Journal of
Nursing and Healthcare of Chronic Illness An International Journal

ORIGINAL ARTICLE doi: 10.1111/j.1752-9824.2011.01086.x

Learning to live with hereditary haemochromatosis: a qualitative descriptive study

Elizabeth O'Connell H. Dip Critical Care Nursing, MSc, DNP Candidate
Lecturer Practitioner, University College Cork, Cork, Ireland

Orla Sheahan MHS, RNT, BNS
Nurse Lecturer, Nurse Education Centre, St. Patricks/Marymount Hospice, Cork, Ireland

Submitted for publication: 1 September 2010
Accepted for publication: 6 February 2011

Correspondence:
Elizabeth O' Connell
University College Cork
Cork
Ireland
Telephone: +353214901622
E-mail: l.oconnell@ucc.ie

O'CONNELL E & SHEAHAN O (2011) *Journal of Nursing and Healthcare of Chronic Illness* **3**, 257–264

Learning to live with hereditary haemochromatosis: a qualitative descriptive study

Aim. This article will report on a study which was conducted to explore the experiences of individuals living with hereditary haemochromatosis (HH).

Background. Hereditary haemochromatosis is the most common genetic disorder affecting the Caucasian race. It causes excessive intestinal iron absorption resulting in organ damage and impaired function. Little is known about the experience, needs or expertise of those living with this disorder.

Methods. A qualitative descriptive approach was used to conduct the study. Purposive sampling was employed to recruit 12 participants attending a haematology clinic in a large teaching hospital in Ireland. Data were collected between February and April 2008 using in-depth interviews and were analysed using content analysis.

Results. Three main themes emerged from the data: 'finding out', 'sluggish lethargy' and 'facing challenges'. These themes describe how participants reacted to the diagnosis, experienced the symptoms and met the challenges of coping with the treatment of this disorder.

Conclusions. Increased awareness of the challenges experienced by those living with HH can inform the delivery of an effective patient-centered service to individuals diagnosed and living with this genetic illness.

Relevance to clinical practice. The knowledge elicited from patients about their experiences of living with HH can be used to inform healthcare professionals about the support and education required to live with this disorder.

Key words: hereditary haemochromatosis, patient's experiences, qualitative research

Introduction

Chronic genetic illness can present sufferers with many daily challenges. Nurses need to be knowledgeable not only about the pathophysiology and clinical expression of these disorders but also of how patient's learn about, live with and manage their condition. Hereditary haemochromatosis (HH) is the most frequently occuring genetic illness to affect the

Caucasian race (Cotoia 1998). Presenting in adulthood, it is most prevalent in Ireland, Britain, Europe, Northern Australia and the eastern coast of the United States (Thompson 2003, Delatychi *et al.* 2005, Irish Haemochromatosis Association, 2007). However, little is known about the experiences, needs and expertise of those living with this disorder. This article is a report of the findings of a qualitative descriptive study that explored the experience of individuals living with HH. The study was undertaken in an outpatient Haematology clinic in a large teaching hospital in Southern Ireland.

Background

Hereditary haemochromatosis is a chronic genetic disorder which occurs when the normal regulation of iron absorbtion is disrupted resulting in the accumulation of excessive iron in the liver, pancreas, heart and joints leading to organ damage and impaired function Lewis *et al.* 2004). It is an autosomal recessive disorder predominantly associated with a mutation of the HFE gene (a protein which regulates iron transport) on chromasome 6 at amino acid 282 (C282Y) (Norris 2007). Patients presenting with HH have a wide range of symptoms. Fatique, arthralgia and loss of libido occur most frequently (Norris 2007) while chest pain, cardiomyopathy, bone disease, abdominal pain, liver dysfunction, altered skin pigmentation and depression are also reported (McDonnell *et al.* 1999). Clinical expression of the disorder can vary and is dependant on age, sex, dietary iron, alcohol use, pregnancy, history of viral hepatitis and other unknown factors (Brandhagen *et al.* 2002, Whitlock *et al.* 2006). Symptoms generally appear when patients reach their 40s or 50s and the severity is associated with the level of iron overload (Thompson 2003). Diagnosis is often delayed as symptoms are attributed to other illnesses (McDonnell *et al.* 1999) and this can lead to life-threatening complications such as cirrhosis or hepatocellular carcinoma(Adams & Barton 2007).

