising healthcare, a new theory of wellbeing, and methodological approaches (such as 'embodied interpretation') that are up to the task of capturing the human dimensions of experience in more poetic ways.



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