Migraine and Chronic Daily Headache: The Patients’ Perspective.

By

Michele Peters

Submitted for the degree of Ph.D.

European Institute of Health and Medical Sciences

University of Surrey

August 2003

© Michele Peters 2003
Abstract

Aim: The aim of this study was to investigate the patients’ perspective of migraine and chronic daily headache (CDH) management.

Methods: The study used a combination of qualitative (Phase 1) and quantitative methods (Phase 2). Both phases were conducted in the UK in adults (aged 18-65), who suffered either from migraine according to the International Headache Society criteria or from CDH. Phase 1 used semi-structured interviews (n=13) that were analysed according to the grounded theory methodology. Phase 2 was based on a postal survey that was administered to migraine, migraine with aura and CDH patients (n=438), who were members of the Migraine Action Association (UK).

Findings: The qualitative findings revealed the patients’ decision-making to treat and prevent headaches, their perceptions of headache and headache management and the holistic set of strategies used for headache management. Patients were highly involved in their headache care and perceived themselves as a key resource to management. The survey showed that a high proportion of headache patients use strategies from 4 areas of management including health care consultations, medication use, general management and social support. The survey also showed that the use of some strategies differs between different types of headaches. Overall, it was generally the CDH patients, who were more active in their headache management than migraine and migraine with aura patients, and some of these findings were statistically significant.

Conclusion: Both the qualitative and quantitative findings of this study showed the patients’ high level of involvement in their headache care. Combining the two methodologies helped to confirm and reinforce the findings. The results of this study can be used to identify headache patients as a key resource to management. Their high level of activity in this study shows the patients’ willingness to be involved in their own headache care. However, since headache patients still report considerable suffering, it may be necessary to educate headache patients to maximise the outcome of their management efforts.
# TABLE OF CONTENTS

## CHAPTER 1: INTRODUCTION

1.1. Migraine and Chronic Daily Headache Management  
1.2. The Expert Patient  
1.3. Patient Self-Management  
1.4. Aim of the Study and Research Question  
1.5. Implications of the Study  
1.6. Rationale for Qualitative Methods  
1.7. Rationale for Combining Qualitative and Quantitative Methods  
1.8. Rationale for the Survey  
1.9. The Presentation of the Thesis  
1.10. The Researchers’ Involvement  
1.11. References

## CHAPTER 2: REVIEW OF THE LITERATURE

2.1. Abstract  
2.2. Headaches  
  2.2.1. Migraine  
  2.2.2. Chronic Daily Headache (CDH)  
2.3. Epidemiology of Migraine  
  2.3.1. Migraine Prevalence  
  2.3.2. Factors Influencing Migraine Prevalence  
  2.3.3. Characteristics of Migraine  
2.4. Epidemiology of CDH  
  2.4.1. CDH Prevalence  
  2.4.2. Characteristics of CDH  
  2.4.3. Factors Influencing CDH  
2.5. The Impact of Migraine and CDH  
  2.5.1. Quality of Life  
  2.5.2. Disability
# TABLE OF CONTENTS

2.5.3. Lost Time  
2.5.4. Cost  

2.6. **Migraine and CDH Management**  
2.6.1. Pharmacological Management of Migraine  
2.6.1.1. Acute Treatment of Migraine  
2.6.1.2. Prophylaxis of Migraine  
2.6.2. Non-pharmacological Management of Migraine  
2.6.3. Management of CDH  

2.7. **Summary**  

2.8. **Migraine and CDH in clinical practice**  
2.8.1. Migraine in Clinical Practice  
2.8.1.1. Consultation Rates for Migraine  
2.8.1.2. Type of Health Professional Consulted and Frequency of Consultations  
2.8.1.3. Consulters' Characteristics  
2.8.1.4. Patients' Beliefs and Attitudes  
2.8.1.5. Diagnosis  
2.8.1.6. Problems with Consultations for Migraine and Proposed Solutions  
2.8.1.6.1. Step-care versus Stratified Care  
2.8.1.6.2. The Doctors' Perspective  
2.8.1.6.3. Communication and Disability Assessment  
2.8.2. CDH in Clinical Practice  
2.8.2.1. Consultation Rates for CDH  

2.9. **The Patients' Management of Migraine and CDH**  
2.9.1. Pharmacological Management of Migraine  
2.9.1.1. Type of Treatment Used  
2.9.1.1.1. Over the Counter vs. Prescription Medication  
2.9.1.1.2. Types of Medication  
2.9.1.2. Factors Influencing Medication Use  
2.9.1.3. Satisfaction with Pharmacological Treatment  
2.9.2. Non-pharmacological Treatment of Migraine  
2.9.3. Pharmacological Treatment of CDH  
2.9.4. Patient Management Behaviour: Comparison of Episodic and Chronic Headache
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.9.5. The Use of Social Support for the Management of Headaches</td>
<td>74</td>
</tr>
<tr>
<td>2.10. Initiatives to Improve Patients’ Self-management in Headache</td>
<td>75</td>
</tr>
<tr>
<td>2.11. Summary</td>
<td>78</td>
</tr>
<tr>
<td>2.12. References</td>
<td>80</td>
</tr>
<tr>
<td>CHAPTER 3: Research into Headache: The Contribution of Qualitative Methods</td>
<td>92</td>
</tr>
<tr>
<td>3.1. Abstract</td>
<td>93</td>
</tr>
<tr>
<td>3.2. Introduction</td>
<td>94</td>
</tr>
<tr>
<td>3.3. Qualitative Research</td>
<td>94</td>
</tr>
<tr>
<td>3.3.1. Compared to Quantitative Research</td>
<td>94</td>
</tr>
<tr>
<td>3.3.2. Definition of Qualitative Research</td>
<td>95</td>
</tr>
<tr>
<td>3.3.3. Methods and Methodologies</td>
<td>97</td>
</tr>
<tr>
<td>3.3.4. The Strengths and Weaknesses of Qualitative Research</td>
<td>97</td>
</tr>
<tr>
<td>3.3.5. Quality in Qualitative Research</td>
<td>99</td>
</tr>
<tr>
<td>3.4. Qualitative and Quantitative Methods in the Research Setting</td>
<td>102</td>
</tr>
<tr>
<td>3.4.1. Choosing Between Qualitative and Quantitative Methods</td>
<td>103</td>
</tr>
<tr>
<td>3.4.2. The Contribution of Qualitative Research</td>
<td>103</td>
</tr>
<tr>
<td>3.5. Qualitative Methods in Health Research</td>
<td>105</td>
</tr>
<tr>
<td>3.6. Qualitative Methods in Headache Research</td>
<td>106</td>
</tr>
<tr>
<td>3.6.1. Headache in Clinical Practice and Qualitative Research</td>
<td>107</td>
</tr>
<tr>
<td>3.6.2. The Headache Patient and Qualitative Research</td>
<td>108</td>
</tr>
<tr>
<td>3.7. Conclusion</td>
<td>110</td>
</tr>
<tr>
<td>3.8. References</td>
<td>111</td>
</tr>
</tbody>
</table>
CHAPTER 4: Patients' Decision-making for Migraine and Chronic Daily Headache Management

4.1. Abstract

4.2. Introduction

4.3. Methods

4.3.1. Grounded Theory

4.3.2. Recruitment, Data Collection and Analysis

4.3.2.1. Recruitment

4.3.2.2. Data Collection

4.3.2.3. Analysis

4.3.3. Ensuring Scientific Rigour

4.3.3.1. Dependability

4.3.3.2. Confirmability

4.3.3.3. Transferability

4.3.3.4. Credibility

4.4. Results

4.4.1. Patients' Characteristics

4.4.2. Management Strategies

4.4.3. The 4 Stages of Decision-Making

4.4.3.1. Headache Severity

4.4.3.2. Evaluation

4.4.3.3. Decision

4.4.3.4. Behaviour

4.5. Discussion

4.6. Conclusion

4.7. References
# TABLE OF CONTENTS

## CHAPTER 5: The Patients' Perceptions of Migraine and Chronic Daily Headache: a Qualitative Study

### 5.1. Abstract

### 5.2. Introduction

### 5.3. Methods

5.3.1. Sampling

5.3.2. Data Collection and Analysis

### 5.4. Results

5.4.1. Headaches

5.4.1.1. Pain and Other Symptoms

5.4.1.2. Differentiating Between Different Types of Headache

5.4.1.3. Perceptions of Headache as Barriers and Facilitators to Management

5.4.2. Headache Impact

5.4.3. Headache as a Health Issue

### 5.5. Discussion

### 5.6. Conclusion

### 5.7. References

## CHAPTER 6: The Patients’ Perceptions of Migraine and Chronic Daily Headache Management

### 6.1. Abstract

### 6.2. Introduction

### 6.3. Methods

6.3.1. Recruitment

6.3.2. Data Collection

6.3.3. Analysis

### 6.4. Results

6.4.1. The Patients’ Use of Management Strategies
### TABLE OF CONTENTS

6.4.2. The Patients' Perceptions of Management Strategies for Headaches 177
6.4.2.1. Health Care Use 177
6.4.2.2. Medication 179
6.4.2.3. Alternative Therapies 181
6.4.2.4. Social Support 183
6.4.2.5. Self-help and Life-style 184

6.5. Discussion 185
6.6. Conclusion 187
6.7. References 188

CHAPTER 7: Phase II Research Design: Survey Methods 191
7.1. Rationale 192
7.2. Aim and Research Questions 195
7.3. Development of the Questionnaire 196
7.4. Content 197
7.4.1. Headache Information 197
7.4.2. Management Strategies 197
7.4.3. Opinions 199
7.4.4. Biographical Information 199
7.5. Design of the Questionnaire 199
7.6. Cover Letter and Information Sheet 199
7.7. Ethical Approval 200
7.8. Pilot Testing 200
7.8.1. Experts' Opinion 200
7.8.2. Patients' Pilot Study 200
7.8.3. Diagnostic Tool- Validity 200
7.8.4. Changes to the Questionnaire 201
7.9. Data Collection/ Administration 201
7.9.1. Mailing 201
7.9.2. Recruitment 202
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.9.2.1. Advertisements</td>
<td>202</td>
</tr>
<tr>
<td>7.9.2.2. Mailing the Questionnaire to Members of the Migraine Action Association</td>
<td>202</td>
</tr>
<tr>
<td>7.10. Questionnaire Processing</td>
<td>203</td>
</tr>
<tr>
<td>7.11. Data Checking</td>
<td>203</td>
</tr>
<tr>
<td>7.11.1. Eligibility</td>
<td>203</td>
</tr>
<tr>
<td>7.12. Analysis</td>
<td>204</td>
</tr>
<tr>
<td>7.13. References</td>
<td>205</td>
</tr>
<tr>
<td>CHAPTER 8: Patients’ Management of Migraine and Chronic Daily Headache: A Survey</td>
<td>207</td>
</tr>
<tr>
<td>8.1. Abstract</td>
<td>208</td>
</tr>
<tr>
<td>8.2. Introduction</td>
<td>210</td>
</tr>
<tr>
<td>8.3. Methods</td>
<td>211</td>
</tr>
<tr>
<td>8.3.1. Questionnaire</td>
<td>212</td>
</tr>
<tr>
<td>8.3.1.1. Respondents and Recruitment</td>
<td>212</td>
</tr>
<tr>
<td>8.3.1.2. Data Preparation</td>
<td>212</td>
</tr>
<tr>
<td>8.3.1.3. Analysis</td>
<td>213</td>
</tr>
<tr>
<td>8.4. Results</td>
<td>213</td>
</tr>
<tr>
<td>8.4.1. Respondents</td>
<td>213</td>
</tr>
<tr>
<td>8.4.2. Headache Symptoms</td>
<td>214</td>
</tr>
<tr>
<td>8.4.3. Headache Impact</td>
<td>215</td>
</tr>
<tr>
<td>8.4.4. Consultations</td>
<td>216</td>
</tr>
<tr>
<td>8.4.4.1. Consultation Rates</td>
<td>216</td>
</tr>
<tr>
<td>8.4.5. Medication Use</td>
<td>218</td>
</tr>
<tr>
<td>8.4.5.1. Acute Medication</td>
<td>218</td>
</tr>
<tr>
<td>8.4.5.2. Prophylactic Medication</td>
<td>220</td>
</tr>
<tr>
<td>8.4.6. General Management</td>
<td>223</td>
</tr>
<tr>
<td>8.4.6.1. Acute General Management</td>
<td>223</td>
</tr>
<tr>
<td>8.4.6.2. Prophylactic General Management</td>
<td>226</td>
</tr>
<tr>
<td>8.4.7. Social Support</td>
<td>229</td>
</tr>
<tr>
<td>8.4.8. Patients' Opinions</td>
<td>229</td>
</tr>
<tr>
<td>8.5. Discussion</td>
<td>232</td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.6. Conclusion</td>
<td>238</td>
</tr>
<tr>
<td>8.7. References</td>
<td>239</td>
</tr>
</tbody>
</table>

## CHAPTER 9: The Patients' Involvement in Migraine and Chronic Daily Headache Management: A Study Using Qualitative and Quantitative Methods |

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.1. Abstract</td>
<td>243</td>
</tr>
<tr>
<td>9.2. Introduction</td>
<td>245</td>
</tr>
<tr>
<td>9.3. Qualitative Phase</td>
<td>247</td>
</tr>
<tr>
<td>9.3.1. Rationale</td>
<td>247</td>
</tr>
<tr>
<td>9.3.2. Methods</td>
<td>248</td>
</tr>
<tr>
<td>9.3.2.1. Recruitment and Participants</td>
<td>248</td>
</tr>
<tr>
<td>9.3.2.2. Data Collection</td>
<td>249</td>
</tr>
<tr>
<td>9.3.2.3. Data Analysis</td>
<td>250</td>
</tr>
<tr>
<td>9.3.3. Qualitative Findings</td>
<td>250</td>
</tr>
<tr>
<td>9.3.3.1. Patients' Decision-making</td>
<td>251</td>
</tr>
<tr>
<td>9.3.3.2. Patients' Perceptions of Headache</td>
<td>253</td>
</tr>
<tr>
<td>9.3.3.3. Patients' Perceptions of Headache Management</td>
<td>254</td>
</tr>
<tr>
<td>9.4. Quantitative Phase</td>
<td>256</td>
</tr>
<tr>
<td>9.4.1. Rationale</td>
<td>256</td>
</tr>
<tr>
<td>9.4.2. Methods</td>
<td>257</td>
</tr>
<tr>
<td>9.4.3. Questionnaire</td>
<td>257</td>
</tr>
<tr>
<td>9.4.4. Respondents and Recruitment</td>
<td>258</td>
</tr>
<tr>
<td>9.4.5. Data Analysis</td>
<td>259</td>
</tr>
<tr>
<td>9.4.6. Quantitative Findings</td>
<td>259</td>
</tr>
<tr>
<td>9.4.6.1. The Respondents</td>
<td>259</td>
</tr>
<tr>
<td>9.4.6.2. Patients' Use of Headache Management</td>
<td>260</td>
</tr>
<tr>
<td>9.4.6.2.1. Health Care Consultations</td>
<td>260</td>
</tr>
<tr>
<td>9.4.6.2.2. Medication Use</td>
<td>261</td>
</tr>
<tr>
<td>9.4.6.2.3. General Management</td>
<td>261</td>
</tr>
<tr>
<td>9.4.6.2.4. Social Support</td>
<td>262</td>
</tr>
<tr>
<td>9.5. Discussion</td>
<td>262</td>
</tr>
<tr>
<td>9.5.1. Combining Qualitative and Quantitative Findings</td>
<td>265</td>
</tr>
<tr>
<td>9.5.2. Limitations and Future Research</td>
<td>269</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>9.6. Conclusion</td>
<td>271</td>
</tr>
<tr>
<td>9.7. References</td>
<td>273</td>
</tr>
<tr>
<td><strong>CHAPTER 10: The Contribution to Knowledge</strong></td>
<td></td>
</tr>
<tr>
<td>10.1. Introduction</td>
<td>278</td>
</tr>
<tr>
<td>10.2. Contribution to Research Methods</td>
<td>278</td>
</tr>
<tr>
<td>10.3. Contribution to Theory</td>
<td>279</td>
</tr>
<tr>
<td>10.3.1. Coping</td>
<td>280</td>
</tr>
<tr>
<td>10.3.2. The Transtheoretical Model</td>
<td>281</td>
</tr>
<tr>
<td>10.3.3. Problem-solving Models and Leventhal's Self-regulatory Model of Illness Cognitions</td>
<td>283</td>
</tr>
<tr>
<td>10.4. Contribution to Knowledge and Understanding of Headache and CDH Management</td>
<td>285</td>
</tr>
<tr>
<td>10.5. References</td>
<td>293</td>
</tr>
</tbody>
</table>
Chapter 2: Review of the Literature

Table 2.1: Migraine Sub-types (Headache Classification Committee of the International Headache Society 1988)

Table 2.2: Migraine Without Aura (Headache Classification Committee of the International Headache Society 1988)

Table 2.3: Classification for Transformed Migraine and Transformed Migraine with Medication Over-use (Silberstein et al, 1994)

Table 2.4: Features of CDH

Table 2.5: Quality of Life in Migraine Sufferers Compared to the Normal Healthy Population and Patients with Other Chronic Diseases

Table 2.6: Migraine-related Disability

Table 2.7: Percentage of Patients Reporting Coping Behaviours At Least Sometimes (Scharff, Turk & Marcus, 1995)

Table 2.8: Behavioural Responses to Headache by Portuguese Migraine Patients- Comparison of 2 Studies

Table 2.9 Patients' behaviours when headaches started on working day and on a day off (Ferrari et al, 1997)

Chapter 3: Research into Headaches: The Contribution of Qualitative Methods

Table 3.1: Comparison of Qualitative and Quantitative Research

Chapter 4: Patients' Decision-making for Migraine and Chronic Daily Headache Management

Table 4.1: Opening Interview Questions

Table 4.2: Interpretative Codes and Themes

Table 4.3: The Participants' Characteristics
**Chapter 7: Phase II Research Design: Survey Methods**

**Table 7.1:** The Five Areas of Management for Migraine and CDH and Their Definitions, According to the Qualitative Study

**Chapter 8: Patients' Management of Migraine and Chronic Daily Headache: A Survey**

**Table 8.1:** Characteristics of the Respondents by Diagnosis

**Table 8.2:** Percentage of M, MWA and CDH Patients Reporting Symptoms

**Table 8.3:** Frequency of Consultations for M, MWA and CDH

**Table 8.4:** Percentage of M, MWA and CDH Patients Using Medication and Other Remedies

**Table 8.5:** Frequency of Use of OTC and Prescription Medication by M, MWA and CDH Patients

**Table 8.6:** Areas of Acute General Management Strategies

**Table 8.7:** Percentage of M, MWA and CDH Patients Using Acute General Management Strategies at Least Sometimes

**Table 8.8:** The Level of Use of Acute General Management Strategies by M, MWA and CDH Patients

**Table 8.9:** Prophylactic General Management Strategies

**Table 8.10:** Percentage of M, MWA and CDH Patients Using Prophylactic General Management at Least Sometimes

**Table 8.11:** Level of Use of Prophylactic General Management Strategies by M, MWA and CDH Patients

**Table 8.12:** Percentage of M, MWA and CDH Patients Using Social Support at Least Sometimes

**Table 8.13:** M, MWA and CDH Patients' Opinions about Headache and Headache Management
Chapter 3: Research into Headaches: The Contribution of Qualitative Methods

Figure 3.1: Quality Criteria in Quantitative and Qualitative Research

Chapter 4: Patients' Decision-making for Migraine and Chronic Daily Headache Management

Figure 4.1: The Patients' Process of Decision-making for Headache (Migraine and CDH) Management

Chapter 6: The Patients' Perceptions of Migraine and Chronic Daily Headache Management

Figure 6.1: Areas of Management of Migraine and CDH

Chapter 8: Patients' Management of Migraine and Chronic Daily Headache: A Survey

Figure 8.1: Impact Reported by M, MWA and CDH Patients

Figure 8.2: Consultations by M, MWA and CDH Patients

Figure 8.3: Types of Acute Medication Used by M, MWA and CDH Patients

Figure 8.4: Types of Prophylactic Medication Used by M, MWA and CDH Patients
Acknowledgements

I would like to thank my supervisors Prof. Huda Huijer Abu-Saad, Prof. Ian Robbins, Dr Vasso Vydelingum, Dr Andrew Dowson, Dr Margaret Murphy, and Prof. Karen Bryan for their support; their incredible faith; the challenges; for letting me work so independently and yet giving me the benefit of their expertise and (sometimes quite unique) wisdom; and for sharing the coffee and chocolate.

I am particularly grateful to all the migraine and chronic daily headache patients, who took part in the interviews, pilot study or survey. This study could not have been carried out without them. I am also grateful for the many letters and telephone calls I received from headache patients who were not eligible to participate in this study, but who nonetheless wanted to share their story or who simply wanted to express their support and gratitude. I hope that you, and other people who are afflicted by headaches, will find a way to ease your suffering.

I thank AstraZeneca Pharmaceuticals, Macclesfield (UK), the Migraine Action Association (UK), the British Council and the Ministry of Education, Luxembourg for providing the funding for this Ph.D. and the (many) courses and conferences I attended.