Therapetic phlebotomy is used primarily to treat HH but success depends on patient compliance (Adams & Barton 2007). Patients are also required to reduce their intake of dietary iron as well as limit alcohol intake as the hepatotoxic effect of alcohol increases disease severity (Scotet *et al.* 2003, Adams & Barton 2007). Research to date on HH has focused mainly on disease detection (McCullen *et al.* 2008) symptoms (McDonnell *et al.* 1999) and approaches to management and treatment (Brissot & Bels 2006) using a quantitative approach. However, little is known about this disease from the patient's perspective. Qualitative research studies are neccessary to explore the experiences, needs and expertise of those living with HH. Such research will provide sufferers with the opportunity to share and compare their experiences and will allow healthcare professionals the opportunity to use patient's views, experiences and expertise in the development of a patient centred, holistic approach to care planning and delivery.

Aim

The aim of the study was to explore the experiences of living with HH from the patient's perspective.

Method

A qualitative descriptive approach was employed. Qualitative research is a form of social inquiry which focuses on how people make sense of their experiences in the world in which they live (Holloway & Wheeler 2009). The purpose of the study was to explore the patient's individual experience of living with HH and a qualitative descriptive approach gave the participants the opportunity to describe these experiences in their own words. Listening to their accounts contributed to a greater understanding of the patient's perspective (Holloway & Wheeler 2009). This knowledge will inform healthcare professionals about the needs and challenges experienced by patients living with HH so care which addresses these can be delivered.

Participants

A total of 12 patients attending a nurse led outpatient haematology clinic in an acute hospital in Southern Ireland were recruited using purposive sampling. The inclusion criteria was that participants must be 18-year-old and over, have been diagnosed with HH prior to the commencement of the study, be currently attending the clinic for venesection, be able to speak and understand English, and be able to give informed written consent. Access to the sample was obtained via the haematology clinical nurse specialist who supplied a list of patients who fulfilled the above criteria. Patients were excluded if they had any other form of haemochromatosis or were considered vulnerable due to learning disability, mental illness or dementia. This was determined through discussion with the clinical nurse specialist and review of the patient's case notes. The researcher randomly selected patients from the list of those who met the inclusion criteria. The researcher contacted the selected eligible individuals by telephone to explain the study and invite them to participate. The researcher arranged to meet those participants who expressed a verbal interest in the study at their next venesection

appointment. At this meeting, they were given verbal and written information about the study to ensure understanding. The voluntary nature of participation was outlined and study participants were informed of their right to withdraw from the study at any time or refuse to answer any question without fear of consequence to their treatment. Those who agreed to partcipate were asked to sign a consent form.

Ethical considerations

Ethical approval to conduct the study was granted by the Local Research Ethics Committee and the principles governing medical research were adhered to throughout all stages of the research process (Gelling 1999).

Data collection

Data were collected using individual semi-structured interviews over a 6-week-period from February to April 2008. Interviews were conducted in a private meeting room in the clinic and all were recorded. Interviews are considered an excellent source of data as they allow the researcher entry into the patient's world (Speziale & Carpenter 2007). A trial interview was conducted by the researcher with a nursing colleague to ensure familiarity with the audio equipment and to enhance the researcher's confidence and interviewing skills and promote a rigorous approach to data collection. A pilot study was then undertaken (n = 2) to review the suitability of the interview guide to elicit the data required to meet the aims of the study. The questions used in the interview guide were developed by the researcher following a review of literature pertaining to HH. Each question was designed to elicit information on a different aspect of the effects or management of HH from the patient's perspective. The interview guide (see Table 1) proved satisfactory and data from the pilot study were included in the final results. Demographic data were also collected from each participant which included age, gender and length of time since diagnosis. The researcher recorded field notes immediately after each interview so as not to interrupt the natural flow of the interview. These field notes were written to assist with memory and recall and consisted of thoughts, experiences and observations made during the interview process.

Table 1 Interview guide

Topics for semi-structured interviews
1) Tell me about your experience of haemochromatosis?
2) How does it affect you physically?
3) How does it affect you psychologically?
4) What has been your experience of the healthcare services since diagnosis?
5) Have you found health care professionals to be knowledgeable about your condition?