I also thank Mrs Ann Turner and the staff of the Migraine Action Association for helping with the recruitment of their members both for the interviews and for the survey. I thank Dr Inez Bandell Hooekstra for triangulation of the qualitative analysis and for letting me have a copy of her Ph.D. thesis, which provided a useful ‘model’ for the presentation of my thesis. I am also grateful to Prof. Sarah Hampson and Prof. Karen Bryan for reviewing the questionnaire; Mrs Rebecca Salt, for helping with the pilot study and validating of the diagnostic part of the questionnaire; and Ms Yvonne Hühner, who kindly volunteered to help fill hundreds of envelopes with questionnaires (it was fun!). I am also indebted to Mrs Enid Tubbs, who was always willing to lend a hand and who knew the answer to every question I ever asked.

I would also like to thank my friends and colleagues, some of whom deserve (or asked for) a special mention, including Antonis (for one of the best holidays I have ever had and Ithaka), Fatima (for MIP and introducing me to Diamond Mine), Felicity (for the entertainment and lending me her stapler), Henry (who did just enough proof-reading to get a mention and his version of the Ketchup song) and Mike (for being my step-supervisor and for buying me that amazing whisk).

Last by not least, I would like to thank my parents Jeanne and Hubert Peters, who, no matter how far-fetched my ventures, have always supported me 110%.
TO HEADACHE SUFFERERS

DON'T EVER GIVE UP!!!
Chapter 1: Introduction
1.1. Migraine and Chronic daily headache management

Migraine and chronic daily headache (CDH) affect 12% (Breslau and Rasmussen, 2001) and 3.2% (Lu et al., 2001) of the general population respectively. Migraine and CDH significantly reduce the sufferers’ quality of life (QoL), with QoL being more severely reduced in CDH patients than in migraine sufferers (Meletiche et al., 2001; Lanteri-Minet et al., 2003). Due to their chronic nature, migraine and CDH need to be managed over a prolonged period of time. A multitude of effective strategies to treat and prevent these headaches is available, but migraine and CDH patients continue to experience high morbidity. Due to a lack of use of effective treatments, often patients do not benefit from current treatments. Research has predominantly focused on migraine, although an increasing number of scientific articles have been published in the last 2 years on CDH.

As far as migraine is concerned, to date, patients remain under-diagnosed and undertreated (Lipton et al., 1992; Lipton et al., 2000). Under-treatment in migraine has been attributed to several factors: 1) the patients having a fatalistic attitude, 2) patients using Over the Counter (OTC) medications rather than prescription drugs (Michel et al., 1996), 3) low consultations rates with doctors (Lipton et al., 1998) and 4) ineffective doctor-patient communication, particularly about headache-related disability (Lipton et al., 1994). Twenty-four studies, using survey design, have been published on migraine and CDH patients’ use of management strategies, but these studies have predominantly focused on consultations with doctors and medication use (Appendix 1). While research into the clinical and pharmacological aspects of migraine management is important, it does not provide the whole picture of migraine and CDH, and the patients’ management of these headaches. A study of the members
of the Dutch Society of Headache Patients showed that although the most frequently reported reason for a reduction in headache-related impact was a change in medication (77%); factors such as a change in lifestyle (56%), more relaxed coping (42%), and support from family (46%) were also considered to contribute to the reduction of headache related-impact by a large proportion of patients (Vos and Passchier, 2003). But studies on the patients’ perspective remain rare, and apart from anecdotal reports, there is little evidence about the use of non-pharmacological management of migraine and CDH. A comprehensive review of the literature of migraine and CDH and their management is presented in Chapter 2.

1.2. The expert patient

With chronic disease having become the principal medical problem, the patients’ opinions have become increasingly important. The patient must become a partner, who contributes at almost every decision and action level of the management of their disease (Holman and Lorig, 2000). The patient becoming a partner and expert in care is an idea whose time has come, and this idea has the potential to create a new generation of patients who are empowered to take action to improve their own health (Donaldson, 2003). The knowledge and experience of the patient has been an untapped resource for too long and in the UK, the Department of Health considers the expert patient a new approach to chronic disease management for the 21st century (Department of Health, 2001). The Disease Management Association of America (2002) defines Disease Management (DM) as a system of co-ordinated health care interventions and communications for populations with conditions in which self-management efforts are significant. Components of DM programmes include patient-self management education and patient empowerment (Disease Management Association of America, 2002).
Patient self-management and decision-making in their chronic disease management introduce a new chronic disease paradigm: the patient and health care professional relationship involving collaborative care and self-management education (Bodenheimer et al., 2002). This paradigm implies that the health professional is the expert about the disease, whilst the patients are the experts about their own lives. Such an approach means that the patients are empowered, i.e. they accept of responsibility to manage their own condition and they are encouraged to solve their own problems with information, but not orders, from health professionals (Bodenheimer et al., 2002). Patients make decisions about their condition everyday (Bodenheimer et al., 2002) and can become key decision-makers (Department of Health, 2001).

1.3. Patient self-management

Patient self-management is an inevitable outcome of the process of being or becoming an expert patient. Self-management of chronic illness implies monitoring and managing symptoms, adhering to treatment regimens, keeping a healthy lifestyle and managing the impact of illness on daily functioning, emotions and social relationships (Schreurs et al., 2003). As far as headaches are concerned, migraine patients have reported a desire for collaborative relationships with their doctors and a team approach to treatment involving both the patient and doctor (Cottrell et al., 2002). Furthermore, good management requires the patients’ active participation in decisions regarding therapeutic interventions (Silberstein et al., 2000). Most headaches occur in the absence of health care professionals. Thus, the major responsibility for headache management lies with the patient and it is therefore important to better understand and to develop the patients’ expertise in headache management.
To date, migraine is under-treated and migraine and CDH patients continue to suffer considerable headache-related disability. Effective treatments are available, but the high levels of suffering suggest that patients do not benefit from these treatments. Patients with chronic diseases may fail to optimally self-manage their disease and help in integrating the required self-management behaviours into their lives may be needed (Schreurs et al., 2003). Improving patient self-management may be a useful tool to improve headache care and enhanced headache self-management may be achieved through gaining better understanding of the patients' perspective, improved collaboration between health care professionals and headache patients and patient education.

Studies to improve patient self-management through education or psychological programmes have been shown to be beneficial in various chronic diseases. A recent review on the use of self-management in asthma concluded that self-management of asthma can be beneficial from both the family physicians' and the patients' perspective (Thoonen and van Weel, 2002). In back pain, a randomized control trial of a cognitive-behavioural programme showed significantly greater reductions in back-related worry and fear-avoidance beliefs for the intervention versus the control group (Moore et al., 2000). Pain intensity was also significantly lower at 6 months and significantly less interference with activities at 12 months was found in the intervention group when compared with the controls (Moore et al., 2000). In diabetes, a psychological intervention to improve lifestyle led to positive experiences for patients. Patients rated the intervention as highly satisfactory and acceptable in comparison to more traditional approaches to managing eating and exercise behaviours (Clark and Hampson, 2001). One study assessed disease management, including headache education, for headache patients attending a Headache Clinic in
the US (Maizels et al., 2003). Although the cost of triptans increased by 19%, headache-related consultations reduced by 32% and emergency department consultations reduced by 49%. Headache frequency was reduced in 86% of patients who had severe headaches more than 2 days per week at their initial clinic visit.

1.4. Aim of the study and research questions

To date, studies on the patients’ perspective of headache management often remain focused on consultations with doctors and medication use. Little remains known of the patients’ perspective of the complete picture of migraine and CDH management. Therefore, the aim of this study was to gain insight into the patients’ perspective of migraine and CDH management. The following research questions were formulated:

1. How do migraine and CDH patients perceive and experience headaches and headache care?

2. What is the patients’ involvement in their migraine and CDH care?

3. Which management strategies do migraine and CDH patients use?

4. What are the differences in the use of management strategies between different types of headache patients (migraine, migraine with aura and CDH)?

1.5. Implications of the study

Investigating the patients’ perspective of migraine and CDH management will contribute to knowledge in several ways. It will help to understand migraine and CDH management outside clinical practice, by gaining insight into the holistic picture of management of migraine and CDH. It will help to identify the patients’
current involvement in their own care and to identify areas for potential patient education and patient self-management.

1.6. Rationale for qualitative methods

If it is the aim of health care to increase user participation in care and try and work to some extent to a user-led agenda, then it is important to use methodologies that give voice to the users and allow patients some scope to lead agendas for change, rather than being restricted to providing data for researcher and health care provider-led agendas (Edwards and Staniszewska, 2000). From the surveys on the patients' management of migraine and CDH, there is little, if any, evidence of patient involvement in the design of the instruments of data collection (usually interviews and questionnaires). Therefore, it can be assumed that studies investigating the patients' perspective of migraine and CDH management have generally been designed by headache clinicians and researchers without the patients' input. Thus, little opportunity has been given to the patients to speak openly and unrestrictedly about their migraine and CDH management. Qualitative research has been advocated as a suitable method to gain access to the users' perspective (Edwards and Staniszewska, 2000). The contribution of qualitative methods to headache research is further outlined in Chapter 3. Qualitative inquiry requires the investigator to listen and try and understand, rather than to control and shape the inquiry (Edwards and Staniszewska, 2000). However, only 2 studies using qualitative methods have been published in headache research. One of these studies used interviews to explore the patients' decision-making for using sumatriptan, one of the acute migraine-specific medications (Ivers et al., 2000). The second study, based on focus groups, investigated the patients' perceptions of migraine (Cotterell et al., 2001).
Thus, studies on migraine and CDH management have predominantly used quantitative methods and have focused on issues that are quantifiable. If research only focused on what can be quantified reliably, many researchers may never discover the strengths of qualitative research (Soafer, 1999) and may never access areas of research that are only amenable by qualitative methods (Pope and Mays, 1995). The use of qualitative methods is advocated to explore research topics that are not amenable by quantitative research. Qualitative research aims to gain insight into the world of those who are being researched (Soafer, 1999) by studying the participants unique experiences of naturally occurring events (Miles and Huberman, 1994) and/or social/human problems (Creswell, 1998) and their interpretations of these experiences (Jones, 1995; Sarantakos, 1998). Qualitative research is a holistic process of enquiry and seeks to understand the phenomenon under study as a complex system that is more than the sum of its parts (Patton, 1990). The strengths of qualitative methods are its validity and its potential to discover new areas, identify patterns, reveal and explain complexity and develop, construct and test concepts or theories (Soaf er, 1999; Creswell, 1998; Pope and Mays, 1995). Suitable topics for qualitative studies in health care, including research into migraine and CDH, comprise decision-making processes; doctor-patient relationship; interactions among patients and clinicians; self-management; care-seeking, illness and compliance behaviour; patients’ perceptions and experiences, and health care delivery (Britten et al., 1995).

Given the limitations of studies to date, the strengths of qualitative research and the research aim, qualitative methods were chosen to answer research questions 1-3 formulated for this study. Grounded theory was chosen, because it is a specific, highly developed and rigorous set of procedures for generating theory (Glaser and
Strauss, 1967). Both patients suffering from migraine and CDH were interviewed in the qualitative phase. The findings of the qualitative study are described in Chapters 4-6.

1.7. Rationale for combining qualitative and quantitative methods

Combining qualitative and quantitative methods has been advocated to enhance the study of chronic diseases (Casebeer and Verhoef, 1997). Previous studies have shown that the integration of qualitative and quantitative methods emphasises the findings (Chan, 2001; Clarke, 2003) or the interpretation of findings was facilitated by the simultaneous use of qualitative and quantitative methods (Etter and Perneger, 1997). Abu et al (2001) found that qualitative findings confirmed the quantitative results and suggest that a combined approach should be used in future studies of the patients’ views of health care.

Using both qualitative and quantitative methods served several purposes. If used as a prerequisite to quantitative research, qualitative research facilitates the development of the quantitative research by identifying the ‘correct’ terminology for inclusion in a survey questionnaire or generating hypotheses (Greene et al., 1989). The qualitative data informed design the research questions and a valid questionnaire that was relevant to migraine and CDH patients. The second purpose of a combined methodology was methods triangulation. This involves comparing data collection through qualitative methods with data collected through quantitative methods (Patton, 1999).
1.8. Rationale for the survey

Given the limitations of qualitative research in terms of generalisability, the study was to comprise a second phase using quantitative methods to make the findings applicable to a larger population. Thus, to increase knowledge about the patients’ use of migraine and CDH management and to make the qualitative findings more objective and more useful for explanation and prediction, a postal survey was carried out. No previous questionnaire had investigated the holistic management of migraine or CDH from the patients’ perspective. The quantitative phase was based on a postal questionnaire that investigated the holistic management of migraine, including health care consultations, medication use, general acute and prophylactic management and social support, as well as the patients’ opinions. The survey was aimed at patients with migraine without aura, migraine with aura or CDH. The aim was to investigate (research question 3) and compare the patients’ use of management strategies (research question 4) in the 12 months preceding the study. The survey compared three groups, rather than the 2 groups (migraine and CDH) used for the qualitative phase, because the qualitative data indicated that patients with different headache diagnoses and increasing headache severity managed their headaches differently. Also, migraine diagnosis has been shown to be more likely when certain symptoms are present, including aura and increasing disability (Lipton et al., 2001). The design of the survey is described in Chapter 7. The results of the quantitative phase are described in Chapter 8. The complete study, reporting and integrating the results of the qualitative and quantitative phases, as well as the added value of combining the two methods are presented in Chapter 9. In Chapter 10, an overview is presented of this study’s contribution to the body of knowledge of migraine and CDH, to the methodology and theoretical understanding.
1.9. The presentation of the thesis

As described in this introduction, this thesis is presented in 10 chapters. Rather than
being presented as chapters in the usual UK style, Chapters 3 to 9 are presented as
articles, one of which has been published, one of which is in press, and the remaining
chapters of which are submitted or in the process of being submitted for publication.
Presenting the thesis in that manner means that repetitions occur within the thesis.
These repetitions are most notable within the methodology sections, as the
qualitative phase is presented as 3 articles (chapters) and the survey design is
described in detail in Chapter 7 and as part of an article in Chapter 8. Presenting the
thesis as such also means that the references are presented at the end of every
chapter, rather than the usual reference list at the end of the thesis.

1.10. The researchers' involvement

The research was carried out as a team effort between the researcher and her
supervisors. The main part of the research was carried out by the researcher, but the
input of her supervisors will be described as appropriate within the chapters. As an
overview, Prof. H. Huijer Abu-Saad (HAS) was involved in designing the qualitative
interview guide, qualitative analysis and questionnaire design. Dr Margaret Murphy
(MM) was involved in the recruitment for the qualitative interviews and
questionnaire design. Dr Andrew Dowson (AD) was the clinical supervisor on
headaches and was involved in diagnosing the interview participants and
questionnaire respondents, questionnaire pilot study and validation of the diagnostic
tool of the questionnaire. Dr Vasso Vydelingum (VV) was involved in the qualitative
analysis and questionnaire design. Prof. Ian Robbins (IR) was involved in the design,
pilot testing and statistical analysis of the questionnaire.
1.1 References


Britten, N., Jones, R., Murphy, E., & Stacy, R. 1995, "Qualitative research methods in general practice and primary care", *Family Practice*, vol. 12, pp. 104-114.


Patton, M. Q. 1990, Qualitative Evaluation and Research Methods, Sage Publications, California, USA.


Chapter 2: Review of the Literature
Chapter 2: Review of the Literature

2.1. Abstract

Migraine and chronic daily headache (CDH) are common, primary headaches that can have a great impact on the lives of the sufferers. Migraine causes at least some disability in the majority of patients and quality of life is significantly reduced when compared to the general population and, in severe cases, to patients suffering from other chronic diseases. CDH leads to an even greater reduction of quality of life than episodic migraine. This review sets out to give the diagnostic criteria for migraine and CDH and to describe their treatments, including pharmacological and non-pharmacological treatments. Then it will outline the management of migraine and CDH in clinical practice, as well as the management strategies employed by patients suffering from migraine or CDH and initiatives taken to improve management.
2.2. Headaches

In 1988, the International Headache Society (IHS) introduced diagnostic criteria for all types of headache (Headache Classification Committee of the International Headache Society, 1988). Translated fully or in abbreviated form into many languages, the primary use of the IHS criteria was for research. Indeed, these criteria are now recognised as the ‘gold standard’ in clinical trials and epidemiological research. The criteria are often used in simplified form in specialist clinical practice, but the adoption of the criteria in primary care has been limited (Lipton et al., 2000a).

There are many different types of headache. Broadly they are divided into primary and secondary headaches. Primary headaches do not have an underlying disease. Secondary headaches have an underlying disease (such as in influenza or brain tumours), of which the headaches are a symptom. Primary headaches comprise migraine, tension-type headaches (TTH), cluster headaches and chronic paroxysmal hemicrania and miscellaneous headaches unassociated with structural lesions such as ice-cream headache (Headache Classification Committee of the International Headache Society, 1988). Chronic daily headache (CDH) is also a type of primary headache, but CDH is not described within the current IHS criteria.

2.2.1. Migraine

Migraine is a disease with many sub-types (Table 2-1), all of which have been described by the IHS (Headache Classification Committee of the International Headache Society, 1988). The two main types of migraine are migraine with aura and migraine without aura, previously called common migraine (Table 2-2).
Migraine with aura, previously called classical migraine, comprises complex focal neurological symptoms, which initiate or accompany attacks (aura). Aura usually develops over 5 to 20 minutes and lasts less than 60 minutes. The headache, with nausea and/or photophobia, develops after an interval of less than an hour and lasts for 4 to 72 hours. Migraine aura can also occur without the headache phase. Auras are mostly visual, such as flashing lights. Other aura symptoms include speech disturbances, pins and needles or vertigo.

Other migraine symptoms, such as premonitory (warning) symptoms or osmophobia, can be present, but these are not necessary for the diagnosis of migraine. Premonitory symptoms, or prodromes, are symptoms that occur before the attack. These can be considered warning signs of migraine attacks. Examples of prodromes are fatigue, thirst and irritability.

The patient needs to have suffered five migraine attacks to fulfil IHS criteria. Secondary headache such as brain tumours, influenza must be eliminated prior to the diagnosis of migraine. Difficulties with the diagnosis of migraine arise from the co-existence of different types of headache within the same patient and the changes in headache diagnosis over time (Oleson and Lipton, 1994).
Table 2-1: Migraine sub-types (Headache Classification Committee of the International Headache Society 1988)

1. Migraine
   1.1. Migraine without aura
   1.2. Migraine with aura
      1.2.1. Migraine with typical aura
      1.2.2. Migraine with prolonged aura
      1.2.3. Familial hemiplegic migraine
      1.2.4. Basilar migraine
      1.2.5. Migraine with acute onset aura
   1.3. Opticokinetic migraine
   1.4. Retinal migraine
   1.5. Childhood periodic syndromes that may be precursors to or associated with migraine
      1.5.1. Benign paroxysmal vertigo of childhood
      1.5.2. Alternating hemiplegia of childhood
   1.6. Complications of migraine
   1.7. Migrainous disorder not fulfilling above criteria

Table 2-2: Migraine without aura (Headache Classification Committee of the International Headache Society 1988)

<table>
<thead>
<tr>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>A) At least 5 attacks fulfilling B-D</td>
</tr>
<tr>
<td>B) Headache lasting 4-72 hours (untreated or treated unsuccessfully)</td>
</tr>
<tr>
<td>C) Headache has at least two of the following characteristics</td>
</tr>
<tr>
<td>1. Unilateral location</td>
</tr>
<tr>
<td>2. Pulsating quality</td>
</tr>
<tr>
<td>3. Moderate or severe intensity (inhibits or prohibits daily activities)</td>
</tr>
<tr>
<td>4. Aggravation by walking stairs or similar routine physical activity</td>
</tr>
<tr>
<td>D) During headache at least one of the following</td>
</tr>
<tr>
<td>1. Nausea and/or vomiting</td>
</tr>
<tr>
<td>2. Photophobia and phonophobia</td>
</tr>
<tr>
<td>E) No evidence of organic disease</td>
</tr>
</tbody>
</table>
2.2.2. Chronic daily headache (CDH)

A considerable number of patients who attend specialty headache centres suffer from daily or near daily headaches (Nappi et al., 1999). However, the criteria of the IHS for classification of headaches do not adequately address the classification of daily or near-daily headaches, which are known as chronic daily headache (CDH). Chronic tension-type headache (CTTH) is the only available classification for high frequency headaches within the IHS system. In 1987, to address these problems, Mathew et al (1987) gave a description of transformed migraine (TM), which is a daily or near daily headache syndrome that evolves from migraine.

As described by Silberstein et al (1994), several studies have shown that the IHS system does not adequately classify daily or near-daily headaches. Thus, the authors proposed a new classification system comprising four daily or near daily headache disorders: 1) chronic tension-type headache (CTTH), 2) transformed migraine (TM) (Table 2-3), 3) new daily persistent headache (NDPH) and 4) hemicrania continua (HC). These chronic headaches have one common feature; they occur at a frequency of 15 or more headache days per month. Silberstein and his colleagues propose specific criteria for the three latter of these types of headaches, as well as providing modified criteria for CTTH and giving criteria on medication overuse in CDH. These criteria for the classification of daily and near-daily headaches were tested and compared to the IHS criteria (Silberstein et al., 1996). This study showed that when using the IHS criteria, 43% of patients could not be classified, whereas when using the Silberstein et al. criteria, 100% of patients could be classified.

Furthermore, when the Silberstein et al. (1994) criteria are applied, patients are given one diagnosis, as opposed to the majority of patients receiving multiple diagnoses
when applying the IHS criteria. According to the IHS only 1.6% of patients have one diagnosis, 27.1% have two, 61.9% have three, 8.3% have four and 1.1% are unclassifiable (Bigal et al., 2002a).