Data analysis

Descriptive statistics were employed to analyse data on the demographic profiles of the study sample. The qualitative data generated from the semi-structured interviews were analysed using the thematic content analysis method (Burnard 1991). This was identified as a comprehensive, systematic approach which would enable accurate representation of the study participants thoughts and feelings and reduce the risk of inadvertent contamination of findings through researcher subjectivity or bias (Burnard 1991). The researcher commenced the process of immersing herself in the data during the data collection phase by careful repeated listening to audiotapes of the interviews to appreciate and comprehend the patient's perceptions of living with HH. The interviews were transcribed verbatim by a research assistant and coded to protect the confidentiality and anonymity of the participants. The researcher then checked each of their interview transcripts against the audio recordings and some inaccuracies were revised to ensure that participant's descriptions were accurately captured, thus enhancing the validity of the transcripts. The interview transcripts and field notes were read repeatedly to gain an understanding of what was seen, heard, implied, experienced and conveyed by the data. Similar data were then organised into clusters until common themes emerged. These were later grouped into higher order headings and reviewed to remove repetitious categories thus generating the final theme. An independent researcher was then asked to verify the coding and categorising of the data as well as to confirm the themes emerging.

Findings

A total of 13 patients were approached to participate in the study during the data collection period. Of these just one patient declined to consent. Consequently, 12 patients were interviewed, 11 men and 1 woman. Age and time since diagnosis of the participants are shown in Table 2. There was no correlation between age and time since diagnosis. This may be explained by the fact that so many of the participants experienced a delayed diagnosis. Three main themes emerged from the data as follows:(1) finding out, (2) sluggish lethargy and (3) facing challenges. These themes appear to correspond to the various stages the participants went through from their initial diagnosis to how they learned to live with HH.

Finding out

Each participant told the story of how they were diagnosed. Four participants were tested following the diagnosis of one of their relatives with HH. Seven of the participants were diagnosed coincidentally when attending their doctors for treatment or investigations of other medical conditions while just one participant went to his GP with symptoms specifically related to HH. This theme had two subthemes: 'mixed feelings' and 'needing to know more'.

Mixed feelings

All participants described their feelings at the time of diagnosis. Several were fearful when they heard the name of the illness for the first time; 'I got a fright and I couldn't pronounce it' (400136). A minority of participants expressed how they were relieved once the disease was explained by their medical practitioners and felt that they could cope with the diagnosis; 'Oh I was fine with it once it wasn't the big C' (400138). However, others became more anxious when they heard the complications associated with the disease; 'Because it is a silent killer. I mean heart disease and your liver can be affected by this' (400081).

Needing to know more

Participants were left with many questions following initial diagnosis and described how they sought information about their illness; 'I learned a bit from my mother who is a nurse and from other family members who got tested long before I did' (400076).

The majority of participants described how they sought information on the internet; 'I got on the internet and read up as much as I could about it' (400075). Some participants felt reassured that they could cope with the illness once they had obtained adequate information about HH:

I found that it is something a lot of people live with and you just come for routine venesection and routine tests and make sure your iron levels are normal… it won't go away but if I don't treat it, it will affect me later in life, my organs will be overworked. (400076)

Participants also suggested how information could best be made available to patients diagnosed with HH:

I suppose there should be more guidelines for people with Haemochromatosis, they should be saying right you should be doing A, B and C. (400138)

Information on diet would be important alright. If there was a dietician involved to know exactly, I mean it would make a difference alright. (00139)

Sluggish lethargy

Most participants felt that the symptoms of HH were difficult to recognise and many said it was family members who noticed them first. The most commonly reported symptom was fatigue:

I didn't feel like I wanted to do anything-a lack of energy to get up and go' My wife would tell you, being irritable and I would be tired. If I stayed in bed all day, I'd still be tired. (400138)

The second most commonly reported symptoms were erectile dysfunction and arthralgia. Participants complained of aches and pains in their smaller joints:

I had a pain in my hip and severe pain in my fingers, ankles and elbows (00139).

Less frequently reported symptoms included experiencing heavy legs or changes in skin colour such as red (high) complexion or jaundice. Table 3 shows prevalence of symptoms as described by the study participants.

Facing challenges

All partcipants spoke about how they faced the challenges of management and treatment of HH. Three subtemes were identified in this category which were related to the three main challenges identfied by the participants: 'venesection', 'managing my diet' and 'getting tested'.