**Table 2-3: Classification for transformed migraine and transformed migraine with medication over-use (Silberstein et al., 1994)**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Criteria</th>
</tr>
</thead>
</table>
| Transformed migraine             | History of episodic migraine meeting IHS criteria  
Daily or almost daily (>15 days/ month) head pain >1 month  
Average headache duration >4 hours (if untreated)  
History of increasing headache frequency with decreasing severity of migrainous features over at least 3 months  
No disorder listed in IHS groups 5-11 |
| Transformed migraine with        | As above and  
At least one of the following for at least 1 month:  
Simple analgesic use (>1000mg ASA/ acetaminophen) >5 days/ week  
Combination analgesics (caffeine, barbiturate-containing medication) (>3 tablets/ day)>3 days/ week  
Narcotics (> 1 tablet/ day) >2 days/ week  
Ergotamine use (1mg PO or 0.5mg PR) >2 days/ week |
| medication over-use              |                                                                                                                                                                                                         |
Chapter 2: Review of the Literature

2.3. Epidemiology of migraine

2.3.1. Migraine prevalence

Migraine can affect any person of any gender, age and ethnicity. However, certain population groups are more likely to be affected as shown by epidemiological studies. When (Stewart et al., 1994a) reviewed 24 studies, they found wide variations in migraine prevalence (3.2-57.1% in women and 1.7-33.1% in men). These variations are largely based on the different definitions used to describe migraine prior to the introduction of the IHS criteria. A more coherent picture of migraine prevalence has emerged from studies using the IHS diagnostic criteria. World-wide (England, USA, Japan and Norway) the estimates for IHS migraine prevalence range from 12.9-18.2% in women and 3.4-7.0% in men (Winnem, 1992; Stewart and Lipton, 1993; Sakai and Igarashi, 1997; Lipton et al., 2001a). An estimated 6 million people suffer from migraine in the UK (Rush, 1996). Most prevalence studies do not differentiate between migraine sub-types. The Genetic Epidemiology of Migraine (GEM) study in the Netherlands found that 64.1% of their sample suffered from migraine without aura, 17.9% had migraine with aura, 12.9% had both types and 5.2% could not be classified (Terwindt et al., 1998).
2.3.2. Factors influencing migraine prevalence

Migraine can affect anybody, but certain groups are more likely to be affected. Factors influencing migraine prevalence include gender, age, race and socio-demographic background. The prevalence figures show that migraine is about three times more common in women than in men, possible as a result of the hormonal differences between women and men (Breslau and Rasmussen, 2001). Migraine prevalence increases from the ages 12 to 38 and decreasing thereafter (Stewart and Lipton, 1993). The median age of migraine onset is 20 years (Steiner et al., 1999). Migraine prevalence was highest between the ages of 26 to 55 years (Goadsby and Oleson, 1997; Steiner et al., 1999). In England, non-whites were significantly less affected by migraine than whites (Steiner et al., 1999). In the US, migraine prevalence was lower in blacks than in whites (Lipton et al., 2001a). It has been speculated that the lower prevalence of migraine in blacks may be partly attributed to genetic differences, rather than cultural or environmental differences (Stewart et al., 1996). A higher proportion of migraine sufferers are in the lower income group (Kryst and Scherl, 1994), with prevalence in the lowest income group being 60% higher than in the highest income group (Lipton et al., 2001a).

2.3.3. Characteristics of migraine

It is generally accepted that migraine attacks have a median duration of 24 hours, and that the median frequency of migraine is once or twice per month (Launer et al., 1999; Steiner et al., 1999). However, migraine is a heterogeneous disorder and migraine duration can vary from less than 4 hours to several days (Henry et al., 1992). As far as migraine frequency is concerned, 25% of migraine sufferers had five
or fewer attacks per year and another 25% had two or more attacks per month (Launer et al., 1999). At least 10% of the migraine sufferers experience four or more attacks per month (Stewart et al., 1994b), in which case it seems likely that they suffer from CDH rather than episodic migraine. Not only is migraine more prevalent in women, female migraine patients reported more frequent attacks than male migraine sufferers (Stewart et al., 1992).

Over 50% of patients report severe or very severe pain (Henry et al., 1992). The most frequently reported migraine symptoms were pulsatile pain (85%), photophobia (80%), phonophobia (76%), nausea (73%), unilateral pain (59%), blurred vision (44%), aura (36%) and vomiting (29%) (Lipton et al., 2001a). Compared with male patients, female migraine patients were more likely to report photo- and phonophobia and nausea (Lipton et al., 2001a).

2.4. Epidemiology of CDH

2.4.1. CDH prevalence

Since there are no IHS criteria for CDH, studies to establish the prevalence of CDH have used different diagnostic criteria, including the Silberstein et al. (1994) criteria. The studies by Scher et al., (1998); Granella et al. (2000); Wang et al. (2000); and Lanteri-Minet et al. (2003) did not use the Silberstein et al. criteria. In a population based study in the US, 4.1% of subjects were found to suffer from frequent headaches (Scher et al., 1998). One year prevalence rates of CDH were 2.98% in France (Lanteri-Minet et al., 2003), 3.2% in Taiwan (Lu et al., 2001) and 4.7% in Spain (Castillo et al., 1999). In a Chinese elderly community-based sample, 3.9% of respondents were found to have CDH (Wang et al., 2000).
Women are more affected by CDH than men. In the US, 5.0% of women and 2.8% of men suffered from frequent headache (Scher et al., 1998). In Spain, 9% of women suffered from CDH (Castillo et al., 1999). In France, 4.18% women versus 1.62% of men (Lanteri-Minet et al., 2003) and in Taiwan, 4.3% of women versus 1.9% of men were affected by CDH (Lu et al., 2001). Of the CDH patients, 72% were women and significantly younger than the male CDH patients (Lu et al., 2001).

The prevalence of the different types of CDH is not clear. Although studies have investigated the different types, different labels and even different diagnostic criteria are used to sub-group CDH. A study in 9 Italian headache centres has acknowledged that only CTTH is included in the IHS criteria, and used CTTH, chronic migraine (CM) and chronic coexisting migraine and TTH (CCMTTH) to describe their sample (Granella et al., 2000). Of the CDH patients, 46.5% were given a diagnosis of chronic co-existing migraine and tension-type headache, 30.2% were classed as CM and 23.3% as CTTH. However, the authors do not define how they classified CDH, CM or CCMTTH.

The most common type of CDH is thought to be TM, also called chronic migraine (CM). Based on the Silberstein et al. (1994) criteria, CM affected 87.4%, new daily persistent headache affected 10.8% of a tertiary care population in the US (Bigal et al., 2002a). Using their own criteria, Silberstein et al. found that in the US 78% of CDH patients suffer from TM, 1.53% from CTTH and 6.7% from other headache disorders (Silberstein et al., 1996). In Spain, 47.2% of CDH patients had CTTH (2.2% of general population) and 50.6% had TM (2.4% of general population) (Castillo et al., 1999). In the Chinese elderly population, 70% suffered from CTTH, 25% from TM and 5% from other CDH (Wang et al., 2000). Reflecting the higher
prevalence of CDH in women, most CTTH (90.5%) and TM (88.9%) were women (Castillo et al., 1999). In France, 29.1% of CDH patients fulfilled the IHS criteria for migraine without aura or migraine with aura, 43.2% fulfilled all these criteria but one, and 27.7% of patients did not have a diagnosis consistent with the diagnosis of migraine (Lanteri-Minet et al., 2003).

Medication overuse is often thought as a causing or contributory factor to the development of CDH and CDH with medication overuse are given within the Silberstein et al. (1994) criteria for the classification of daily and near-daily headaches. The prevalence of CDH with medication over-use is about 2% (Castillo et al., 1999). In Taiwan, 34% of CDH patients over-used medication (Lu et al., 2001), whereas in Spain, medication overuse was found in 19% of CTTH patients and in 31.1% of TM patients (Castillo et al., 1999). These levels of medication overuse are low in comparison with those found in an American tertiary care population, in which 81.7% of CDH patients were overusing medication (Bigal et al., 2002a).

2.4.2. Characteristics of CDH

Unlike the characteristics of migraine, which have been well studied and are accepted as described above, knowledge about the features of CDH is mainly based on clinical experience. Only recently studies have investigated the features of CDH. The first important feature to diagnose CDH is headaches occurring at a frequency of 15 or more days per month. This means that the actual number of days with headaches in CDH can vary by 15 days per month (i.e. a headache frequency between 15 and 30 days per month). Some studies have investigated the number of headache days in CDH. In Taiwan, 0.5% of participants and 15% of the CDH patients (n=16) had daily headaches i.e. headaches 30 days per month (Lu et al.,
In Brazil, 80% of TM patients reported daily headaches and 20% had almost daily headaches (>15 days per month) (Galego et al., 2002). In Canada, TM patients had a mean headache frequency of 26.92 days per month (out of a 28-day month) (Magnusson and Becker, 2002).

The clinical presentation of CDH has been described in 4 studies. Table 2-4 summarises the findings of these studies. Drawing conclusions on the features of CDH is difficult, due to the differences in study designs. The items or headache features included within the different studies were not consistent. Furthermore, the type of headache studied and the diagnostic criteria used differed between the studies. The French study based their headache classification on the IHS criteria (Lanteri-Minet et al., 2003). The study by Galego et al (2002) compared episodic and transformed migraine and only included 40 patients of each diagnosis. Krymchantowski and Moreira (2001) compared male and female CDH patients, including 3 of the 4 different types of CDH (as defined by Silberstein et al, 1994). They analysed the data according to gender, and not according to the type of CDH, despite headache features differing between the various types of CDH. Also, the 2 studies in Brazil (Krymchantowski and Moreira, 2001; Galego et al., 2002) have been carried out in headache specialist centres. The headache population within specialist centres may differ from headache sufferers in the general population, who do not consult headache specialists or specialist headache centres, and therefore the findings of these studies may not be generalisable to the general population.
### Table 2-4: Features of CDH

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Country</th>
<th>Study design and sample</th>
<th>Items studied</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Granella et al., 2000</td>
<td>Italy</td>
<td>Multi-centre study in 9 headache centres 245 patients, 53 men and 192 women.</td>
<td>Headache characteristics</td>
<td>Migraine with aura preceded CDH in 72.3% of cases, episodic TTH preceded 13.6% of CDH cases.</td>
</tr>
</tbody>
</table>
| Krymchantowski and Moreira, 2001 | Brazil | Clinical retrospective study 300 consecutive CDH patients at a subspecialty headache centre, of which 217 women and 54 men fulfilled criteria for TM, 26 (16 women and 11 men) for chronic tension-type headache (CTTH) and 3 men for new daily persistent headache (NDPH) To compare clinical presentation of CDH between men and women | 1. Localisation  
2. Severity  
3. Headache quality  
4. Headache associated symptoms  
5. Full blown intermittent migraine attacks  
6. Excessive medication consumption | 1. Bilateral fronto-temporal headaches in 54.3% of women and 51.8% of men. Diffuse headaches in 28.5% of women and 20.3% of men. Alternating hemicranial pain in 5.5% of women and 12% of men. Unilateral fronto-temporal alternating sites in 11.5% of women and 14.8% of men.  
2. Mild severity in 25.3% of women and 37% of men. Moderate severity in 53% of women and 40.7% of men and moderate to severe or severe in 21.6% of women and 22% of men.  
3. Dull or pressure in 72.8% of women, 59.2% of men. Pulsatile in 20.2% of women and 31.5% of men, pressure and pulsatile pain in 3.7% of women and 5.5% of men. Burning pain in 3.2% of women and 3.7% of men.  
4. Nausea in 61.7% of women and 57.4% of men. Vomiting in 8.7% of women and 11.1% of men. Photophobia in 44.2% of women and 29.6% of men, phonophobia in 32.3% of women and 33.0% of men and osmophobia in 22.6% of women an 20.4% of men.  
5. Full-blown intermittent migraine in 95.4% of women and 81.5% of men.  
6. Excessive consumption of symptomatic medication was found in 83.8% of women and 87% of men. |
Table 2.4: Features of CDH

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Country</th>
<th>Study design and sample</th>
<th>Items studied</th>
<th>Results</th>
</tr>
</thead>
</table>
| Galego et al., 2002 | Brazil  | Prospective study at a Headache Outpatient service. 80 patients, 40 with IHS migraine (episodic migraine EM), 40 with transformed migraine (TM) according to Silberstein et al (1994) | 1. Localisation  
2. Pain type  
3. Headache intensity  
4. Headache frequency | 1. 75% of EM patients reported hemicrania headache vs. 80% TM patients  
2. 100% of EM patients had pulsating pain. 57.5% of TM patients had pulsating pain, 40% of TM patients had pulsating and non-pulsating pain; and 2.5% of TM patients non-pulsating pain.  
3. 72.5% of EM patients had attacks of severe intensity and 27.5% reported moderate intensity. 62.5% of TM sufferers reported moderate to severe intensity and 37.5% mild to severe intensity.  
4. EM attacks occurred every 2-4 weeks in 65% of patients, every 1-2 weeks in 12.5% and every two months or less in 7.5%. In TM patients, headaches occurred daily in 80% of patients and almost daily in 20%. |
| Lanteri-Minet et al., 2003 | France  | National representative sample (n=10,585) to identify headache patients (n=3087)  
As a second phase, face-to-face interviews (n=1486) to identify CDH patients (n=151)  
Symptoms were assessed according to IHS, but distinguished between CDH with and without migrainous features | 1. CDH symptoms | 1. Pulsatility in 76.8% of CDH patients, lateralisation in 42.2% patients, aggravation with effort reported by 58.9% patients, mild to severe nausea in 22.5% CDH sufferers, vomiting reported by 6% of patients and photo/phonophobia by 84.8% patients. |
2.4.3. Factors influencing CDH

The most commonly reported factor to cause or contribute to the development of CDH is medication overuse, although more recently questions as to whether medication overuse is a consequence rather than a cause of CDH have been raised. In most instances, CDH is a progressive form of a primary disorder (usually migraine), that is likely to be influenced, if not determined, genetically (Srikitakkhachorn, 2002). A recently published debate presents both data supporting and rejecting medication overuse as a cause of CDH (Tepper and Dodick, 2002). More than half of CDH patients who are detoxified improve (usually by their headache pattern returning to episodic migraines), particularly if prophylaxis follows detoxification. However, not all episodic migraine patients who overuse medication develop CDH, and not all is caused by medication overuse. Furthermore, as outlined in the debate, population-based studies have shown that the majority of patients do not overuse medication. Therefore, the debate concludes that it appears that causality is bi-directional and that daily headache and medication overuse may coexist.

Some associations between CDH and other medical conditions have been investigated and specific types of CDH have been shown to be strongly correlated to certain somatic conditions or behaviours. CM is associated with allergies, asthma, hypothyroidism, hypertension and daily consumption of caffeine and CM with analgesic overuse was associated with hypertension and daily consumption of caffeine (Bigal et al., 2002b).

Little is known about the long-term prognosis of CDH, but a study in Taiwan provides insight into outcome predictors. At the 2-year follow-up for the study population in Taiwan, 35% of the CDH patients still had CDH (Lu et al., 2001).
Significant predictors for chronic CDH were age > 40, CDH onset after 32 years of age, CDH duration over 6 years, medication overuse and 'daily' headaches.

2.5. The impact of migraine and CDH

Not all symptoms outlined by the IHS criteria for migraine need to be present to diagnose a patient with migraine. This flexibility of the criteria and the presence or absence of the aura, prodromes and postdromes already indicate the heterogeneous nature of the disorder. Indeed, migraine is highly individual and different people are affected at different levels of severity. Migraine changes over time, thus affecting sufferers differently at different points of their lives. The impact of migraine can be reduced through the use of management strategies, as was shown by a study of members of the Dutch Society of Headache Patients (Vos and Passchier, 2003). Seventy percent of the sample (n=448) reported reduced headache impact. Those patients who reported reduced impact had less migraine attacks and a higher quality of life. The most frequently reported reasons for reduced impact was a change in medication (77%). Other reasons included a change in life-style (56%), more relaxed coping (42%), reduction of stress in general (28%), reduction of work-related stress (24%), more regular life-style (21%) and social support strategies such as the support by the Dutch Society of Headache Patients (58%) and family (46%).

Headache severity and frequency in migraine and CDH give some indication of the impact of these headaches and of the disruption they can cause to the sufferers’ lives. Since the heterogeneous nature of migraine makes it difficult to capture its severity, other measures, along with the frequency, pain severity and duration of headaches have been used to describe the burden of migraine. The impact of migraine has been a current topic of interest within headache research and multiple studies have been
Chapter 2: Review of the Literature

published. The impact of CDH has also been investigated, but fewer studies have focused on CDH rather than migraine impact. This following section will discuss the impact of migraine and CDH in the following areas: quality of life, disability, lost time and cost.

2.5.1. Quality of life

Health-related quality of life (HRQoL) is one measure to assess the burden of migraine. HRQoL instruments measure global aspects of a person's health status over a period of time, including time with and without illness (Dahlof and Solomon, 1998). Studies have shown that migraineurs have a poorer quality of life (QoL) than the normal, healthy population (Table 2-5). QoL is also poorer in severe migraineurs than in people suffering from other chronic diseases that are considered a more serious health problem, such as diabetes and hypertension (Table 2-5). Reduced QoL is also reported between attacks, when migraine symptoms are absent (Dahlof and Dinemas, 1995). Decrements in QoL in migraine are associated with increased lost activity days (Lipton et al., 1999), increased frequency of migraine attacks (episodic vs. transformed migraine) (Terwindt et al., 1998; Meletiche et al., 2001) and increasing levels of disability (Lipton et al., 1999). Over the last three months, TM patients had statistically (p<0.05) and clinically significantly lower QoL scores than migraine patients on physical functioning, bodily pain, general health, vitality, social functioning, role-emotional and mental health (as assessed by Short-Form 36 scores) (Meletiche et al., 2001). In France, using the QVM (qualité de vie et migraine) questionnaire, CDH patients scored significantly (p<0.01) worse than migraine patients (Lanteri-Minet et al., 2003).
HRQoL instruments, particularly those that are disease-specific, tend to be sensitive to the specific disorder (Lipton et al., 2000a). The disadvantage with QoL measurements is, that the instruments are often difficult and lengthy to score, are often not intuitively meaningful to the physician and are difficult to translate into economic terms. Therefore they are not suitable for routine use in clinical practice, where brevity, simplicity and clinical meaning are needed (Lipton et al., 2000a).
Table 2-5: Quality of life in migraine sufferers compared to the normal healthy population and patients with other chronic diseases

<table>
<thead>
<tr>
<th>Author(s), Year</th>
<th>Design and sample</th>
<th>Country</th>
<th>Findings about migraineurs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Osterhaus et al., 1994</td>
<td>General population n=845, Questionnaire including SF-36 Health Survey</td>
<td>USA</td>
<td>Increasing migraine severity was associated with a decrease in quality of life. Moderate, severe or very severe migraine had significantly lower quality of life (measures of pain, physical role function and social functioning) than the general population. Migraine had lower scores than hypertension, diabetes, osteoarthritis</td>
</tr>
<tr>
<td>Dahlof and Dinemas, 1995</td>
<td>Gothenburg migraine clinic n=145 3 questionnaires: Minor Symptoms Evaluation Profile, Subjective Symptoms Assessment Profile, Psychological Well-Being Index</td>
<td>Sweden</td>
<td>Migraineurs between attacks reported disturbed contentment, vitality and sleep, more subjective symptoms and a reduced sense of well being compared to a control group. Emotional distress, anxiety and sex lives were all worse in migraineurs</td>
</tr>
<tr>
<td>Clarke et al., 1996</td>
<td>Hospital Trust employees n=4200, migraineurs n=158 Questionnaire</td>
<td>UK</td>
<td>66% reported fear of letting others down, 54% reported interference with family and social relations, 34% believed not to be in control</td>
</tr>
</tbody>
</table>
Table 2.5 (continued). Quality of life in migraine sufferers compared to the normal healthy population and patients with other chronic diseases

<table>
<thead>
<tr>
<th>Author(s), Year</th>
<th>Design and sample</th>
<th>Country</th>
<th>Findings about migraineurs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lipton et al., 1999</td>
<td>Population-based sample, controls n=200 and migraineurs n=200 Multi-stage: Telephone interview (n=5769) and Short Form 36-Item Health Survey</td>
<td>USA</td>
<td>Migraine sufferers scored significantly lower for physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health than the controls</td>
</tr>
<tr>
<td>Terwindt et al., 2001</td>
<td>General population n=5998, patients with migraine in the last year n=620 Multi-staged: Telephone interview and RAND 36-item Health Survey</td>
<td>Netherlands</td>
<td>Migraine patients reported diminished social, physical and mental functioning when compared to controls. HRQL decreased with increased migraine frequency. Compared to asthma patients, migraine sufferers scored significantly lower on social functioning, emotional role limitations, mental health, pain and vitality. Compared with controls, patients who had migraines and asthma had significantly lower scores for physical functioning, physical role limitations, mental health, pain, vitality and general health perceptions. Comorbid asthma and migraine led to significantly lower scores for physical functioning and general health perception than migraine alone.</td>
</tr>
</tbody>
</table>
2.5.2. Disability

The World Health Organisation (WHO) defines disability in terms of consequences of illness on ability to function in various settings, including paid work, household work and non-work activities (National Academy of Sciences/Institute of Medicine, 1991). Migraine causes little or no disability during mild attacks and prolonged incapacitation in severe attacks (Stewart et al., 1994a). The majority of migraineurs report at least some disability (Holmes et al., 2001a). Moderate disability was most common (40%), followed by severe impairment (30%) and women were more likely to suffer from severe disability than men (Sakai and Igarashi, 1997). According to the Global Burden of Disease study (Murray and Lopez, 1997), severe migraine was rated as disability class VII, alongside dementia and quadriplegia. Levels of migraine-related disability have been assessed world-wide and are summarised in Table 2-6. All the studies used the IHS criteria for the diagnosis of migraine.

Studies on disability for CDH have focused on TM to draw a comparison with episodic migraine. In Canada, no difference was found in the levels of disability between TM and EM (To and Wu, 1995). However, although the number of headache days between TM and EM were significantly different (p<0.001), the mean headache frequency of EM patients (9.22 headache days per 28-day month), was above the median migraine frequency.

Several studies have assessed disability using the MIDAS (Migraine Disability Assessment) questionnaire, which collects disability information in terms of missed days of paid work or school, housework and leisure time in the last 3 months (Stewart et al., 1999). In France, 74.2% of CDH patients reported some disability from their headaches. MIDAS scores of CDH were significantly worse than the
scores of migraine patients (p<0.01), with CDH patients with migrainous symptoms scoring the worst (Lanteri-Minet et al., 2003). In a headache specialist centre population, although both migraine and TM patients were classed as severely disabled, according to their MIDAS scores (scores of 21 or more correspond to severe disability), TM patients reported significantly higher MIDAS scores (70.7 versus 27.3, p>0.05) (Meletiche et al., 2001). A further study in a specialist headache centre used the MIDAS questionnaire to compare disability between TM and migraine patients (Bigal et al., 2003). Patients with TM had a mean of 66.7 days with headaches in the last 3 months, whereas migraine patients had 15.5 headache days (p<0.001). TM patients missed significantly more work or school days (5.3 vs. 2.3; p=0.0007), had more days with reduced effectiveness at work or at school (11.9 vs. 4.6; p=0.0001), missed more days of housework (16.5 vs. 3.3; p=0.0001) and missed more days of family, social and leisure activities (7.0 vs. 5.5; p=0.03). Patients with TM were more likely to be in the severe disability group (64.3% vs. 43.2%; p=0.01) and the mean MIDAS score for TM patients was 34.9 (severe disability) vs. a mean score 19.3 (moderate disability) for episodic migraine. However, the studies by Meletiche et al (2001) and Bigal et al (2003) have been carried out in a specialist sub-group of patients, and the findings may not be representative of the general population. Patients who do not consult at specialist centres may experience different levels of disability.

Assessing headache-related disability is important, since disability information has been shown to be an important determinant of physicians' judgements of migraine severity and treatment needs (Slater et al., 1999). Furthermore, disability, through lost time, particularly from work, captures the economically most significant aspect of migraine (de Lissovoy and Lazarus, 1994).
**Table 2-6: Migraine-related disability**

<table>
<thead>
<tr>
<th>Author (s), Year</th>
<th>Sample and Design</th>
<th>Country</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Pryse-Philipps et al., 1992 | Population-based multi-stage design  
- Prevalence survey n=24159 households  
- Telephone survey migraine (n=138) and tension-type headache patients (n=83)  
Diary study migraine (n=95) and tension-type headache patients (n=55) | Canada | Of the IHS migraine sufferers, 77% had limited ability to function, 50% reported to discontinue normal activities and 30% retired to bed. In over 70% personal relationships are impaired, 35% reported migraine to interfere with social plans, 40% were worried about the possible occurrence of a headache at a future event and 45% were worried about driving. Migraine was shown to have greater impact on work, family and social occasions, than tension-type headache. |
| Edmeads et al., 1993 | General Practice patients n=230 | Norway | 70% of migraine patients needed bed rest and 55% stayed home from work |
| Winnem, 1992 | Serious headache sufferers n=647  
Questionnaire | Kentucky, USA | Of the patients with serious headaches, 73.6% reported that their headaches adversely affected their lifestyle in at least one way. Migraine sufferers reported significantly more interference in family relations, work attendance and work-efficiency than patients with non-migraine headaches. |
Table 2.6 (continued): Migraine-related disability

<table>
<thead>
<tr>
<th>Author(s), Year</th>
<th>Sample and Design</th>
<th>Country</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stewart and Lipton, 1993</td>
<td>Questionnaire to 15000 households</td>
<td>USA</td>
<td>86% of women and 82% of men reported at least some disability. 35.5% reported severe disability and needed bed rest</td>
</tr>
<tr>
<td>Clarke et al., 1996</td>
<td>Hospital Trust employees n=4200, migraine sufferers n= 158, Questionnaire</td>
<td>UK</td>
<td>90% reported postponing household chores, 76% required bed rest, 73% had limited work ability, 72% had limited work performance, 67% cancelled appointments/meetings</td>
</tr>
<tr>
<td>Sakai and Igarashi, 1997</td>
<td>Population-based, multi-stage, Telephone survey 38 779 telephone calls to obtain n=4029, Questionnaires sent to recurrent headache sufferers n=1597</td>
<td>Japan</td>
<td>74% reported migraine to significantly ruin daily activities</td>
</tr>
</tbody>
</table>
2.5.3. Lost time

Lost time arises from absenteeism and from reduced productivity. Time is lost from school, work, family and social lives due to migraine. The inclusion of time lost due to reduced productivity is important, since migraine sufferers avoid taking time off work for headache (Michel et al., 1999). Migraine sufferers spent 15.5 days at work with migraine vs. 2 days of absenteeism due to headache a year (Clarke et al., 1996). Time lost is highly individual, thus reflecting the highly individual severity of migraine. In the UK, 76% of migraine patients had not taken any time off work in the three months prior to the survey, 13% had taken 1 day, 6% had taken 2 days, 6% 3-5 days, and 1% over 6 days (Clarke et al., 1996). Despite avoiding sick leave for headache, overall sickness-related absenteeism in migraine patients is higher than in controls, due to migraine co-morbidities (Michel et al., 1999). In Canada, mean productivity losses due to migraine amounted to 84 hours of paid work, 48 hours of unpaid work and 113 hours of leisure time lost (Caro et al., 2000), for a total of 245 hours lost per patient per year. Interest on lost time has mainly focused on time lost from work, because this captures the economic burden of migraine.

2.5.4. Cost

The burden of migraine through cost is expressed through direct and indirect cost. Direct costs involve the medical costs, such as visits to the GP and specialist, medication and in the US, the use of emergency services.

For individual patients, direct cost averaged $280 (£120) per patient per year and indirect cost was estimated to be Can$ 1949 (£719) per patient per year in Canada (Caro et al., 2000). In France, per capita drug consumption for CDH was six times
higher (Euro 73.5 per year, i.e. £52.3 per year) than in the migraine group (Euro 11.5 per year, i.e. £8.2 per year) (Lanteri-Minet et al., 2003). Overall, direct cost in Europe and Australia amounts to tens of millions of pounds per year (Ferrari, 1998). The use of emergency services in the US mean that American direct cost of migraine are up to twice the cost of Europe and Australia (Ferrari, 1997).

Indirect costs arise from time lost from work that can be attributed to migraine. Indirect cost in France was 5.22 billion French Francs (£500 million) per year, based on a total of approximately 0.7% of the annual number of working days lost on average per individual (Michel et al., 1999). In a Trust hospital in the UK, lost time due to migraine was estimated to be over £50,000 of work time each year (Clarke et al., 1996). The indirect cost of migraine in the UK has been estimated at £611 million (Cull et al., 1992). Annual indirect cost in the US was estimated to between $1.4 to 17.2 billion (de Lissovoy and Lazarus, 1994).
2.6. Migraine and CDH Management

At present, there is no complete "cure" for migraine (Lance and Goadsby, 1998). However, a wide range of management strategies is available to help deal with the attacks, achieve relief of pain and associated symptoms and to improve the quality of life of the sufferers. Management strategies include pharmacological and non-pharmacological strategies for either acute or prophylactic treatment of migraine.

2.6.1. Pharmacological management of migraine

The pharmacological treatment of migraine is divided into acute and prophylactic treatment. In recent years, guidelines and scientific articles have been published to help doctors choose appropriate treatment for their patients. Different sets of guidelines have been published in various countries, such as the 'Migraine in Primary Care Advisors' (MIPCA) guidelines in the UK (Dowson et al., 2000), the 'US Headache Consortium' guidelines in the US (Silberstein and the US Headache Consortium, 2003), the 'Deutsche Migräne und Kopfschmerzgesellschaft' (DMKG) in Germany (Diener et al., 2000) and guidelines for diagnosis and clinical management (Pryse-Phillips et al., 1997a) and non-pharmacological management in Canada (Pryse-Phillips et al., 1997b). No international guidelines have been published by the IHS. It may not be feasible to try and implement international guidelines given the variations between health care systems of different countries.

The following sections describe both acute and prophylactic migraine treatments, and give a brief overview on how the treatments are selected.
2.6.1.1. Acute treatment of migraine

Goadsby and Oleson (1996) divided drug-based acute migraine treatments into 2 categories: non-specific and specific compounds. Non-specific treatments are analgesics with anti-pain actions that are not specific to migraine. Specific compounds with anti-migraine action do not have any general anti-pain actions, such as non-steroidal anti-inflammatories (NSAIDs) and combination analgesics and anti-emetics.

Specific compounds, which are prescription medications, include ergotamine (ergotamine tartrate or dihydroergotamine) and triptans. Ergotamine has been used in the treatment of migraine for over 50 years (Lance and Goadsby, 1998). Triptans were only first introduced about ten years ago. Triptans have dramatically changed the treatment of migraine and are often the drug of choice for moderate to severe migraine (Goadsby, 1999; Goadsby and Oleson, 1997). The triptans, currently available in the UK are sumatriptan (Imigran), zolmitriptan (Zomig), rizatriptan (Maxalt), naratriptan (Naramig), eletriptan (relpax), almotriptan (almogran) and frovatriptan (migard). The triptans are available in different formulations, including tablets, wafers, nasal sprays, injections and suppositories.

All migraine patients need acute medication (Lipscombe et al., 2003) and most patients need acute treatment only for episodic migraine (Tfelt-Hansen and Welch, 1993). Mild to moderate attacks may be treated with the non-specific medications, whereas moderate to severe attacks should be treated with the specific prescription medications (Celentano et al., 1992). Acute treatment should be tailored to the individual patients' clinical and personal needs, which are determined by assessing migraine severity, migraine impact, headache frequency and duration, and the
patients' co-morbidities, individual lifestyle needs and preferences (Lipscombe et al., 2003).

2.6.1.2. Prophylaxis of migraine

Some patients need prophylactic medication in addition to their acute treatment. Few migraine sufferers take prophylactic medication (Clarke et al., 1996; Edmeads et al., 1993). Prophylaxis may be recommended for a frequency of or above 4 attacks per month (Dowson et al., 2000); for particularly severe and disabling attacks; when acute treatments are contra-indicated, ineffective, over-used or have serious side effects; in special circumstances such as hemiplegic migraine or the when the patient is psychologically unable to cope with the attacks (Tfelt-Hansen and Welch, 1993; Silberstein, 1997; Lance and Goadsby, 1998; Silberstein et al., 1999). Preventive medications are given on a daily basis, whether or not the patient is suffering from a headache (Silberstein et al., 1999). Treatment can be episodic, sub-acute or chronic (Silberstein, 1997). Even with successful preventive treatment, the medication should be gradually withdrawn after 6 to 12 months, to ascertain whether prophylaxis is still necessary (Tfelt-Hansen and Welch, 1993). The main drugs that are used for migraine prophylaxis include beta-blockers, anti-depressants, calcium channel blockers, serotonin agonists, anti-convulsants and non-steroidal anti-inflammatories (NSAIDs) (Silberstein, 1997; Lance and Goadsby, 1998; Silberstein et al., 1999). The obvious initial choice of prophylaxis in the UK is a beta-blocker, which is the only prophylactic drug licensed for migraine in the UK (Lipscombe et al., 2003).
2.6.2. Non-pharmacological management of migraine

Non-pharmacological treatments are employed both acutely and prophylactically. There are two main types of non-pharmacological management: self-help measures and alternative therapies. Prophylactic non-pharmacological management (self-help) aims to help the migraine sufferer identify situations that make the attacks worse and to encourage their modification (Goadsby, 1999), such as trigger identification and avoidance and lifestyle changes, such as regular meals and sleep and avoiding stress. Non-pharmacological prophylactic methods to treat migraine also include approaches such as psychological management, relaxation, biofeedback, meditation, hypnotherapy, acupuncture, exercise, elimination diets, behavioural modification, herbal remedies such as Feverfew, osteopathy and chiropractic treatment (Lance and Goadsby, 1998) and education, coping skills training (Gauthier et al., 1996).

For alternative therapies, there is some evidence for the effectiveness of acupuncture (Allais et al., 2002); homeopathy (Walach et al., 2000) and chiropractic spinal manipulation (Tuchin et al., 2000). The herbal remedy Feverfew has also been shown to be effective in two studies (Johnson et al., 1985; Murphy et al., 1988). However, the study by Murphy et al, although a randomized, double-blind, placebo controlled trial, only included 59 patients (18 of which had previously tried Feverfew and 11 had found it helpful) and migraine was not diagnosed according to IHS. The study by Johnson included only 17 patients and tested discontinuation of Feverfew, rather than the effect of the herb. The positive findings of these 2 studies have not been confirmed in a larger double-blind, multi-centre, randomized placebo-controlled dose-response study, comprising 147 IHS migraine patients. This study failed to show a significant prophylactic effect of Feverfew (Pfaffenrath et al., 2002).
A comprehensive review of empirical findings from controlled studies on non-pharmacological treatments for migraine has been presented by Gauthier et al., (1996).

2.6.3. Management of CDH

Studies on the management of CDH focus on prophylactic treatment and in the case of TM, breakthrough migraines are treated with the same acute treatments that are used in the acute treatment of episodic migraine. In 1999, Rothrock concluded that there were few reports on treatment trials for the management of CDH and that clinicians use anecdotal and personal experience to guide CDH management (Rothrock, 1999). Based on previous data, Rothrock proposed 4 different pathways for pharmacological treatment, sequential administration of divalproex sodium, amitriptyline, amitriptyline plus phenelzine or methadone. Outcome was considered successful treatment if more than 15 headache free days within 30-day period were achieved. Sixty-seven percent of patients reported a 50% or greater reduction in headache days per month following initiation of treatment. Divalproex sodium was attributed the most positive treatment response, but was the first treatment administered. The other treatments were only given if this treatment was unsuccessful and few patients proceeded to the next treatment. Furthermore, the study only included 33 patients, of which only 29 completed treatment and there was no control group.

To help evaluate the pharmacological management of CDH, (Redillas and Solomon, 2000) have summarised the studies on prophylactic agents that have been reported to be effective in the treatment of CDH. This study shows the extent of publications on the prophylactic management of CDH. However, as the authors concluded many of
the reports on CDH prophylactics are anecdotal and have often been published as abstracts or letters to the editors and most studies are open rather than double-blind studies, with the majority not defining criteria for efficacy and using a small number of patients. Still, the study revealed that there is a great availability of prophylactic pharmacological agents for CDH, of which only anti-depressants have been studied extensively. Prophylactic medications include anti-depressants (tri-cyclic, tetracyclics, monoamine oxidase inhibitors, selective serotonin re-uptake inhibitors); anti-convulsants, muscle relaxants, 5-HT₁ agonists, ergots, 5-HT₂ agonists, anti-anxiety agents and miscellaneous drugs.

In other types of headaches, the use of non-pharmacological management is recommended in conjunction to drug therapy. Thus non-pharmacological management may also be a suitable method in the management of CDH. Two studies have investigated the use of non-pharmacological management of CDH, but these management techniques have been studied in conjunction with pharmacological treatments and both studies have focused on only one type of CDH and one type of non-pharmacological management.

A randomized control trial in the US (Holroyd et al., 2001) showed that both tricyclic anti-depressants and stress management therapy produced greater reductions in headache activity, use in analgesics, and headache related-disability than placebo after 6 months. Improvement occurred more rapidly with anti-depressants than with stress management. Combined therapy of anti-depressants and stress management was more likely to produce a clinically significant effect (i.e. 50% or more reduction of headaches) than anti-depressants (p=0.006), stress management (p=0.003) or placebo (p=0.001). However this study was carried out in CTTH patients only.
The combined treatment of medication and biofeedback for the treatment of TM has been investigated in one study (Grazzi et al., 2002). Patients (n=69) with TM with analgesics overuse were recruited through a neurology institute in Italy. The study showed that at 36 months follow-up, patients who had received the combined treatment (n=14) had a significantly greater reduction in headache days (18.1 vs. 11.2) (p<0.01) and used significantly less analgesics (monthly consumption 4.9 vs. 20.1) (p<0.01) than patients in the pharmacological treatment group (n=32). Within 1 year, 20% of patients of the pharmacological treatment group and in 10% of the patients in the combined treatment group relapsed into CDH. After three years, significantly more patients (42.1%) in the pharmacological treatment group had relapsed vs. 12.5% of patients in the combination treatment group (p<0.04). However, as with other studies on the management of CDH, the sample size was small and few patients completed the study. Furthermore, there was no control group, although the pharmacological treatment group could be considered a control group.

2.7. Summary

Migraine and CDH are primary headaches that affect a large proportion of the general population. Migraine and CDH can vary in their symptomatology and some patients are more severely affected than others. Generally, patients who suffer from migraine or CDH report high levels of headache-related disability and have a reduced quality of life. Due to the higher frequency of their headaches, CDH patients are more significantly affected by their headaches than patients who suffer from episodic migraine.

A multitude of strategies to treat and prevent these headaches is available. Strategies include pharmacological and non-pharmacological treatments both for acute
treatment and the prophylaxis. The specific treatments given to a patient vary depending on the patients’ level of headache severity, frequency and duration, as well as level of disability and the patients’ individual needs and preferences.

The following section sets out to describe migraine and CDH management in clinical practice, including consultation rates, factors influencing consultations and proposed solutions to maximise the outcome of consultations in terms of achieving appropriate management for patients. Finally, the patients’ management, including pharmacological and non-pharmacological behaviours will be described.
2.8. Migraine and CDH in clinical practice

2.8.1. Migraine in clinical practice

When consulting a doctor, General Practitioners (GPs) are the most common primary medical contact for migraine sufferers, as most migraine patients have access to primary care, with only a small minority having access to neurologists (Shapero, 1999). It is thought that GPs are well suited to manage migraine because of their position within the health care system and their long-standing relationship with the patient (Shapero, 1999). Indeed, most of the consultations for migraine were with a GP (41%); 26% of migraine sufferers had consulted a specialist and 15% had consulted other health care professionals (Lavados and Tenhamm, 2001). When patients consult a doctor, effective migraine treatment includes making a diagnosis, explaining the condition to the patient, developing a treatment plan and setting priorities to deal with the symptoms that the patient finds the most disturbing (Silberstein et al., 1999).

2.8.1.1. Consultation rates for migraine

Consultation rates for migraine have increased in the last decade, but still consultation rates remain lower than estimates from prevalence studies (Holmes et al., 1999). From 1990 to 1998, doctors' consultations for migraine doubled from 9.4 visits per 1000 persons to 18 consultations per 1000 persons (Gibbs et al., 2003). In the UK, general practice consultations for headache significantly increased from 1993 to 1997 (Laughey et al., 1999).
Chapter 2: Review of the Literature

Studies concerned with doctors' consultation rates for migraine mainly examine the proportion of migraine patients who consult and who do not consult. The consultation rates are usually linked to a time frame and often a one-year period has been used as a cut-off point. According to Lipton and Stewart (1999), migraine patients who had ever consulted a physician are divided into two groups: those who had consulted within the last year (current consulters) and those who had not seen a physician within the last year (lapsed consulters). Fewer data are available on follow-up consultations or lapsed consulters than ever consulters. Based on their consultation definition, Lipton and Stewart (1999) found that 46.7% of migraine patients were current consulters, 20.6% were lapsed consulters and 32.3% had never consulted for their migraine. Other studies, that have investigated consultation rates over 12 months, found 5.6% male and 13.9% female consulters (age group 12-29) in the US (Linet et al., 1991); 30.6% in Japan (Sakai and Igarashi, 1997) and 45% in a more recent US study (Adelman et al., 2000a). A multi-national study, including the US, the UK, France, Germany and Italy showed consultation rates of 48% (range 41-63%) within the last 12 months (MacGregor et al., 2003).

Further studies have used other time frames to examine consultation rates for migraine. In France, based on a 6-months time frame, significantly more migraine sufferers (76%) had consulted their GPs than controls (69%) (Michel et al., 1996). However, these consultations were not necessarily for headache. Forty-seven percent of men and 60% of women reported having discussed headaches with a doctor (Michel et al., 1996). Another UK study revealed that only 32% of migraineurs had consulted a GP three months prior to the study (Clarke et al., 1996). Ever consultations (i.e. consultation for headache at some point in their lives) were reported by 13.6% of men and 26.7% of women (Linet et al., 1991), 64% in Canada
Chapter 2: Review of the Literature

(Edmeads et al., 1993); 68% of women and 57% of men in the USA (Lipton et al., 1998), 63% of in Chile (Lavados and Tenhamm, 2001) and 75% in the UK (Dowson and Jagger, 1999). The different time frames make it difficult to compare the findings of these studies, but it is generally accepted that the majority of migraine patients do not currently consult their doctor about migraines. Furthermore, studies on consultation rates have mainly been carried out in the US. The differences in health care systems make it difficult to draw inferences from the findings on consultations, since the health care systems may influence consultations and findings from one country may not be applicable to other countries. Differences in health care systems include the use of emergency rooms for migraine treatment and managed care in the US and the National Health Service (NHS) and the GP gate-keeping system in the UK.