Table 2 Age and time since diagnosis of participants participants

Age group	%	*n*	Time since diagnosis (years)	%	*n*
30–39	8·2	1	0–2	33·3	4
40–49	50	6	2–5	42	5
50–59	25	3	5–10	8·2	1
60–69	16·4	2	10–20	0	0
–	–	–	>20	16·5	2

Table 3 Prevalence of symptoms of HH described by

	Participants	
Symptom	%	*n*
Fatique	66·6	8
Painful joints	16·6	2
Erectile dysfunction	16·6	2
Heavy legs	8·3	1
High complexion	8·3	1
Jaundice	8·3	1

Venesection

Partcipants described how they coped with venesection and the discomfort they experienced with it; 'I'll never get used to the venesection, the minute I go in I start sweating' (400136). However, some participants stated that they get used to it while others feel it is worth the discomfort because it means they are preventing long-term complications:

Well, I don't like it and some of them (doctors) have difficulty finding a vein. One day they had to give me injections into the arm to deaden it. With the needles being so difficult, I thought I wouldn't bother but when I read up and found out how it can affect your organs I knew I didn't have a choice really. (400085)

Managing my diet

Many participants spoke about dietary restrictions and while some had a good understanding of the foods to avoid others felt that they needed more guidance and information.

I wasn't given any special diet. I was told red meat would be one, alcohol would affect it and my attitude changed over time. Since then I have found out that a lot of vegetables contain a lot of iron, broccoli and cabbage, I was delighted for the excuse not to eat them. (400076)

Getting tested

Another issue that was raised by many participants was the need for genetic screening for HH; 'I think there should be some sort of screening program, males after the age of 18' (400081). One of the participants felt strongly about the need for family members of patients with HH to be tested.

Well, there is a great reluctance for a lot of family members to go and have a gene test because they fear that if it comes up positive they will have to put it on their insurance. They are far better off getting tested because first of all there could already be damage done and secondly if they are picked up on it then it is more advantageous. (400080)

Another participant felt the decision about testing was up to each individual; 'They are all adults; it is up to them to make up their own mind but I would assume that they all would have been tested' (400077).

Overall patients had a sense of acceptance of their disease. None of the participants expressed prolonged emotional distress although they acknowledged the need to be vigilant with their diet and the importance of attending for regular venesection.

It hasn't affected me that much you know, just to come over for half an hour, give the blood and that is it. I think if is managed well then it is not a problem. (400075)

Discussion

It is clear from the results of this study that the initial diagnosis of HH elicited anxiety uncertainty and fear in many of the patients interviewed as they knew very little about the disease or what implications it would have for them. Although HH is a genetic illness, these feelings of fear and anxiety are similar to those reported in studies investigating the experiences of patients with other chronic illness (Whittemore & Dixon 2008). However, patients are no longer passive in the face of uncertainty (Faircloth *et al.* 2004) and seeking information has been increasingly documented as a coping strategy as patients adjust to illness (Lambert & Loiselle 2007). Patients seek information from family and friends, television, radio, books, magazines and the Internet (Ayers & Kronenfeld 2007). The Internet has been well-documented as a source of information frequently used by patients with chronic illness as they seek information on disease management (Ayers & Kronenfeld 2007). The results of this study suggest that patients diagnosed with genetic illnesses are also likely to use the Internet as a source of information. Web-based information is a valuable resource for patients with many conditions although its reliability and quality has been questioned (Griffin *et al.* 2004). The internet allows people affected by illness to access information at a time when they are ready to learn (Oermann 2003) but they may lack the skills needed to evaluate the credibility of the information they find (McMullan 2006). Healthcare professionals have an important role in evaluating web sites and directing patients and carers to sites which provide accurate and up-to-date information (Oermann 2003). Standards have been developed which can be used to evaluate the quality of health information on the Internet against criteria set by organisations such as Health on the Net Foundation (Health on the Net Foundation 2010).