Follow-up consultations are less widely studied. The available data shows that follow-up consultations are rare and rates decrease rapidly. In Canada, only 32% of migraineurs returned for follow-up care (Edmeads et al., 1993) and in the US 32% had lapsed from care within 1 year (Adelman et al., 2000a). Less than half of the Chilean migraine consulters (36% of men and 47% of women) underwent treatment within the practice for more than one year (Lavados and Tenhamm, 2001). Forty-six percent of British patients only consulted once and the mean number of headache consultations was 3.09 per consulting patient (Laughery et al., 1999), which is low considering that many patients suffer from migraine for most of their life.
2.8.1.2. Type of health professional consulted and frequency of consultations

Studies on the type of health professional consulted generally focus on consultations with the doctor for migraine and there is little evidence on consultations with other health professionals. Consultations with doctors predominantly occur within the primary care setting, both in terms of initial consultations and frequency of consultations (Lipton et al., 1998). Initial consultations in the US were with the general/family practitioner (46.4% of women and 48.1% of men), neurologist (13.6% of women and 10.4% of men), internist/paediatrician (11.5% of women and 14.1% of men), obstetrician/gynaecologist (4.2% of women), ophthalmologist (3.6% of women and 1.9% of men), emergency physician (3.4% of women and 1.9% of men), pain/headache specialist (1.6% of women and 4.7% of men) and other (15.7% of women and 18.0% of men). Most frequent consultations were with the general/family practitioner (43.8% of women and 38.5% of men), neurologist (12.3% of women and 10.3% of men), internist/paediatrician (14.9% of women and 15.4% of men), obstetrician/gynaecologist (2.6% of women), ophthalmologist (0.4% of women), emergency physician (0.9% of women), pain/headache specialist (1.3% of women and other (23.8% of women and 23.8% of men) (Lipton et al., 1998).

Based on medical records in the US, primary care physicians (family medicine, internal medicine, pediatrics and obstetrics/gynaecology) were the most frequently consulted doctors for migraine consulted (72.2%) (Gibbs et al., 2003). Neurologists only accounted for 17.3% of consultations, but they had the highest frequency of consultations per physician (87.4 visits per physician per year) (Gibbs et al., 2003).
As far as consultations with health professionals other than physicians are concerned, few data are available. Edmeads and colleagues (1993) reported that many headache patients consulted chiropractors, acupuncturists, masseuses, homeopaths and nutritionists, but they did not give any details on consultation rates and/or frequency. A further Canadian study revealed that 15.1% of migraine patients reported consulting a nurse, 71.4% had consulted a dental practitioner, 42.5% an optician, 23.9% a pharmacist, 6.9% a physiotherapist, 14.8% a chiropractor and 11.7% a psychologist, social worker or other counsellor (To and Wu, 1995). However, due to its design, this study did not allow to conclude whether these visits were for migraine.

The data on the type of health professional consulted and frequency of consultation remain limited to the US (Lipton et al., 1998; Gibbs et al., 2003) and Canada (Edmeads et al., 1993; To and Wu, 1995). Thus again it may not be appropriate to draw conclusions on the type of health care professional consulted in other countries. Furthermore, the studies have focused on a variety of health care professionals, but the type(s) of health care professionals differed within each study. Apart from the study by Gibbs et al (2003), which examined medical records, the studies relied on the patients' reports to investigate which types of health care professionals were consulted by migraine patients.

2.8.1.3. Consulters characteristics

Consultation behaviour differs not only between countries, but also according to gender, marital status, level of education, headache characteristics, impact (disability) and medication use. Female migraine sufferers are more likely to ever consult than male migraine patients (Linet et al., 1991; Lipton et al., 1998; Lavados
Chapter 2: Review of the Literature

and Tenhamm, 2001; Gibbs et al., 2003). In female sufferers, consultation was also more likely with increasing age and being married (Linet et al., 1991; Lipton et al., 1998). The highest frequency of consultations for migraine occurred in patients aged 40 to 49 (25.8 visits per 1000 persons) (Gibbs et al., 2003). However, in Chile migraine patients were more likely to consult if they were younger (Lavados and Tenhamm, 2001). Migraine sufferers in the US and in Chile with a higher level of education were less likely to have obtained medical advice for headache (Linet et al., 1991; Lavados and Tenhamm, 2001).

Men and women who had consulted a physician within the last year, reported their headaches to be more severe, of longer duration (women only), of higher disability and were more likely to have migraine characteristics than headaches of persons who had not consulted within the last year (Linet et al., 1991; Lipton et al., 1998; Lavados and Tenhamm, 2001). However, in the USA, 61% of the sufferers who had never consulted reported severe or very severe pain and 67% reported severe disability (Lipton et al., 1998). In the UK, despite 94% of sufferers reporting suffering from moderate to severe headaches, only 32% had consulted their GP and 60% had never consulted a health professional (Clarke et al., 1996).

2.8.1.4. Patients' beliefs and attitudes

Few studies have been published on the patients' perspective of migraine, and again they have predominantly been carried out in the US. Gaining better understanding of the patients' beliefs and attitudes is important as beliefs and attitudes may have an influence on the patients' consultation behaviour. Nearly 70% of the headache patients thought to cope as well as possible and as well as other headache sufferers (Barnat and Lake, 1983). Despite this, nearly half of the patients reported that their
headaches caused frequent disruptions in functioning. In the UK, of migraine patients who had never consulted, 17% believed that their doctor would not treat their migraine seriously enough, 76% said that they did not need a doctor’s opinion to treat their migraines, 52% reported that their headaches were not that bad and 50% said that they had a treatment option that worked (Dowson and Jagger, 1999). However, 42% of those with headaches in the US said that there was nothing the doctor could do, 41% said that seeing a doctor was too inconvenient and 32% said that seeing a doctor was too expensive (Lipton and Stewart, 1999). The lapsed consulters (65%) said they had not seen a doctor within the last year, because the prescribed treatment was working and 59% said that their headaches had improved. Conversely, 26% had lapsed because they thought there was nothing the doctor could do for their migraines, 20% said that their doctor did not help them and 15% believed that their doctor was not interested in headache (Lipton and Stewart, 1999). Another study showed that reasons not to seek medical advice included statements like the following: “it’s only a headache” (28%), “OTC treatments work for me” (32%), “the doctor would not be able to do any more for me” (10%) or “previous visit to a doctor was unsatisfactory/ treatment did not work” (6%) (MacGregor et al., 2003). At the same time, 65% of migraine patients from the US, the UK, Germany, France and Italy believe that not enough is being done to help them (Brandes, 2002).

To achieve better understanding of the patient and in response to the development of patient preference trials, research efforts have been focused on studying the migraineurs’ preferences and satisfaction. Studies included comparisons of medication formulation (tablet vs. wafer) (Adelman et al., 2000b), dosing (Dowson et al., 1999; Salonen et al., 1999) and different drugs (Pascual et al., 2001). Although
these studies are important to understand the pharmacological preferences of the patients, they do not provide the whole picture of patient preference.

These studies have been based on quantitative designs, and little opportunity has been given to the patients to freely speak about their perceptions. If headache researchers want to truly understand the patients’ perspective, they will need to let patients speak freely and listen to the patients’ point of view, rather than obtain answers to questions determined by the researchers. Qualitative methods allow participants to speak freely and permit access to areas not amenable by quantitative methods. Qualitative methods have been advocated for use in headache research to gain access to areas such as the patients’ perceptions (Peters et al., 2002). One qualitative study, using focus groups, aimed to identify the areas that migraine patients consider the most problematic as living with their headache and the type of physician assistance the patients believe would be most helpful (Cottrell et al., 2002). Six main categories were identified, including: 1) effect on social functioning, 2) effect of family functioning, 3) effect on work, 4) effect on relationships, 5) issues related to physician care and 6) problems with insurance and drug companies. The authors concluded from their findings that migraine patients are interested in understanding their condition and in securing relevant information about migraines, as well as obtaining pain relief. Furthermore, the patients desired collaborative relationships and wanted a team approach to treatment that involved both patient and doctor.

2.8.1.5. Diagnosis

In the US, the proportion of patients reporting a physician’s diagnosis of migraine has increased from 38% in 1989 to 48% in 1999 (Lipton et al., 2001b). Still, a large
proportion of migraine sufferers world-wide report never having received a physician’s diagnosis for their condition, despite some of them having consulted. The proportion of migraine sufferers reporting a physician’s diagnosis range from 33% in Japan (Sakai and Igarashi, 1997), to 44-48% in the US (Lipton et al., 1998; Lipton et al., 2001b), 46% in the Netherlands (Launer et al., 1998), to 62% in the UK (Clarke et al., 1996). However, in the UK study, of the 1903 responders to the questionnaire, 158 suffered from IHS migraine, but 293 had been diagnosed as suffering from migraine by their GP (Clarke et al., 1996). One of the problems with diagnosis at the primary care level is a lack of familiarity with the IHS criteria and a lack of appreciation of the variability in migraine within and between sufferers (Shapero, 1999).

In the US, the likelihood of receiving a physician’s diagnosis is increased in patients with higher income, migraine with aura, vomiting, higher disability, older age and being female (Lipton et al., 1992; Lipton et al., 2001b). Physician’s diagnosis is also related to the migraine symptoms. Patients who reported having received a physicians diagnosis were more likely to report nausea, vomiting, unilateral pain, blurred vision, aura, neurological signs, extremely severe head pain and the need for bed rest (Lipton et al., 2001b). In the Netherlands, migraine patients from the lowest socio-economic group, who were either over 40 years of age or who suffered from photophobia, nausea and aura or who used analgesics more than 4 times per week, were more likely to receive a physician’s diagnosis (Launer et al., 1998).
Chapter 2: Review of the Literature

2.8.1.6. Problems with consultations for migraine and proposed solutions

2.8.1.6.1. Step-care versus stratified care

As outlined above, problems with consultations include low consultation rates, and under-diagnosis and under-treatment. One reason for the delay of appropriate treatment may be the step-care approach (Lipton et al., 2000b), which prevails in migraine management. Step-care involves first line treatment with simple analgesics. Combination treatments and migraine specific drugs are only given as second or third line treatments. During this period, sufferers often lapse from care and never receive the benefits they need (Micieli, 1993).

Since under-treatment may be related to the step-care approach, Lipton et al (2000b) propose stratified care as an alternative model for selecting therapy. Stratified care involves treating patients based on their individual needs rather than escalating treatment when one treatment has failed (step-care). Initial treatment in stratified care is based on headache-related impact. Stratified care may facilitate treatment choice by improving understanding of the patient’s needs. Stratified care was investigated in the Disability In Strategies for Care (DISC) trial (Lipton et al., 2000b) to compare the clinical benefit of stratified vs. step-care. Headache response was measured on a 4-point scale (0-4, no to severe pain) at baseline, 1, 2 and 4 hours. Disability was recorded on a 0-100-point scale (0 represented inability to do any activities and 100 was normal functioning). It was shown that stratified care provided significantly better clinical outcomes (headache response and disability time) than step care. Since the DISC trial has only been carried out recently, there is no evidence yet on its uses in clinical practice.
2.8.1.6.2. The doctors’ perspective

Even headache interested doctors (neurologists, general practitioners, internists and others) do not fully understand the migraine patients’ perspective (Lipton and Stewart, 1999). The doctors correctly predicted the most important attributes of acute migraine therapy (rapid pain relief, complete pain relief) and the patients preferred route of administration for acute drugs. But they failed to recognise the importance of lack of recurrence of the headache, to correctly predict the most frequent reasons for patients’ dissatisfaction with their acute medications and to identify the attributes that were important in consultations.

Since doctors often do not diagnose or treat migraine effectively (Holmes et al., 2001a), it may be assumed that physicians’ knowledge about migraine management needs to be improved. Guidelines to help doctors deal with migraine have been published by several headache groups and countries. These guidelines are based on clinical experience and evidence. In the UK, the ‘Migraine in Primary Care Advisors’ (MIPCA) (Dowson et al., 2000) have their set of guidelines. Other guidelines have been published in the US (Silberstein 2000), in Canada (Pryse-Philipps et al., 1997a) and in Germany (Diener et al., 2000). No international guidelines have been published by the IHS.

2.8.1.6.3. Communication and disability assessment

Clinical intuition suggests that doctors and patients do not always communicate effectively about headache, particularly headache disability (Lipton et al., 1994). According to doctors only about one third of migraine sufferers report headache-related disability, when it is known that the majority of sufferers are affected. This information, in most cases had to be solicited by the doctor, but doctors ask for
disability information less often than other symptoms (Holmes et al., 2001b). This study was carried out with North American and European neurologists and primary care physicians with an interest in headache and it is likely that disability information is sought even less often by physicians who do not have this special interest in headache. However, disability information does affect treatment. The study further showed that physicians were 27% more likely to rate migraine severity as “severe” or “very severe”, if disability information was available. Also they were 37% more likely to recommend immediate acute plus prophylactic treatment, 41% more likely to choose triptans as a treatment, and 18% more likely to make a future appointment (Holmes et al., 2001b).

To help physicians assess migraine disability and to close the communication gap, two tools to assess migraine disability have been developed: the Migraine Disability Assessment (MIDAS) Questionnaire and the Headache Impact Test (HIT). MIDAS is a 7 question paper questionnaire. HIT is an internet questionnaire and is available as a printed version as HIT-6, a short form of HIT.

MIDAS shows the key attributes of a disability instrument, which can be used in clinical practice and epidemiological research, i.e. it is simple to administer, easy to score, reliable, valid and intuitive (Stewart et al., 1999; Stewart et al., 2001a). MIDAS involves grading migraine severity in terms of disability to allow appropriate treatment selection (Lipton et al., 2000b). The use of MIDAS has been shown in several studies, including the DISC study and studies to assess treatment needs and satisfaction. MIDAS grade 1 (no or little disability) patients predominantly (90%) use OTCs, and 92% were either satisfied or very satisfied with this treatment, with 80% always achieving relief from their medications (Lipton et al., 2001c). MIDAS
grade IV (severe disability) patients tend to use prescription medications and do not achieve high levels of satisfaction with their treatment (Stewart et al., 2001b).

HIT-6 has been shown to be a reliable and valid measure for the impact of headache (Garber et al., 2001; Ware et al., 2001). Scores for HIT and HIT-6 are easy to interpret and to compare (Dahlof et al., 2001). Both tools are suitable for use in clinical practice, since they are precise, brief and inform the physician about the degree of headache-related impact on of individual migraine patients (Dahlof et al., 2001). HIT scores were related to consultation rates, with the proportion of migraineurs increasing with increasing HIT scores (Dowson et al., 2001).

2.8.2. CDH in clinical practice

2.8.2.1. Consultation rates for CDH

Consultation rates, as well as the type of physician consulted, consultation frequency, and factors influencing consultations, for CDH are less well studied than consultation rates for migraine. However, it is known that CDH is the most common reason for consultation in specialist clinical practice. In the UK, 60% of patients who had attended a specialist headache clinic suffered from CDH, and only 33% of patients suffered from migraine (Dowson, 2003). This study also showed that women were more likely to consult (65.2% of women vs. 34.8%) of men. In a community-based survey of Chinese elderly, it was found that only 23% of CDH patients had consulted a doctor for their headaches in the year prior to the study (Wang et al., 2000).

In France, CDH patients consulted on average 5.36 times for headaches over 6 months (Lanteri-Minet et al., 2003). Of these visits per subject per six months, 1.89 were with GPs, 2.60 visits were with specialists, and 0.87 were with alternative
medical practitioners. A total of 46% of patients had consulted their GP. The number of GP visits was significantly higher for CDH than for other headaches. Psychiatrists were the most frequently consulted specialist, but ophthalmologists were the specialist consulted by the highest proportion of patients. In Taiwan, 57% of CDH patients had consulted physicians for their headaches during the last 12 months. Nineteen percent of patients had consulted physicians more than 10 times. Family doctors were consulted the most frequently (41%), followed by neurologists (28%) (Lu et al., 2001).

2.9. The patients' management of migraine and CDH

As described in section 2.4, multiple strategies are available to treat and prevent migraine and CDH. However, the high levels of disability and severely impaired QoL of the patients suggest that patients do not adequately manage their condition. This may be due to a discrepancy between treatment availability and treatment use. To date, little is known about the use of non-pharmacological management, as research mainly focuses on the pharmacological and medical therapies. However, studies on the use of pharmacological and medical management strategies, indicate that these strategies are under-used by patients. Therefore, the patients may need help to integrate these strategies within their self-management regimens.

Migraine, as described above, is under-diagnosed and consequently under-treated. Even sufferers who receive an accurate diagnosis may not receive suitable therapy (Lipton et al., 1994). The spectrum of severity means that diagnosis alone does not provide sufficient information to allow the selection of optimal therapy (Lipton et al., 1995). Furthermore, despite 83% of primary care consultations for migraine being concluded with one or more prescriptions (Krobot et al., 1999), the majority of
migraineurs use OTC medication for the treatment of their migraines. The predominant use of OTC medication, taken together with the low consultation rates and the under-diagnosis, may contribute to the patients' low levels of satisfaction with their acute treatment (Celentano et al., 1992; Edmeads et al., 1993), the reduced quality of life and great burden of migraine. This section sets out to describe the patients' use of management strategies, including pharmacological treatment, factors influencing treatment, satisfaction with treatment, non-pharmacological management and the use of social support.

2.9.1. Pharmacological treatment of migraine

2.9.1.1. Type of treatment used

2.9.1.1.1. Over the Counter vs. prescription medication

Most migraine sufferers rely on some form of pharmacological treatment to help relieve their symptoms. Ninety-five percent of migraine patients in the US (Stewart and Lipton, 1993), 91% in France (Lucas et al., 2000) and 80.8% in Japan (Sakai and Igarashi, 1997) rely on some acute medication for their attacks. Five to eleven percent of migraine patients use prophylactic medication (Edmeads et al., 1993; Lucas et al., 2000).

World-wide the majority of migraine sufferers do not use prescription medications but rely predominantly on Over the Counter (OTC) preparations. The use of prescription medication ranges from 28% of migraineurs in the UK (Clarke et al., 1996) to 41% in the US (Lipton et al., 2001b) and 44% in France (Lucas et al, 2000). It could be assumed that patients who do not rely on prescription medication have low treatment needs and low levels of disability. However, of the migraine patients
reporting disability, 46.8% relied only on non-prescription medications (Kryst and Scherl, 1994). A high proportion of sufferers (34% of women and 43% of men) who have 3 or more migraines a month and 47% of female and 61% of male migraine sufferers with moderate to severe disability do not use prescription medication (Stewart and Lipton, 1993).

In the US, 58.5% of women and 66.5% of men took OTC medication and 3.1% of women and 4.5% of men did not take any medication (Celentano et al., 1992). In France, more than twice as many migraine patients had taken OTCs than prescription medication (44 vs. 91%) (Lucas et al., 2000). Japanese migraine patients also predominantly relied on OTC medication (56.8%) (Sakai and Igarashi, 1997). In the UK, more than half of migraine sufferers were taking simple analgesics to treat their attacks (Dowson and Jagger, 1999).

Even when on prescription medication, migraine patients still rely on taking analgesics (Dowson and Jagger, 1999). In Japan, only 5.4% of migraine patients relied solely on prescription medication, whereas 18.6% used both (Sakai and Igarashi, 1997). In a multi-national study, including the UK, 53% of patients supplemented their prescription medication with OTCs medication (MacGregor et al., 2003). Sufferers try a range of medication and do not necessarily believe that their current medication is the best they have ever tried (Dowson and Jagger, 1999). Different types of acute migraine medication are not only used to treat separate attacks, but in any given migraine attack, 38.4% of patients used a second type of treatment and 10.7% a third (Lucas et al., 2000).
2.9.1.2. Types of medication

The majority of studies have concentrated on the differences in use of OTC and prescription medication. One multi-national study also investigated the types of medication used. The most common types of treatment prescribed for migraine were simple analgesics (38%) and NSAIDs (18%). Triptans were prescribed only to 10.4% of patients (range 3% in Italy to 19% in the US) (MacGregor et al., 2003).

2.9.1.2. Factors influencing medication use

The use of prescription medication is higher in women than in men (Stewart and Lipton, 1993), which is not surprising since female migraine patients are more likely to consult than male migraine sufferers. Other factors influencing the prescription of medication are certain migraine symptoms (vomiting and aura), high frequency, high disability, and duration of the attacks (Celentano et al., 1992). Patients’ decision-making on which drug (sumatriptan vs. analgesics) to use to treat an attack is influenced by the efficacy of the drug selection, pain severity and other migraine characteristics, contextual and environmental factors and expectations (Ivers et al., 2000). Interestingly in France, migraine patients with the highest attack frequency (>1 migraine per week) were less likely to take medication than migraine patients with an attack frequency of 1-2 attacks per fortnight and patients with migraines less than once a month (55% vs. 73-78%) (Michel et al., 1996).

2.9.1.3. Satisfaction with pharmacological treatment

The low level of satisfaction with treatment illustrates that migraine treatment is suboptimal. Only 29% of migraine sufferers in the US (Lipton et al., 1998) were “very satisfied” with their acute treatment. In the UK, less than 1 in 4 patients were totally
Chapter 2: Review of the Literature

satisfied with any of the migraine treatments (Dowson and Jagger, 1999). A more recent international study showed that only 27% of migraine patients reported that their medication was consistently effective and associated levels of satisfaction were low, with only 36% of migraine patients being ‘very satisfied’ with their current therapy (Brandes, 2002). Only about 19% of Canadian migraine sufferers achieved complete relief with their acute treatment, and 62% were partially relieved (Edmeads et al., 1993). Sufferers most frequently reported dissatisfaction about overall relief, delayed onset of relief and the incidence of side effects (Lipton et al., 1998). The determinants of patients’ satisfaction with their acute migraine treatment included being pain free at 2 hours, absence of associated symptoms and lack of headache recurrence (Davies et al., 2000). These determinants of satisfaction are current clinical endpoint in trials on migraine treatment.

2.9.2. Non-pharmacological treatment

The use of non-pharmacological treatment for the management of migraine are advocated by headache specialists (Pryse-Philipps et al., 1997b; Dowson et al., 2000; US Headache Consortium, 2000), but they have not been as extensively studied as physicians’ consultations and medication use. Data include information on the patients’ behavioural and coping responses to headache and the use of alternative therapies. These studies show that these non-pharmacological management strategies are usually employed in conjunction with the more widely studied physicians’ consultations and medication use.

In the US, patients with migraine, TTH or a combination of migraine and TTH showed that the patients were all active users of behavioural management during a headache (Scharff et al., 1995) (Table 2-7). Behavioural responses differed


according to the headache diagnosis. TTH patients were significantly less likely to engage in the behavioural responses (p<0.01 for all behaviours), including avoidance/ reduction of light, reduction of social contacts or sleep and carrying on despite the pain. No significant differences were found between the TTH and combined headache group, and the only significant difference between migraine and the combined group was that migraine patients were significantly more likely to reduce social contact (p<0.002).

Table 2-7: Percentage of patients reporting coping behaviours at least sometimes (Scharff, Turk, & Marcus 1995)

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Total sample (n=172)</th>
<th>Migraine (n=69)</th>
<th>TTH (n=52)</th>
<th>Combined migraine and TTH (n=53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take time off</td>
<td>75.0</td>
<td>78.3</td>
<td>73.1</td>
<td>69.3</td>
</tr>
<tr>
<td>Avoid physical activity</td>
<td>91.2</td>
<td>94.2</td>
<td>88.2</td>
<td>90.0</td>
</tr>
<tr>
<td>Avoid/reduce lights</td>
<td>87.9</td>
<td>94.2</td>
<td>76.9</td>
<td>90.4</td>
</tr>
<tr>
<td>Avoid/reduce noise</td>
<td>92.5</td>
<td>95.7</td>
<td>88.5</td>
<td>92.3</td>
</tr>
<tr>
<td>Reduce social contacts</td>
<td>86.7</td>
<td>95.7</td>
<td>78.9</td>
<td>82.7</td>
</tr>
<tr>
<td>Lie down</td>
<td>90.8</td>
<td>94.2</td>
<td>82.7</td>
<td>94.2</td>
</tr>
<tr>
<td>Go on with activities</td>
<td>81.7</td>
<td>71.6</td>
<td>71.6</td>
<td>88.2</td>
</tr>
<tr>
<td>Take medication</td>
<td>93.0</td>
<td>92.7</td>
<td>92.7</td>
<td>94.2</td>
</tr>
<tr>
<td>Sleep</td>
<td>75.6</td>
<td>83.6</td>
<td>83.6</td>
<td>76.9</td>
</tr>
</tbody>
</table>
In the UK, 13% of migraine patients used alternative therapies such as homeopathy, yoga and acupuncture (Clarke et al., 1996). In Japan, 40% of patients used sleep, 21% used shoulder and neck massage, 12% used compressions of the head and 9% used cooling of the head to relieve migraine (Sakai and Igarashi, 1997). Portuguese patients spontaneously reported using an average of 2.9 manoeuvres to help relieve migraine pain. When prompted by a questionnaire, the patients reported an average of 6.4 behaviours (Pavão Martins and Parreira, 2001a). However, this study only included 55 migraine patients recruited from a specialist headache outpatient clinic.

In a further study by the same authors, a comparison was drawn between migraine and TTH patients behavioural response to headache (Pavão Martins and Parreira, 2001b). This study showed that migraine patients used more strategies to relieve pain than TTH patients (average of 6.2 vs. 3). The percentage of patients using the specific strategies, from both studies, are summarised in Table 2-8. The most recent study on the patients coping behaviours was an international study in 5 countries (the US, the UK, Germany, France and Italy). This study revealed that 62% of patients supplemented their prescription medication with bed rest, 33% with avoidance of triggers, 20% with stress management, 19% with relaxation therapy, 18% with regular exercise, 14% with herbal remedies and 7% with homeopathic remedies (MacGregor et al., 2003).
Table 2-8: Behavioural responses to headache by Portuguese migraine patients—comparison of 2 studies.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Pavão Martins and Parreira, 2001a (%)</th>
<th>Pavão Martins and Parreira, 2001b (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take medication</td>
<td>98.2</td>
<td>100</td>
</tr>
<tr>
<td>Changing eating habits</td>
<td>----</td>
<td>85.7</td>
</tr>
<tr>
<td>Avoid foods/ not eating</td>
<td>61.8</td>
<td>62.9</td>
</tr>
<tr>
<td>Eat special foods</td>
<td>23.6</td>
<td>22.9</td>
</tr>
<tr>
<td>Vomit</td>
<td>----</td>
<td>80.5</td>
</tr>
<tr>
<td>Spontaneously</td>
<td>67.3</td>
<td>59.7</td>
</tr>
<tr>
<td>Induced</td>
<td>16.4</td>
<td>20.8</td>
</tr>
<tr>
<td>Sleep</td>
<td>58.2</td>
<td>60</td>
</tr>
<tr>
<td>Local cold pads</td>
<td>50.9</td>
<td>50</td>
</tr>
<tr>
<td>Local pressure</td>
<td>78.2</td>
<td>74.2</td>
</tr>
<tr>
<td>Change position</td>
<td>100</td>
<td>97.1</td>
</tr>
<tr>
<td>Lie down</td>
<td>----</td>
<td>88.8</td>
</tr>
<tr>
<td>Use more pillows than usual</td>
<td>----</td>
<td>33.8</td>
</tr>
<tr>
<td>Do not move/ immobility</td>
<td>88.9</td>
<td>88.1</td>
</tr>
<tr>
<td>Isolation</td>
<td>94.4</td>
<td>95.3</td>
</tr>
<tr>
<td>Massage</td>
<td>----</td>
<td>3.8</td>
</tr>
<tr>
<td>Other</td>
<td>----</td>
<td>28.5</td>
</tr>
</tbody>
</table>

2.9.3. Pharmacological treatment of CDH

As for migraine, the majority of CDH patients use acute medications to treat their headaches. Also, as in migraine, the use of OTC medication was more common than the use of prescription medication. In France, 84.4% of CDH patients used acute medications, (55.0% used analgesics, 24.5% used NSAIDs and 5.3% used triptans), but only 43.0% of patients found this to be effective in relieving their headaches (Lanteri-Minet et al., 2003). In Taiwan, most CDH patients used OTC medications (73%), followed by 22% of patients using prescription medication and 5% of patients using both (Lu et al., 2001). In a UK specialist headache clinic, 66% of CDH patients
used regular analgesia, and 14% had used triptans prior to their visit to the clinic (Dowson, 2003).

Given the concerns of medication overuse in the development of CDH and the actual use of acute medications by CDH patients, it is necessary to carefully monitor the use of acute medication. Of the 108 CDH patients in the study by Lu et al (2001), 34% had overused medication and 65% of the patients overusing medication had done so for more than 6 months in the previous year. Medication abuse was significantly more likely in older patients (p<0.005). According to the Silberstein et al. criteria (1994), 83.8% of female and 87% of male TM patients in Brazil overused medication (Krymchantowski and Moreira, 2001). Headache prophylaxis is given to reduce the number of headache days and consequently the amount of acute medications taken. However, few patients use prophylactic medications, and the levels are as low as 5% in Taiwan (Lu et al., 2001) and 6.6% in France (Lanteri-Minet et al., 2003). The highest use of prophylaxis was found in an audit in a UK specialist headache clinic, where 15% patients used prophylaxis at their initial visit (Dowson, 2003). At the clinic visit, 74% of patients were prescribed prophylaxis (Dowson, 2003).

2.9.4. Patient management behaviour- comparison of episodic and chronic headache

One study explored and compared the episodic (EH) and chronic (CH) headache patients' behaviour of analgesic drug taking (Ferrari et al., 1997). CH patients had a headache frequency of above 15 days per month. The study showed that the majority of patients (54%, 56.1% of EH and 23.8% CH) thought it was better to treat with OTC medications, 39.3% EH and 21.7% CH patients preferred prescription analgesic and 4.6% EH and 9.5% CH preferred not to take medication. In terms of actual
behaviours, 49\% (52\% EH and 44\% CH) of patients used OTCs, 43\% (40.9\% EH and 46.5\% CH) used prescription medication and 8\% (7.1\% EH and 9.5\% CH) reported not to use any medication. The study also examined the patients’ use of analgesic on working days and on days off. On working days, 13\% of patients reported to break off work, whereas 52\% continued to work after taking medication and 35\% continued to work without taking medication. On days off, 44\% of patients discontinued their activities; 38 \% took an analgesic and continued their activity and 18\% carried on regardless. The authors concluded that behaviour was significantly different on working days and on days off (p<0.0001), but they did not describe the direction of this statement. Furthermore, they compared the behaviours between the EH and CH in a table (Table 2-9 as given below), which showed that behaviours differed significantly between EH and CH patients on their days off (p<0.05), but again the authors did not describe the direction of this difference. Furthermore, the percentages given in the table for taking analgesics and carrying on working/activities on days off, do not match with the overall percentage given for the two groups.

Table 2-9: Patients’ behaviours when headaches started on working day and on a day off (Ferrari et al, 1997)

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Working day</th>
<th>Day off*</th>
</tr>
</thead>
<tbody>
<tr>
<td>went on working/activities without taking any drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>episodic headache (n=196)</td>
<td>38.8</td>
<td>16.3</td>
</tr>
<tr>
<td>chronic headache (n=84)</td>
<td>26.2</td>
<td>22.6</td>
</tr>
<tr>
<td>took analgesic and went on working/activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>episodic headache (n=196)</td>
<td>47.9</td>
<td>35.2</td>
</tr>
<tr>
<td>chronic headache (n=84)</td>
<td>60.7</td>
<td>4.52</td>
</tr>
<tr>
<td>interrupted work/activities</td>
<td>13.3</td>
<td>48.5</td>
</tr>
<tr>
<td></td>
<td>13.1</td>
<td>32.1</td>
</tr>
</tbody>
</table>

NB. Values given in percentages, * p<0.05
2.9.5. The use of social support for the management of headaches

The patients' use of social support for the management of their headaches has received little attention and no studies have directly investigated the patients' use of social support. Still, the importance of social support has been shown by a study of members of the Dutch Society of Headache Patients. Of the study participants who reported reduced impact of their migraines, 58% attributed their reduced impact to social support offered by the Society, 46% to family support and 28% to the support of their GP (Vos and Passchier, 2003).

An American study investigated the volume and nature of telephone calls over the period of one month in a specialist headache practice in the US (Loder and Geweke, 2002) and give an indication for the use of social support in the management of headache. A total of 165 calls were received (mean 3.17 calls per hour of clinic scheduled). The majority of calls (65%) were generated by 36% of callers. Of the patients who placed more than one call, 50% suffered from CDH, 53% had a personality disorder and 38% had both. Furthermore, not all the telephone calls were from the patients themselves, but as many as 27% of calls were placed by friends, family members, pharmacies, health professionals or insurance companies. The reasons for the calls included request for a refill (58%), report of new symptom or side effect (17%), general request for information (13%), request for treatment changes (5%) and discussion about the patient (5%).
2.10. **Initiatives to improve patients’ self-management in headache**

Chronic disease has become the principal medical problem and therefore the patients’ opinion has become increasingly important. Thus it is believed that the patient must become a partner, who contributes at almost every decision and action level (Holman and Lorig, 2000). The Department of Health in the UK considers the expert patient as a new approach to managing chronic disease in the 21st century (Department of Health, 2001). A new chronic disease paradigm implies that the health professional is the expert about the disease, whereas the patients are the experts about their own lives. Patients are empowered, which means that they accept responsibility to manage their own condition and are encouraged to solve their own problems with information, but not orders, from health professionals (Bodenheimer et al., 2002).

For the patient to be or to become an expert, patient self-management is inevitable. Self-management of chronic illness implies patients monitoring and managing symptoms, adhering to treatment regimens, keeping a healthy life-style and managing the impact of illness on daily functioning, emotions and social relationships (Schreurs et al., 2003). Good headache management requires the patients’ active participation in decisions regarding therapeutic interventions (Silberstein et al., 2000). Headaches mostly occur in the absence of health care professionals and therefore, the major responsibility for headache management lies with the patient.

To date, migraine is under-treated and migraine and CDH patients continue to suffer considerable headache-related disability. Effective treatments are available, but the
high levels of suffering suggest that patients do not benefit from these treatments, either because they do not receive/ or use the management strategies or they fail to use the strategies effectively. Patients with chronic disease may need help in integrating the required self-management behaviours into their lives (Schreurs et al., 2003).

The effect of headache education on quality of life and locus of control has been assessed on three different groups of migraine patients in the US (Allen et al., 2000). Group 1 (n=51) had participated in a 1-hour education session, Group 2 (n=13) were patients who had received individual headache education and Group 3 (n=15) were patients who reported not to have received any headache education. The findings showed that patients who had received headache education (either group or individual) had higher quality of life scores than patients who had not received headache education. These findings were clinically significant, but it is not known whether the findings were statistically significant. No statistically significant differences were found between locus of control between the 3 groups. The population was selected from a neurology department, which may not be a representative sample for migraine patients within the general population. Also the sample size was small and disproportionate.

One study assessed disease management (DM) for headache patients (n=264) attending a Headache Clinic in the US (Maizels et al., 2003). The patients included in the study suffered from migraine (n=76), TM with medication overuse (n=205), TM without medication overuse (n=38), CTTH (n=3), CDH (n=14), cluster headache (n=5) and miscellaneous, missing or unknown (n=23). The programme started with a group education session led by a registered nurse practitioner. Patients were educated
on migraine diagnosis, pathophysiology, triggers and treatments with emphasis on drug rebound headache. The group session was followed by a consultation with the nurse practitioner or a doctor. Where appropriate, patients were prescribed a triptan. Although the cost of triptans increased by 19%, headache-related consultations reduced by 32% and emergency department consultations reduced by 49%. The total cost saving from the programme (taking into account the increase in triptan cost) was $18,757 (£11,254). The main outcome measure of the study was cost and the number of visits to the headache clinic and emergency department. The only patient outcome measured was headache frequency and the only result given was for patients who initially had suffered more than 2 severe headaches per week (n=75). Headache frequency was reduced in 86% of those patients. The reduced cost and lower use of headache clinics and emergency department may be interpreted as showing that disease management programmes can be effective in headache management. However, the study did not have a control group and it is not possible to conclude whether any change in the direct cost of migraine was due to the programme. Also, with the study including headache patients with different diagnoses, it is not possible to conclude whether the outcomes differed between the headache types. Furthermore, there was no restriction on how many triptans were prescribed and it cannot be concluded whether the change in direct costs was due to increased use of triptans, the patient education or a combination of the two.

Another DM programme was designed in the US to improve patient self-management in migraine (Solomon et al., 2002). This programme aimed to

- increase the proportion of migraine patients who achieve symptom relief and return to normal activities within two hours after taking medication;
increase proportion of patients taking prophylactic medications (patients with more than 3 attacks per month)

increase the proportion of patients reporting knowledge on potential triggers

decrease utilisation of emergency departments

increase satisfaction with migraine treatment

increase satisfaction with health plan and/or provider.

The results of this study are not yet available, although early feedback from patients and health care providers have been positive.

2.11. Summary

To summarise, migraine and CDH are prevalent, chronic conditions that can severely impair the patients' quality of life. This review has described the diagnostic criteria for migraine and CDH and has outlined the wide range of management strategies, including pharmacological and non-pharmacological management strategies for the acute treatment and prophylaxis of migraine and CDH. Although effective management strategies are available, migraine and CDH patients continue to suffer. Thus, the review has examined the management of migraine and CDH in clinical practice, as well as the patients' management, including medication use and the use of non-pharmacological management. Overall, the review has revealed that more studies have focused on the management of migraine than CDH. In line with this, initiatives to improve headache care have focused on migraine. Initiatives include tools to assess headache-related disability to improve communication between
doctors and patients, the use of stratified care (vs. step-care) and the implementation of education or disease management programmes.

The review has also shown that the majority of studies examining the patients' use of headache management strategies have adopted quantitative designs and there is scope to investigate migraine and CDH management using qualitative research methods. Furthermore, no study has been identified that investigated the complete picture of migraine and CDH management. Qualitative methods are suitable to reveal the complex picture of the patients' management behaviours. These qualitative findings can be used to underpin and validate a quantitative study to make the qualitative findings applicable to a larger population and relevant to headache patients.
2.12. References


Chapter 2: Review of the Literature


Headache Classification Committee of the International Headache Society 1988, "Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain", Cephalalgia, vol. 8, 1-96


Chapter 2: Review of the Literature


Chapter 2: Review of the Literature


Chapter 2: Review of the Literature


Osterhaus, J. T., Townsend, R. J., Gandek, B., & Ware, J. E. J. 1994. "Measuring the functional status and well-being of patients with migraine headache". *Headache* 34, 337-343. (Abstract)

Pascual, J., Muñoz, R., & Leira, R. 2001, "An open preference study with sumatriptan 50 mg and zolmitriptan 2.5 mg in 100 migraine patients", *Cephalalgia*, vol. 21, pp. 680-684.


Chapter 2: Review of the Literature


Silberstein, S. D., Lipton, R. B., Goadsby, P. J., & Smith, R. T. 1999, *Headache in Primary Care* ISIS Medical Media Ltd..


Chapter 2: Review of the Literature


Chapter 2: Review of the Literature


Chapter 3: Research into Headache: the contribution of qualitative methods.

Chapter 3: Research into headache: The contribution of qualitative methods

3.1. Abstract

Concerned with understanding the world and perspective of those who are being researched, qualitative research aims to gain insight into new phenomena and to describe and explain complex realities and processes. Qualitative research is also useful to explain, interpret and validate quantitative findings and translate quantitative findings into clinical practice. Headache research has given little attention to qualitative methods and few qualitative studies have been published. This chapter aims to define qualitative methods, to compare it to quantitative research, and describe their contribution to health and particularly headache research.
Chapter 3: Research into headache: The contribution of qualitative methods

3.2. Introduction

Historically qualitative research has been used in anthropology and later in the social sciences. Initially, qualitative research struggled to find its place in health research. However, an increasing number of researchers want to better understand qualitative research and the claims made by qualitative researchers about their findings (Mays and Pope, 2000a). Researchers attempt to maximise knowledge by using both qualitative and quantitative approaches and to answer new research questions that cannot be answered by quantitative methods alone. Such a strategy is important for progress in health research and practice. Consequently, the divide between both approaches and the respective researchers is diminishing. Qualitative research is increasingly applied in various areas of health research (Pope and Mays, 2000) and published in medical and related journals (Mays and Pope, 2000a).

The wider use of qualitative methods in health research (Pope and Mays, 2000) has not yet been adopted in headache research. Experimental or quantitative designs prevail in headache research and few qualitative studies have been published. This chapter sets out to define qualitative research methods and to explore their contribution separately and in conjunction with quantitative methods in headache research.

3.3. Qualitative research

3.3.1. Compared to quantitative research

Belonging to a distinctively different paradigm, qualitative research is considered the antithesis of quantitative research. Quantitative research, based on a positivist
Chapter 3: Research into headache: The contribution of qualitative methods

paradigm, is experimental, deductive, numeric, and realist. Qualitative research, on the other hand based on an interpretive paradigm, is naturalistic, inductive, contextual, non-numerical, and constructionist (Richardson, 1994). The main strengths of quantitative research are its reliability and generalisability, whereas the strengths of qualitative methods are its validity and its potential to discover new areas, to identify patterns, to reveal and explain complexity and to develop, construct and test concepts/theories (Creswell, 1998; Pope and Mays, 1995). In qualitative research, the generation of hypothesis replaces the testing of hypothesis, explanation replaces measurement and understanding replaces generalisability (Jones, 1995). To outline their differences, the main features of qualitative and quantitative research are outlined in Table 3.1.