The symptoms reported by the participants of this study were similar to those reported in the nursing literature (McDonnell *et al.* 1999). Fatigue is identified as the most common presenting symptom, with greater than 60% of patients experiencing this symptom (Norris 2007). Fatique is a very common and distressing symptom in many illnesses including cancer (Luctkar-Flude *et al.* 2007), multiple sclerosis (Mollaoglu & Unstun 2009) and renal disease (Lee *et al.* 2007) and can adversly affect patient's home, work and social lives (Stewart *et al.* 2007). Research on fatique has focused on the factors contributing to it (Mollaoglu & Unstun 2009) as well as strategies to manage it (Luctkar-Flude *et al.* 2007). Nurses caring for patients with HH have an ideal opportunity to educate patients on how to manage

their fatique. Patients should be encouraged to explore the factors that cause fatique and informed about the benefits of aerobic excercise and strength training in reducing fatigue (Luctkar-Flude *et al.* 2007). Other frequently reported common symptoms include arthralgia/arthritis and loss of libido (McDonnell *et al.* 1999, Norris 2007). It is important that patients with HH are given the opportunity to discuss any symptoms they are experiencing. They can then be referred to the most appropriate member of the multidiscipliniary team for symptom management.

The greatest challenge faced by the particpants of this study was coping with regular venesection. Venesection remains the cornerstone of treatment for HH (Adams & Barton 2007) and patient compliance is essential to it success (Sheahan & O'Connell 2009). However, it is often an uncomfortable procedure and lack of compliance has been associated with physiological intolerance and anxiety (Adams & Barton 2007). Nurses have an important role in preparing patients for venesection and supporting them throughout the treatment. They should encourage patients to eat a well-balanced meal and drink 1–2 l of fluid prior to the procedure and to bring reading material or music with them to relieve tedium during the procedure. The patient should be informed about the use of anaesthetic gel to relieve discomfort during the venepuncture and reassured that they will be monitored throughout the procedure for any adverse events and will have immediate access to medical personnel if required (Parker *et al.* 2004). Managing dietary restrictions were also identified by the participants as a significant challenge. They expressed a need for clear guidelines on how to manage their illness particularly in relation to diet. They reported getting unclear and sometimes conflicting advice about what foods they should avoid. Patients diagnosed with HH need to be provided with educational resources in relation to their diet. These should be developed collaboratively by the multidisciplinary team and made available to the patients in different formats including leaflets and educational DVDs. Nurses meeting patients when they present for follow-up appointments or venesection have an ideal opportunity to clarify any question they may have in relation to diet. Patients need to be advised to avoid eating iron rich foods, cooking in iron utensils, to limit Vitamin C supplements to 500 mg daily (as these increase iron absorption) and to limit their intake of alcohol (Brandhagen *et al.* 2002, Brissot & Bels 2006).

Another significant issue identified by many participants was in relation to genetic screening with participants expressing different opinions on the need for screening. Opinions within research literature also vary with regard to the justification of population screening for HH (Adams & Barton 2007). Some experts blame the lack of information on the burden of this disease as a contributing factor to the lack of endorsement of population screening (Cogswell *et al.* 1999, Haddow & Bradley 1999). Other arguments against the need for population screening include the infrequent evidence of disease in the general population due to HH and insufficient evidence of the benefit of routine phlebotomy on patients with haemochromatosis who are symptom free (Whitlock *et al.* 2006). Fear of genetic discrimination and diminished insurability are reported in different countries with concerns varying by nationality, race and demographic factors (Hall *et al.* 2005). Cost has been promoted as an argument against genetic testing for haemachromatosis. However, in many countries there is little difference in cost when compared with iron tests such as transferrin saturation and serum ferritin (Adams & Barton 2007). However, targeted screening of patients who are at risk of developing HH is essential to prevent organ damage through early-treatment intervention (Sheahan & O'Connell 2009). The high number of participants in this study diagnosed coincidentally would perhaps support the need for a national screening program in countries in Northern Europe where there is such a high incidence of HH. Because many of the symptoms associated with HH can be quite vague diagnosis can be delayed and patients can already be exhibiting signs of organ damage by the time they are diagnosed (Adams & Barton 2007) as was the case with three of the participants in this study who were diagnosed coincidentally. There is a need for doctors working in primary care to become 'genetically literate' (Emery & Hayflick 2001, p. 322) to aid early detection and management of HH. Doctors need to inform families of patients with HH about how the disorder is inherited and advise them in relation to screening. Transferrin saturation is seen as the most effective screening tool for HH with sensitivity and specificity reported at 94% when levels of iron are greater than 45% (Dolby 2001, Norris 2007).