3.3.2. Definition of qualitative research

The main aim of the interpretive paradigm, which underlies qualitative research, is to understand the world of those who are being researched (participants), thus giving voice to those who are rarely heard (Soafer, 1999). To gain insight into the participants' world, qualitative research deals with the participants unique experiences of naturally occurring events (Miles and Huberman, 1994) and/or social/human problems (Creswell, 1998) and their interpretations of these experiences (Jones, 1995; Sarantakos, 1998). As a holistic process of enquiry, qualitative research seeks to understand the phenomenon under study as a complex system that is more than the sum of its parts (Patton, 1990).
### Table 3.1: Comparison of qualitative and quantitative research

<table>
<thead>
<tr>
<th></th>
<th>Qualitative research</th>
<th>Quantitative research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>Understanding</td>
<td>Quantification</td>
</tr>
<tr>
<td></td>
<td>Exploration</td>
<td>Measurement</td>
</tr>
<tr>
<td></td>
<td>Concept development</td>
<td>Hypotheses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verification</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>Taxonomy or classification</td>
<td>Statistical</td>
</tr>
<tr>
<td></td>
<td>Interpretive</td>
<td></td>
</tr>
<tr>
<td><strong>Approach/ reasoning</strong></td>
<td>Inductive</td>
<td>Deductive</td>
</tr>
<tr>
<td></td>
<td>Natural</td>
<td>Rational</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Artificial</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experimental</td>
</tr>
<tr>
<td><strong>Conditions/ setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rich, deep, real</td>
<td>Hard</td>
</tr>
<tr>
<td></td>
<td>Non-replicable</td>
<td>Replicable</td>
</tr>
<tr>
<td></td>
<td>Non-numerical</td>
<td>Numeric</td>
</tr>
<tr>
<td><strong>Data</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Flexible</td>
<td>Precise and thoroughly planned</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Structural</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Functionalist</td>
</tr>
<tr>
<td><strong>Generalizability</strong></td>
<td>Tentative explanation of one time and one place</td>
<td>Generalizable to other places and other times</td>
</tr>
<tr>
<td><strong>Methodologies</strong></td>
<td>Interviews</td>
<td>Experimental</td>
</tr>
<tr>
<td></td>
<td>Focus groups</td>
<td>Survey</td>
</tr>
<tr>
<td></td>
<td>Participant observation</td>
<td></td>
</tr>
<tr>
<td><strong>Perspective</strong></td>
<td>Insider</td>
<td>Outsider</td>
</tr>
<tr>
<td></td>
<td>Point of view of those who are being researched</td>
<td>Point of view of researcher</td>
</tr>
<tr>
<td><strong>Philosophical basis</strong></td>
<td>Naturalistic, interpretive paradigm</td>
<td>Positivism</td>
</tr>
<tr>
<td><strong>Research questions</strong></td>
<td>What is X?</td>
<td>How big is X?</td>
</tr>
<tr>
<td></td>
<td>How does X vary in different circumstances and why?</td>
<td>How many Xs are there?</td>
</tr>
<tr>
<td></td>
<td>What is the purpose of X?</td>
<td>How often does X occur?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How does X vary in certain circumstances?</td>
</tr>
<tr>
<td><strong>Researcher</strong></td>
<td>Active</td>
<td>Passive</td>
</tr>
<tr>
<td></td>
<td>Involved</td>
<td>Distant</td>
</tr>
<tr>
<td><strong>Sampling method</strong></td>
<td>Purposive</td>
<td>Random</td>
</tr>
<tr>
<td></td>
<td>Theoretical</td>
<td>Statistical</td>
</tr>
<tr>
<td><strong>Study population</strong></td>
<td>Few</td>
<td>Many</td>
</tr>
</tbody>
</table>
Chapter 3: Research into headache: The contribution of qualitative methods

Methods and methodologies

Qualitative research comprises different methodologies that share features such as open research question(s); a flexible, yet rigorous design; a small number of participants; purposive or theoretical sampling; no statistical analysis and the researcher as instrument of data collection, analysis and interpretation. Qualitative research often adopts a ‘multi-method’ approach that reflects an attempt to secure an in-depth understanding of the phenomenon under study (Denzin and Lincoln, 2001b). It involves the studied use and collection of a variety of empirical materials such as case study, personal experience (Denzin and Lincoln, 1994), participant observation (Atkinson and Hammersley, 1994), individual (Kvale, 1996; Britten, 1995) or group interviews (Kitzinger, 1995; Morgan, 1997; Kitzinger, 2000). Methodologies include grounded theory, phenomenology, ethnography and hermeneutics. These methodologies are not the subject of this review and have been described by Denzin and Lincoln (2001a).

3.3.3. The strengths and weaknesses of qualitative research

The strengths and weaknesses of qualitative research both relate to the study the participants as individuals and the participants’ experiences and interpretations (Sarantakos, 1998). The strengths include researching people in their natural settings and achieving deeper understanding of the participants’ world. The research process is humanised by raising the role of the participants and by considering their perspectives. It allows greater flexibility, presents a more realistic view of the world and accesses, reveals information, views, perceptions and attitudes that cannot be obtained by quantitative methods.
Qualitative research has been criticised for many reasons and suffers foremost from the 'stigma of the small n'. However, this feature is irrelevant to the strength of the approach in expert hands (Mays and Pope, 2000b). As the researcher is the main instrument of data collection, analysis and interpretation, the outcome and quality of the research depend greatly on the skills of the researcher. The qualitative researcher needs knowledge about the relevant literature of the area of inquiry and the methodology; a self-disciplined and informed approach to data collection and analysis and considerable degree of judgement, interactive and interpretive skills (Pope et al., 2000; Britten et al., 1995) for the cumbersome and difficult data analysis. To strengthen the interpretations of the data and to reduce bias from preconceptions, multiple researchers, including independent researchers, are involved in the analysis to verify or triangulate the findings.

Qualitative research also remains criticised for its subjectivity and lack of reliability, randomisation and generalisability (Pope and Mays, 2000). However, qualitative research does not seek to be or to make claims to being objective, reliable, randomised and generalisable (Schwandt, 1997; Mays and Pope, 2000b) If research only focused on what can be quantified reliably, many researchers may never discover the strengths of qualitative research (Soafer, 1999). All research is interpretive and is guided by a set of beliefs and feelings about the world and how it should be understood and studied (Denzin and Lincoln, 2001b). Each interpretive paradigm makes particular demands on the research, including, the questions asked and the interpretations the researcher brings to them. Quantitative research may ignore factors that are significant in explaining important realities, complexities and phenomena in natural settings. Benefits gained by the rich and valid information of
Chapter 3: Research into headache: The contribution of qualitative methods

qualitative research, which are not open or amenable by quantitative research (Pope and Mays, 2000) may be lost.

3.3.4. Quality in qualitative research

As in quantitative research, the basic strategy to ensure rigour in qualitative research is a systematic and self-conscious research design, data collection, interpretation and communication (Mays and Pope, 1995). Furthermore, the aim is to create an account of method and data, which can stand independently (i.e. another researcher could analyse the same data in the same way and come to essentially the same conclusions) and to produce a plausible and coherent explanation of the phenomenon under scrutiny (Mays and Pope, 1995). The criteria to assess quantitative research are reliability, validity, objectivity and generalisability. Some researchers believe that the same criteria should be used in qualitative methods, but with modified means of assessment to suit the distinctive aims of qualitative methods (Mays and Pope, 2000a). Other researchers take the view that, due to its different purpose, qualitative research needs a distinct set of criteria. First described by Guba and Lincoln (1989), these criteria, refer to, but are not the same as, the quantitative criteria (Figure 3.1). The criteria are dependability, confirmability, transferability and credibility.
Figure 3.1: Quality criteria in quantitative and qualitative research

Credibility

Qualitative

- Credibility
- Dependability
- Confirmability
- Transferability

Quantitative

- Truth Value
- Consistency
- Neutrality
- Applicability

Validity

- Internal validity
- Reliability
- Objectivity
- Generalisability
Dependability refers to consistency (reliability). It focuses on the process of inquiry and the researchers’ responsibility for ensuring that the research process was consistent, logical, traceable and documented (Miles and Huberman, 1994; Schwandt, 1997), while adapting to the changes of the studied environment and to new inputs during the study (Hamberg et al., 1994). Dependability is enhanced through the clarity of questions, the researchers role and status, involvement of multiple researchers, collection of data across the full range of appropriate settings, sampling, use of appropriate recording equipment and keeping notes and memos.

Confirmability refers to neutrality (objectivity). Confirmability is concerned with establishing the fact that the data and interpretations of the data do not distort the reality they set out to describe and were not merely figments of the researchers’ imagination (Schwandt, 1997). It also ensures that the findings and concepts were founded in the data and not the result of poorly performed analysis and preconceived assumptions (Hamberg et al., 1994). Techniques to enhance credibility include the involvement of multiple researchers in the study, questioning findings and rethinking and critically reviewing the data.

Transferability refers to applicability (generalisability). Findings must be understandable to others and be regarded as reasonable (Hamberg et al., 1994). To achieve transferability, researchers must provide the readers with sufficient information on the study to make it possible for the readers to decide whether the findings are relevant to the situation and applicable to other situations and contexts (Hamberg et al., 1994; Miles and Huberman, 1994).

Credibility relates to truth value (validity) to establish whether truthful and credible findings and interpretations were produced. The researchers need to provide
assurances of the fit between the participants’ experiences and the researchers’ reconstruction and representation of these experiences (Schwandt, 1997). Credibility is highly dependent on the researchers’ skills during data collection and analysis (Hamberg et al., 1994). Considered a strength of qualitative research, credibility is ensured by triangulation and the inclusion of ‘deviant’ or ‘negative’ cases, in which the researchers’ interpretations and explanations seem weak or contradicted by the evidence (Mays and Pope, 1995). Triangulation is a means of checking the integrity of the inferences the researchers draw. The researcher looks for patterns of convergence to develop an overall interpretation (Mays and Pope, 2000b). Triangulation can involve the use of multiple data sources, multiple investigators, multiple theoretical perspectives, multiple methods or all of these (Schwandt, 1997).

3.4. Qualitative and quantitative methods in the research setting

Due to their particular attributes, some researchers consider the two methods as contradictory and fundamentally different, and rigid demarcations do not encourage movement between the two traditions (Pope and Mays, 1995). Qualitative and quantitative researchers operate within different sets of assumptions about the world and ways of learning about the world (Casebeer and Verhoef, 1997). Qualitative and quantitative researchers are often ignorant of each other’s work and argue that their particular approach is best (Sarantakos, 1998).

Other researchers see qualitative and quantitative methods as the extremes of the same continuum. They believe that every research project, although predominantly quantitative or qualitative, contains aspects of the other methods (Hammersley, 1992; Sarantakos, 1998). They believe that qualitative and quantitative methods are not mutually exclusive, but complementary (Richardson, 1994) and that the two methods
Chapter 3: Research into headache: The contribution of qualitative methods

can and should co-exist as potential tools of the research trade (Casebeer and Verhoef, 1997). Qualitative and quantitative methods can investigate a similar topic by addressing a different research question (Jones, 1995), collecting different types of data and producing different sorts of answers (Barbour, 1999). This view is increasingly accepted in health research (Barbour, 1999).

3.4.1. Choosing between qualitative and quantitative methods

Both qualitative and quantitative methodologies are good and right, depending on the circumstances and the research question under study (Sarantakos, 1998). The strengths and weaknesses of either method determine their suitability for a given research project. First, the choice of method depends on the research question(s). To answer questions such as ‘how many’, ‘how much’, ‘what size’ or numerically measurable associations between factors, a survey is appropriate (Miller and Crabtree, 1994). To answer questions such as ‘if _, then _’ or ‘is _ more effective than _’, an experimental style is appropriate (Miller and Crabtree, 1994). Questions that concern meanings, experience, patterns, relationships and values are best addressed by qualitative methods (Miller and Crabtree, 1994). For research questions that can be addressed by either design, the choice is based on the aims and objectives of the study, or a combined/ mixed qualitative and quantitative study can be used.

3.4.2. The contribution of qualitative research

Qualitative research can be used as “stand alone” approach or in combination with quantitative research. Mixed or combined designs help to maximise knowledge by providing different perspectives of the same problem and adding scope to a study
Qualitative research, if used as a prerequisite to quantitative research, facilitates the development of the quantitative research (Greene et al., 1989) by identifying the 'correct' terminology for inclusion in a survey questionnaire or generating hypotheses. This is useful to explore areas that have received little previous attention (Pope and Mays, 1995) and may help to ensure the validity of the quantitative data (Pope and Mays, 2000). When quantitative work precedes qualitative research, quantitative findings can be validated, explained and reinterpreted with help of qualitative research (Miles and Huberman, 1994).

When used together, qualitative research helps to interpret quantitative findings with more insight and quantitative research allows testing of hypotheses raised by qualitative research, thus leading to conclusions and outcomes that would have been different without the qualitative input (Wenger, 1999). Furthermore, combining randomised controlled trials (RCTs) with qualitative and quantitative studies of process are believed to be the best means of assessing whether interventions work and why, thus increasing the generalisability of findings from RCTs (Weaver et al., 1996). Approaches to combine RCTs with quantitative and qualitative observational studies will generate information to help to successfully implement effective interventions in natural settings and to further refine the interventions (Weaver et al., 1996).
3.5. Qualitative methods in health research

Qualitative research enriches health research (Huston and Rowan, 1998) by enabling access to areas not amenable by quantitative research. In health research, the gap between qualitative and quantitative approaches has been closing and it is increasingly believed that a creative dialogue between the two methods is of considerable mutual benefit (Jones, 1995). There is a slow but important movement towards a more collaborative use of qualitative and quantitative methods in health research, particularly for the study of chronic disease (Casebeer and Verhoef, 1997).

Original qualitative research is more widely used and published in the medical and health related fields both in specialised qualitative journals (e.g. Qualitative Health Research) and medical or health-related journals such as the British Medical Journal (BMJ), and Social Science and Medicine. Some journals now have reviewers trained in qualitative research (Miller and Crabtree, 1994). Qualitative research, alongside quantitative methods, for health care and health services research, is introduced, reviewed and advocated by publications in leading medical journals such as the BMJ and the Lancet and by funding agencies (such as the Medical Research Council in the UK (MRC Topic Review, 1997).

On the whole, people are more complex than the subjects in the natural sciences and health care deals with people as either patients or health professionals. Numerous research areas dealing with the patients’ or the health professionals’ perspectives are suitable for qualitative investigation. They include: lay and professional health beliefs; lay diagnosis; consultation and decision making processes; doctor-patient relationship; interactions among patients, families and clinicians; coping with illness; self-management; care-seeking, illness and compliance behaviour; patients’
perceptions, experiences, expectations, preferences, satisfaction and beliefs; the personal meaning of events and health care delivery (Britten et al., 1995; Pope and Mays, 1995; Faltermayer, 1997; Soafer, 1999).

Qualitative research methods have been used successfully and have added to the body of knowledge in many areas of health care research. Studies have been carried out in pain (Borkan et al., 1995; Johanssen et al., 1999), epilepsy (Ridsdale et al., 1999), asthma (Clark and Nothwehr, 1997) and cancer (Sheik and Ogden, 1998); in health care settings such as general practice (Chew-Graham and May, 1999; Britten et al., 2000) or in management approaches (Armstrong et al., 1996; Britten et al., 2000) from both the patients' (Peters et al., 1998) and the health professionals' perspectives (Armstrong et al., 1996). Carried out in different settings and investigating different population groups, these studies shared one common feature. Their research aims and objectives were to describe, explore and assess the relationships of the findings of the studied topic.

### 3.6. Qualitative methods in headache research

Headache is one of many specialised areas of health research. Current headache research interests include topics that are suitable for and would benefit from qualitative methods. Headache research has yet to discover the benefits of qualitative research. To date, quantitative and experimental methods prevail and few qualitative studies have been published. However, headache research would benefit from qualitative input by improving understanding of clinical practice and the physicians' and the patients' perspectives.
3.6.1. Headache in clinical practice and qualitative research

In clinical practice, there is a discrepancy between treatment availability and delivery for migraine (Lipton et al., 1994). Consisting of a body of ‘rules’ represented by the ‘evidence-based approaches’, clinical practice is founded on the randomised controlled trials (RCTs) and a set of improvisational skills to adapt the RCTs findings to individual cases (Dingwall et al., 1998). Physicians may encounter difficulties when applying information from RCTs to individuals (Miller and Crabtree, 1994), since traditional scientific knowledge frequently does not fit the patients’ uniqueness (Meyer, 2000). The heterogenous nature of migraine means that translating research findings into clinical practice is a challenging task, particularly for clinicians with limited headache experience. The discrepancy between treatment availability and delivery in migraine suggests that quantitative methods do not provide the whole picture of the complex behaviours, attitudes, preferences and interactions that are part of the consultation process and clinical decision-making. Migraine management is highly individual and the role of qualitative research becomes more important, the more individualized an intervention becomes (Dingwall et al., 1998). Therefore, qualitative methods could help to provide a more holistic picture and findings that are more meaningful to practitioners. This may facilitate translating findings from clinical trials into clinical practice, in all areas of health care including primary and specialised headache care.

Furthermore, qualitative research may be particularly important for the health professionals who do not specialise in headache. The majority of headache sufferers who seek help from a physician consult their General Practitioner (GP) about their headache (Laughey et al., 1999). However, GPs only see an average of 27 migraine
patients a year (MacGregor, 1999) for consultations lasting an average of eight minutes. Unlike headache specialists GPs have little opportunity to develop an intuitive understanding of headache disorders through clinical experience. Hence, there is a need to provide health care professionals with information about a disorder that, although it can cause severe disability (Clarke et al., 1996; Stewart and Lipton, 1993; Lipton et al., 2001) is still receiving little attention in health research and clinical practice. Qualitative research, particularly studies focusing on the patients’ perspective, may help to increase GPs understanding about headache disorders, the meaning, experience and impact of headache.

3.6.2. The headache patient and qualitative research

Few studies have been conducted on the patients’ perspective on headache. Patients’ characteristics (Lipton et al., 1998) influencing consultation behaviour, patients’ preferences (Lipton and Stewart, 1999; Salonen et al., 1999; Pascual et al., 2001) have been studied. Previous research has mainly focused on clinical practice, consultation behaviours and pharmacological treatment. Furthermore, the studies examined issues predetermined by the researchers and listed, rather than explained, behaviours and predictive factors. Qualitative research, by exploring behaviours, can help explain complex issues such as factors influencing behaviours and decisions.

Furthermore, qualitative research may help to reveal the benefits of a ‘hidden health care system’, based on self-management strategies. Migraineurs often have a fatalistic attitude and learn to cope with their condition without seeking medical care (Michel et al., 1996). They rely on self-management strategies, such as avoiding triggers (Scharff et al., 1995) and self-medication with Over The Counter drugs rather than using prescription medication (Celentano et al., 1992; Edmeads et al.,
Chapter 3: Research into headache: The contribution of qualitative methods

1993; Forward et al., 1998). Of headache patients who are prescribed medication, 52% have been shown not be compliant with their medication (Packard and O'Connell, 1986). A qualitative study revealed factors involved in patients' decision-making and compliance with their treatment (Ivers et al., 2000). Qualitative research is useful to understand and explain health seeking behaviours (Sheik and Ogden, 1998) and variations in adherence to treatment (Britten et al., 1995). Improved insight into the migraineurs' behaviours and perceptions may help identify patients as competent persons to cope with their illness, at least partly independent from physicians. This may lead to more patient-centred health practice (Faltermaier, 1997), which is the preferred approach of primary care patients (Little et al., 2001). This may be of particular importance in view of improving the educational and behavioural interventions that headache management guidelines (Diener et al., 2000) advocate in addition to pharmacological therapy.

With the recent development of patient preference studies (Torgerson et al., 1996), patient preference in headache therapy needs greater understanding. Migraine is more than a headache and the current endpoints of clinical trials need further development, as for example measuring headache relief as an endpoint alone does not capture the complete picture about the new treatments (Goadsby, 2000). By letting the headache patients speak openly and freely about their preferences in qualitative studies, greater understanding of the patients' opinions about the benefits and disadvantages of headache therapy, their expectations, their treatment preferences and their preferred outcome can be achieved. Thus giving voice to the patients, in a flexible, yet rigorous research process, would provide a more realistic assessment of headache treatments and may help to make soft and subjective endpoints, such as impact, more acceptable outcome measures.
Chapter 3: Research into headache: The contribution of qualitative methods

Conclusion

Qualitative research is concerned with the understanding of social or human problems in their natural settings. It has a strong potential for discovery of new areas, to reveal complexity, to identify patterns and processes, to develop theories and to move towards explanation. Qualitative research can complement and validate quantitative research. Health researchers increasingly recognise the strengths of qualitative research. Consequently, qualitative studies are increasingly being carried out in health research to answer research questions that cannot be answered by traditional quantitative methods. The knowledge gained by qualitative methods in health research justifies the integration of qualitative research into specialised areas of health research including headache. In headache research, areas such as improving the physicians understanding, translating quantitative findings into everyday clinical practice, gaining insight into the patients’ perspectives and behaviours may particularly benefit from a qualitative input.
3.7. References


Chapter 3: Research into headache: The contribution of qualitative methods

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Year</th>
<th>Pages</th>
<th>Journal</th>
<th>Volume, Issue, Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>California</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hamberg, K., Johansson, E., Lindgren, G., &amp; Westman, G.</td>
<td>Scientific rigour in qualitative research: Examples from a study of women's health in family practice</td>
<td>1994</td>
<td>176-181</td>
<td>Family Practice</td>
<td>11, pp. 176-181</td>
</tr>
<tr>
<td>Huston, P. &amp; Rowan, M.</td>
<td>Qualitative studies. Their role in medical research</td>
<td>1998</td>
<td>2453-2458</td>
<td>Canadian Family Physician</td>
<td>44, pp. 2453-2458</td>
</tr>
<tr>
<td>Jones, R.</td>
<td>Why do qualitative research?</td>
<td>1995</td>
<td>2</td>
<td>British Medical Journal</td>
<td>311, p. 2</td>
</tr>
<tr>
<td>Kitzinger, J.</td>
<td>Introducing focus groups</td>
<td>1995</td>
<td>299-302</td>
<td>British Medical Journal</td>
<td>311, pp. 299-302</td>
</tr>
<tr>
<td>Kvale, S.</td>
<td>Interviews</td>
<td>1996</td>
<td></td>
<td>Sage Publications</td>
<td></td>
</tr>
</tbody>
</table>


Chapter 3: Research into headache: The contribution of qualitative methods


Patton, M. Q. 1990, Qualitative Evaluation and Research Methods Sage Publications, USA.