The results of this study suggest that a diagnosis of a genetic illness such as HH is not associated with the same degree of turmoil and distress (Kralik 2002) associated with other chronic illness. However, the different phases experienced by the participants of this study as they came to terms with the diagnosis are similar to the processes of adjustment to chronic illness (Jarret 2000, Paterson 2001). Participants identified the challenges they encountered from diagnosis through the treatment and this has helped to clarify the role of healthcare professionals in educating and supporting patients with HH.

Limitations

This study was conducted in a single centre in one geographical area. A larger multicentre study is needed to confirm that the views of the participants in this study are representative of patients living with HH.

Relevance for practice

The findings of this study provide clinicians with a valuable insight into the experiences of individuals living with HH. The participants have identified the need for information about the diagnosis and prognosis of HH. They have also highlighted the need for support in managing the symptoms and treatment associated with this disorder. This article will provide clinicians with guidance on how best to meet the needs of individuals with HH. It makes explicit the need for clear, accessible and specific information in relation to the diagnosis, treatment and management of HH. It also demonstrates the need for all members of the multidisciplinary team to be knowledgeable about this genetic disease to recognise and manage symptoms and support patients through their treatment. The knowledge elicited from the participants of this study can inform the delivery of an effective patient-centered service to individuals diagnosed with and living with HH.

Conclusion

A diagnosis of HH will affect a patient's quality of life as he/she meets the challenges of lifelong treatment to prevent potentially life-threatening complications.

The issues identified by the participants in this study will inform healthcare professionals about the education and support required by patients with HH thus ensuring that HH is an illness 'they can live with'.

Acknowledgements

We wish to thank the patients for sharing their perspective of living with hereditary haemochromatosis. Furthermore, we acknowledge Martha Mc Menamin Scholarship for kindly funding this project. We would like to confirm that our sponsors had no involvement in the study design, collection, analysis or interpretation of data, writing of the report or decision to submit this paper for publication. Sincere thanks to Maire Warren (Clinical Nurse Specialist), Dr. Oonagh Gilligan (Consultant Haematologist) and Dr. Mary Cahill (Consultant Haematologist) for approving this study and assisting with patient access and recruitment. In addition, we would like to thank Professor Fitzpatrick and Professor Mc Carthy for their advice regarding this project.

Contributions

Study design: EOC, OS; data analysis: EOC; manuscript preparation: EOC, OS.

References

Adams PC & Barton JC (2007) Haemochromatosis. *The Lancet* **370**, 1855–1860.

Ayers SL & Kronenfeld JJ (2007) Chronic illness and health-seeking information on the Internet. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* **11**, 327–347.

Brandhagen DJ, Fairbanks VF & Baldus W (2002) Recognition and management of hereditary haemochromatosis. *American Family Physician* **65**, 853–860.

Brissot P & Bels F (2006) Current approaches to the management of hemochromatosis. *Hematology. American Society of Hematology Education Program* **1**, 36–41.

Burnard P (1991) A method of analyzing interview transcripts in qualitative research. *Nurse Education Today* **11**, 6.

Cogswell ME, Burke W, McDonnell SM & Franks AL (1999) Screening for Hemochromatosis: A public health perspective. *American Journal of Preventative Medicine* **16**, 134–140.

Cotoia JB (1998) Diagnosing haemochromatosis. *Journal of the American Academy of Nurse Practitioners* **10**, 323–327.

Delatychi MB, Allen KJ, Nisselle AE & Collins V (2005) Use of community genetic screening to prevent HFE-associated hereditary haemochromatosis. *The Lancet* **366**, 314–316.

Dolby CH (2001) Hemoochromatosis: a review. *Clinical Journal of Oncology Nursing* **5**, 257–260.

Emery J & Hayflick S (2001) The challenge of integrating genetics into primary care. *British Medical Journal* **322**, 1027–1030.

Faircloth CA, Boylstein C, Rittman M, Young ME & Gubrium J (2004) Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness* **26**, 242–261.

Gelling L (1999) Ethical principles in health care research. *Nursing Standard* **13**, 39–42.

Griffin E, McKenna K & Worrall L (2004) Stroke education materials on the world wide w*eb:* an evaluation of their quality and suitability. *Topics in Stroke Rehabilitation* **11**, 29–40.

Haddow JE & Bradley LA (1999) Hereditary haemochromatosis: to screen or not. Conditions for screening are not yet fulfilled. *British Medical Journal* **319**, 531–532.

Hall MA, McEwen JE, Barton JC, Walker AP, Howe EG, Reiss JA, Power TE, Ellis SD, Tucker DC, Harrison BW, McLaren GD, Ruggiero A & Thomson EJ (2005) Concerns in a primary care population about genetic discrimination by insurers. *Genetics in Medicine* **7**, 311–316.

Health on the Net Foundation (2010) *The HON Code of Conduct for medical and health Web sites*. Available at: http://www.hon.ch/HONcode/Conduct.html (accessed 25 November 2010).

Holloway I & Wheeler S (2009) *Qualitative Research in Nursing and Healthcare*. Wiley-Blackwell, Oxford.

Irish Haemochromatosis Association (2007) Dr. Barry Kelleher's Presentation on Haemochromatosis at 2007 AGM. Summer/ Autumn Newsletter 2007. Available at: http://www.haemochromatosis-ir.com/images/IHA-summer-web.pdf (accessed 9 September 2009).

Jarret L (2000) Living with chronic illness: a transitional model of coping. *British Journal of Therapy and Rehabilitation* **7**, 40–44.

Kralik D (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* **39**, 146–154.

Lambert SD & Loiselle CG (2007) Health information-seeking behavior. *Qualitative Health Research* **17**, 1006–1019.

Lee B-O, Lin C-C, Chaboyer W, Chiang C-L & Hung C-C (2007) The fatique experience of haemodialysis. *Journal of Clinical Nursing* **16**, 407–413.

Lewis SM, Heitkemper MM & Dirksen SR (2004) *Medical-Surgical Nursing: Assessment and Management of Clinical Problems*, 6th edn. Mosby, Mosby.

Luctkar-Flude MF, Groll DL, Tramner JE & Woodend K (2007) Fatique and physical activity in older adults with cancer. *Cancer Nursing* **30**, 35–45.

McCullen MA, Crawford DH & Hickman Pen (2008) Screening for hemochromatosis. *New England Journal of Medicine* **358**, 221–230.

McDonnell SM, Preston BL, Jewell SA, Barton JC, Edwards CQ, Adams PC & Yip R (1999) A survey of 2 851 patients with hemochromatosis: symptoms and response to treatment. *The American Journal of Medicine* **106**, 619–624.

McMullan M (2006) Patients using the Internet to obtain health information: How this affects the patient-health professional relationship. *Patient Education and Counseling* **63**, 24–28.

Mollaoglu M & Unstun E (2009) Fatique in multiple sclerosis patients. *Journal of Clinical Nursing* **18**, 1231–1238.

Norris S (2007) Treatment of Haemochromatosis. Available at: http://haemochromatosis-ir.com/suzanne.html (accessed 30 August 2010).

Oermann M (2003) Using health web sites for patient education. *Journal of Wound, Ostomy and Continence Nurses* **30**, 217–223.

Parker DM, Deel PC & Arner SS (2004) Iron out the details of therapeutic phlebotomy. *Nursing* **34**, 46–47.

Paterson BL (2001) The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship* **33**, 21–26.

Scotet V, Merour M, Mercire A, Chanu B, Le Faou T, Raguenes O, Le Gac G, Mura C, Nousbaum J & Ferec C (2003) Hereditary hemochromatosis: Effects of excessive alcohol consumption on disease expression in patients homozygous for the C282Y mutation. *American Journal of Epidemiology* **158**, 129–134.

Sheahan O & O'Connell E (2009) Hereditary haemochromatosis: patient support and education. *Nursing Standard* **24**, 49–56.

Speziale HS & Carpenter DN (2007) *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Lippincott, Philadelphia.

Stewart TM, Tran ZV & Bowling A (2007) Factors related to fatique in multiple sclerosis. *International Journal of MS Care* **9**, 29–34.

Thompson S (2003) When it Runs in the Blood Iron Overload is One of the Most Common Genetic Disorders. So why don't more of us Know about it. Available at: http://www.haemochromatosis-ir.com/sylvia.html (accessed 30 August 2010).

Whitlock EP, Garlitz BA, Harris EL, Beil TL & Smith PR (2006) Summaries for patients, screening for hemochromatosis: Recommendations from the U.S. preventative services task force. *Annals of Internal Medicine* **145**, 204–223.

Whittemore R & Dixon J (2008) Chronic illness: the process of integration. *Journal of Nursing and Healthcare of Chronic Illness* **17**, 177–187.