Chapter 3: Research into headache: The contribution of qualitative methods


Chapter 4: Patients' decision-making for migraine and chronic daily headache management.

4.1. Abstract

Objective: To gain insight into the patients’ decision-making for migraine and chronic daily headache management.

Methods: Patients were recruited by theoretical sampling in Surrey (UK). Semi-structured and tape-recorded interviews (n=13) were conducted, transcribed verbatim, coded and analysed according to the grounded theory methodology.

Results: Thirteen patients (8 migraine and 5 chronic daily headache) described their management. All patients employed multiple behaviours to manage their headaches. From the patients’ descriptions emerged their decision-making. Based on experience, perceptions and new information, the decision-making process involved four stages: headache severity, evaluation, decisions and behaviours. Although the participants were passive with regards to certain management strategies, overall they were actively involved in treating and preventing their headaches. Furthermore, they were active decision-makers in choosing appropriate management.

Conclusions: Migraine and chronic daily headache patients are actively involved in managing their headaches. They are key decision-makers and should not be overlooked as a resource for effective management.
4.2. Introduction

Affecting about 12% of the population (Breslau and Rasmussen, 2001), migraine is a chronic disease with acute episodes and needs to be managed over a prolonged period of time. To date, migraine is under-diagnosed and under-treated (Lipton et al., 1992; Lipton et al., 2000a). Initiatives taken to improve management in clinical practice have mainly focused on facilitating the physicians’ role in the management of migraine by providing guidelines (Dowson et al., 2000; US Headache Consortium, 2000), disability assessment tools (Lipton and Silberstein, 2001) and stratified care (Lipton et al., 2000b). The low consultation rates and the under-use of prescription medication, suggest that migraineurs learn to cope and live with their disease, rather than actively seek effective treatment (Michel et al., 1996). Consequently the burden of migraine remains great, and most migraineurs suffer at least some disability and have a reduced quality of life. However, with the wide range of management strategies available, it is possible to improve headache management and ease the suffering of many migraineurs.

Since “headache control is best when patients play an active role in their treatment” (p S46) (Silberstein et al., 2000), the patients’ involvement in the treatment of their disease is essential. Selecting a suitable and effective therapy can be a complex task for both the physician and the patient. Recent publications (Silberstein et al., 2000) and headache management guidelines (Pryse-Philipps et al., 1997a; Pryse-Philipps et al., 1997b; Dowson et al., 2000; US Headache Consortium, 2000) predominantly educate the physician on selecting appropriate drug therapy for individual migraineurs. The “Migraine in Primary Care Advisors” (MIPCA) guidelines (Dowson et al., 2000) additionally educate practice nurses and pharmacists about
migraine management, to move towards patient centred care. However, since the majority of migraineurs do not consult their physician about their condition (Edmeads et al., 1993; Lipton et al., 1999), they do not benefit from the physician’s expertise and from prescription medication. Furthermore, as attacks occur generally in the absence of the physician, patients, even those who do consult, need, and maybe even prefer, to make their own choices for managing their migraines.

Few studies have addressed the patients’ perspective in the management of headache. Studies to date focus on what migraine patients want from medical consultations (Packard, 1979) and their satisfaction (Pascual et al., 2001) and preferences for acute drug therapy to compare medication (Salonen et al., 1999) or different doses of the same medication (Salonen et al., 1999). These studies shed some light on the patient perspective, but by remaining focused on physicians’ consultations and acute medications, they fail to recognise other management strategies that the patients may choose to adopt, as well as the factors that influence the patients’ decision-making.

Furthermore, the issues investigated in these studies were determined by the researchers. Little opportunity has been given to the patients to speak openly and unrestrictedly about the factors that influence their decisions for migraine and chronic daily headache (CDH) management. Qualitative research provides the opportunity to address these limitations. Qualitative research has been applied in non-headache research to explore similar research questions, for example in asthma management (Clark and Nothwehr, 1997). Concerned with understanding the perspectives, interpretations and meanings of the world of those who are being researched (Jones, 1995; Sarantakos, 1998), qualitative research reveals new phenomena and complexity by giving voice to those whose views are rarely heard (Soafer, 1999). The data presented in this article are part of a study, which aimed at
gaining insight into the patients’ perspective and into the factors influencing migraine and CDH management. This chapter sets out to describe the factors involved in the patients’ decision-making.

4.3. Methods

4.3.1. Grounded theory

First described by Glaser and Strauss (1967), grounded theory is a specific, highly developed and rigorous set of procedures for generating theory through comparative analysis. The theory emerges out of and is created through and grounded on empirical data (Sarantakos, 1998). Grounded theory is mostly concerned with sampling and data analysis. There is no specified method of data collection, although interviews are commonly used. The steps involved in grounded theory include theoretical sampling, data collection and analysis through coding, writing notes and memos about key concepts and their relationships until theoretical saturation. The steps are closely interrelated and may be employed simultaneously.

Theoretical sampling is non-probability sampling based on seeking participants who have the most experience of the topic of interest (Cutliffe, 2000). Recruitment of participants is driven by the emerging theory. Analysis reveals gaps in the data and theories, and the researchers need to collect more data to fill these conceptual gaps (Charmaz, 2000). This is achieved by recruiting participants who add to the fullness of the concepts. Therefore, a grounded theory study is best conducted if each participant is only selected after the data from the previous participant has been analysed. Sampling continues until each concept is saturated.
Analysis begins early and data is analysed as it is collected. Analysis involves generating conceptual categories by comparing similar and different facts from the raw data (for example interview transcripts). Coding starts the chain of theory development. Data are studied to create codes or categories of data, which are grouped to gain a new perspective on the data and to collect further data (Charmaz, 2000). Once initial categories have been established, additional data are collected to further compare concepts with more empirical indicators and with each other to sharpen the definition of the concepts and to define their properties (Schwandt, 1997). Theories are formed from proposing plausible relationships among sets of concepts (Schwandt, 1999). The evidence from which the categories and concepts emerge is used to illustrate the concepts (Glaser and Strauss, 1967). Comparisons continue until theoretical saturation, i.e. additional data do not contribute anything new to the concepts (Schwandt, 1999).

4.3.2. Recruitment, Data Collection and Analysis

Ethical approval was obtained from the University of Surrey Ethics Committee (Appendix 2). Recruitment, data collection and analysis were carried out simultaneously by the researcher (unless stated otherwise), in accordance with the grounded theory methodology. This allowed for theoretical sampling, revision of the interview guide, to help with data interpretation and to identify emerging themes and data and theoretical saturation.

4.3.2.1. Recruitment

Based on theoretical sampling, a convenience sample, consisting of 15 adults, was recruited in Surrey (UK). The participants, aged 18-65 years, were suffering from migraine according to the International Headache Society (IHS) criteria (Headache
Chapter 4: Patients’ decision-making for migraine and chronic daily headache management

Classification Committee of the International Headache Society, 1988). Patients with co-existing headaches or patients who had developed CDH were not excluded. For the purpose of this study, CDH was defined as headaches occurring at a frequency above 15 days per month. Initially participants were recruited through personal contacts (the researcher and MM). Since this mainly led to recruitment of migraineurs within the University, posters (Appendix 3) were put up in 2 local supermarkets to broaden the background of the participants. Finally, letters were sent to 20 members of the Migraine Action Association to complete the sample. A total of 39 patients had been contacted and 15 were recruited consecutively. The selection of participants was based on the findings from previous interviews. Potential participants were given a letter to introduce the study (Appendix 4) and an information sheet to explain the procedure of the study (Appendix 5). The patients, who were not recruited, did not suffer from IHS migraine, could not be interviewed during the time of the study or could not contribute to the emerging theory.

The participants were recruited to reflect a range of characteristics (dissimilar cases). The aim was to include 1 male to every 3 female sufferers (to reflect migraine prevalence), a variety of socio-demographics and one participant per age group, per disability group and per consultation group. Socio-demographic factors were determined by the participants’ marital and employment status, type of employment and/ or level of education. There were 4 age groups: 18-29, 30-39, 40-49 and 50-65. Consultation status was determined according to Lipton and Stewart’s criteria (Lipton and Stewart, 1999). Patients who had never consulted a physician about migraine were classed as ‘never consulter’. Patients who had consulted within the last year were classed as ‘current consulter’ and those who had not consulted for more than one year were classed as ‘lapsed consulter’. Disability assessment (by
Chapter 4: Patients' decision-making for migraine and chronic daily headache management

MIDAS questionnaire) was used to include patients with varying levels of headache severity, which was reflected in their current headache status of migraine or CDH.

4.3.2.2. Data Collection

Interviews were semi-structured, individual and tape-recorded. A flexible interview guide (Appendix 6) was devised based on recent migraine literature to comprise opening and more specific follow-on or clarifying questions and prompts. Opening question were aimed to be non-leading (Table 4.1), whereas follow-on questions tended to be more leading. Initially the interviews focused on migraine experience, physician consultations and treatments for migraine. However, with the emerging theory, and as part of the verification procedure, the interview guide was further developed to include previously raised issues and emerging concepts (Appendix 7).

Additional questions focused on patients' preferences, choices and decisions and a more holistic approach to management (i.e. beyond physicians' consultations and pharmacological treatments).

Table 4.1: Opening interview questions

1. How would you describe your migraines/ headaches?
2. How do your migraine/ headaches affect your everyday life?
3. How do you treat your migraines/ headaches?
4. What are the reasons for using this treatment?
5. How satisfied are you with your treatment?
6. What do you expect from migraine/headache treatment?
7. Who gives you advice about your migraines/ headaches (who do you consult)?
8. Tell me more about talking to your GP about your migraine / headaches.
9. What are the reasons for consulting/ not consulting your GP?
10. How satisfied are you with your migraine/ headache consultations?
11. Who/ what else do you think may be able to help with your migraine/ headaches?
Chapter 4: Patients' decision-making for migraine and chronic daily headache management

Interviews were arranged to the participants' convenience, at their home, workplace or at the University of Surrey. One participant withdrew before the interview and 14 migraineurs, who all signed the consent form (Appendix 8), were interviewed once. Interviews lasted up to 2 hours with recording time averaging 1 hour (range 50-90 minutes). The first interview served as a pilot interview and was not included in the analysis. HAS and VV read interviews to assess interview technique and content. Interviewing finished with data saturation. Interviews were transcribed verbatim. An example of a transcript is included in Appendix 9. Participants were offered a copy of their interview transcript.

4.3.2.3. Analysis

Interviews were prepared for analysis and coded using QSR NUD*IST5 (N5), a qualitative software package. The interview transcripts were imported as text files into N5 to be coded. In N5, data are coded by units of text (either paragraphs, lines or sentences). In this study, the raw data were coded sentence by sentence. The aim of N5 is to code and re-arrange data according to the emerging codes and to build a hierarchical taxonomy within the software, while keeping memos with the raw data and the emerging codes.

To reduce bias of the coding scheme and emerging taxonomy and concepts, all authors, as well as an independent researcher, were involved in different stages of the analysis. A guide (Appendix 10) was devised (by the researcher and HAS) to standardise the coding procedure for triangulation. One by one, the first 5 interviews were summarised (by the researcher, HAS, VV and an independent researcher). Then the interviews were coded sentence by sentence to give an initial coding scheme (the researcher, VV and independent researcher). No notable differences were found
between the coding of different researchers. Codes were grouped into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and discussions between the researcher and her supervisors. The last 8 interviews, coded according to the same technique, were used to verify the coding scheme and refine the emerging taxonomy and concepts. First, a summary of the concepts and later detailed definitions, descriptions and interpretations of the main concepts were discussed by all authors.

4.3.3. Ensuring scientific rigour

Qualitative research stresses the participants’ personal interpretation of meaning and how such experiences construct their social reality (Vydelingum, 1998). The basic strategy to ensure rigour in qualitative research is a systematic and self-conscious research design, data collection, interpretation and communication (Mays and Pope, 1995). The aim of scientific rigour in qualitative research is to create an account of method and data, which can stand independently (i.e. another researcher could analyse the same data in the same way and come to essentially the same conclusions) and to produce a plausible and coherent explanation of the phenomenon under scrutiny (Mays and Pope, 1995). First described by (Guba and Lincoln, 1989), the criteria used to ensure scientific rigour in qualitative research are dependability, confirmability, transferability and credibility.

4.3.3.1. Dependability

Dependability refers to consistency (reliability). It focuses on the process of inquiry and the researchers’ responsibility for ensuring that the research process was consistent, logical, traceable and documented (Miles and Huberman, 1994) (Schwandt, 1997), while adapting to the changes of the studied environment and to
Chapter 4: Patients’ decision-making for migraine and chronic daily headache management

new inputs during the study (Hamberg et al., 1994). In this study, dependability was enhanced in several ways. First, the interview guide was developed through the collaboration of the researcher and her supervisors. One pilot interview was carried out to ensure the clarity, suitability and content of the interview guide. Based on the taxonomy and theory emerging from the analysis of the initial interviews, the interview guide was further developed in a dynamic fashion to include issues raised by the participants, as suggested by Glaser and Strauss (Glaser and Strauss, 1967) when following the grounded theory approach.

Secondly, dependability is ensured through the use of appropriate recording equipment and keeping notes and memos. In this study, all the interviews were tape recorded and transcribed verbatim to give a true account of the participants’ reports. Furthermore, the emerging themes, taxonomy and theory were clearly defined and documented in memos within QSR N5, the qualitative software package for data analysis and management, used in this study.

Thirdly, dependability was further achieved by using multiple researchers. In this study, the analysis of the data and the hierarchical grouping of the emerging themes were carried out by the researcher, HAS, VV and an independent researcher to verify the emerging themes and taxonomy.

Finally, dependability was also enhanced by a decision trail (Silverman, 1993) in the clear explanation of the processes involved in eliciting the categories and themes. This involved the development (by the researcher and HAS) of a coding guide (Appendix 10) that was used to standardise the coding procedure.
4.3.3.2. Confirmability

Confirmability refers to neutrality and is concerned with establishing the fact that the data and interpretations of the data do not distort the reality they set out to describe and were not merely figments of the researchers' imagination (Schwandt, 1997). It also ensures that the findings and concepts were founded in the data and not the result of poorly performed analysis and preconceived assumptions (Hamberg et al., 1994). In this study, techniques to enhance credibility included the triangulation of data interpretation, by involving multiple researchers in the data analysis and interpretation. As described above, several researchers, from different areas of expertise (including expertise about qualitative methods, pain, health care and headache research) contributed to the data analysis and interpretation.

Confirmability was also enhanced by a process, which involved the questioning of findings and the rethinking and critical reviewing of the data. The data were collected and analysed simultaneously, to allow comparing the findings from initial interviews with the findings from later interviews. Also, group meetings between the researcher and her supervisors were used to discuss, rethink and critically review the findings and interpretations.

4.3.3.3. Transferability

Transferability refers to applicability. Findings must be understandable to others and be regarded as reasonable (Hamberg et al., 1994) and is referred to as 'fittingness' by Guba and Lincoln (1989). To achieve transferability, researchers must provide the readers with sufficient information on the study to make it possible for the readers to decide whether the findings are relevant to the situation and applicable to other
Chapter 4: Patients’ decision-making for migraine and chronic daily headache management

situations and/or contexts (Hamberg et al., 1994; Miles and Huberman, 1994) or ‘fit into’ situations and experiences outside the study situation. In study, transferability was enhanced by tape-recording and transcribing the interviews. This allowed the use of verbatim quotes when reporting the data, to illustrate the themes and emerging taxonomy and theory. A test of this ‘fittingness’ was whether the audiences (migraine and CDH patients) view the findings as meaningful and relevant in terms of their own experiences. Moreover, most of the findings have been validated by other studies from the current literature. Transferability was further enhanced by the confirmation of the qualitative data through the survey.

4.3.3.4. Credibility

Credibility relates to truth value to establish whether truthful and credible findings and interpretations were produced. The researchers need to provide assurances of the fit between the participants’ experiences and the researchers’ reconstruction and representation of these experiences (Schwandt, 1997). To achieve credibility, verbatim quotes from the interviews portrayed the vivid and faithful interpretations of human experience of migraine and CDH sufferers in a way that could be recognised by other sufferers.

Furthermore, credibility is highly dependent on the researchers’ skills during data collection and analysis (Hamberg et al., 1994). The interview skills of the researcher were assessed by the more experienced researchers and a migraine patient in a pilot interview. The involvement of multiple researchers, with varying experience of using qualitative methods, helped to ensure credibility within this study. Furthermore, quotes from the interviews, which had been tape-recorded, were used when reporting the findings of this study to illustrate the decision trail of the researchers.
Credibility is ensured by triangulation (through multiple participants) and the inclusion of 'deviant' or 'negative' cases, in which the researchers' interpretations and explanations seem weak or contradicted by the evidence (Mays and Pope, 1995). Thus, the study recruited multiple and dissimilar cases, in terms of the participants' personal characteristics and their headache severity. The recruitment of participants was an ongoing process to allow triangulating findings from previous interviews, by raising previously discussed issues within the later interviews. Data collection continued until data saturation was reached, i.e. until no new issues were raised within the interviews.

4.4. Results

The descriptive codes that emerged from the interviews related to the interview questions. These codes were grouped into three main themes: headaches, consultations and management. These themes gave the base data of the participants to describe the patients' characteristics and the patients' subjective reality of headache management (consultations and strategies).

Furthermore, the patients explained their reasons for using or not using management strategies, by relying on and generalising from their subjective experiences, which they perceived as significant in their management decisions. The interpretative codes (Table 4.2) of the descriptive themes, revealed the patients' involvement in their headache management and the 4 stages of decision-making. Drawing on their experiences, the patients were the key decision-makers for the management of their headaches.
### Table 4.2: Interpretative codes and themes

<table>
<thead>
<tr>
<th>Headache severity</th>
<th>Symptoms</th>
<th>Evaluation</th>
<th>Decision</th>
<th>Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis (headache types)</td>
<td>Pain severity</td>
<td>Impact</td>
<td>Specific</td>
<td>Management strategies</td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td>Headache changes over time</td>
<td>Non-specific</td>
<td>Pharmacological</td>
</tr>
<tr>
<td></td>
<td>Duration</td>
<td>Awareness</td>
<td>Explicit</td>
<td>Acute</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Headache severity</td>
<td>Implicit</td>
<td>Prophylactic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experiences of management</td>
<td>Active</td>
<td>Self-help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Outcome and limitations of management</td>
<td>Passive</td>
<td>Social support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Management available (knowledge)</td>
<td></td>
<td>Alternative therapies</td>
</tr>
</tbody>
</table>

**Perceptions**

- Balancing options with perceptions
- Information gathering
- Perceptions

**Health professionals**

- Doctor
- Other health professionals

**Management available (knowledge)**

- Information gathering
- Perceptions

**Attitudes**

- Perceptions
- Expectations

**Beliefs**

- Information gathering
- Perceptions

**Expectations**

- Information gathering
- Perceptions

**Satisfaction**

- Information gathering
- Perceptions

**Preferences**

- Information gathering
- Perceptions
4.4.1. Patients' characteristics

All thirteen participants (9 women and 4 men, aged from 24 to 60) suffered from IHS migraine. Three patients also suffered from tension-type headache (TTH). Based on their headache frequency above 15 days per months, 6 patients were classed as CDH patients. These patients experienced higher frequency and lower severity headaches, as well as full migraine attacks. Of these 6 patients, one had been effectively treated and did not suffer from CDH at the time of the study. One participant was a 'never consultant' for migraine, 6 participants were 'lapsed consultants' and 6 participants were 'current consultants'. Current consultations were associated with the diagnosis of CDH. Four participants (1 lapsed and 3 current consultants) had consulted either a headache specialist or a neurologist. MIDAS scores ranged from 0 to 47. The individual patients' characteristics are described in Table 4.3.

### Table 4.3: The participants' characteristics

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Frequency</th>
<th>Pain severity</th>
<th>MIDAS score</th>
<th>Consultation status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>38</td>
<td>Female</td>
<td>Migraine, TTH</td>
<td>4</td>
<td>3</td>
<td>17</td>
<td>Never consultant</td>
</tr>
<tr>
<td>2</td>
<td>24</td>
<td>Male</td>
<td>CDH</td>
<td>24</td>
<td>9</td>
<td>47</td>
<td>Current consultant</td>
</tr>
<tr>
<td>3</td>
<td>58</td>
<td>Female</td>
<td>CDH</td>
<td>Most</td>
<td>5</td>
<td>21</td>
<td>Current consultant</td>
</tr>
<tr>
<td>4</td>
<td>52</td>
<td>Female</td>
<td>Migraine</td>
<td>3</td>
<td>---</td>
<td>5</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>5</td>
<td>55</td>
<td>Male</td>
<td>Migraine</td>
<td>&lt;1</td>
<td>5</td>
<td>3</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>6</td>
<td>38</td>
<td>Female</td>
<td>Migraine, TTH</td>
<td>3</td>
<td>6</td>
<td>5</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>7</td>
<td>28</td>
<td>Female</td>
<td>CDH</td>
<td>15</td>
<td>10</td>
<td>15</td>
<td>Current consultant</td>
</tr>
<tr>
<td>8</td>
<td>34</td>
<td>Male</td>
<td>Migraine</td>
<td>10</td>
<td>5</td>
<td>18</td>
<td>Current consultant</td>
</tr>
<tr>
<td>9</td>
<td>60</td>
<td>Female</td>
<td>Migraine</td>
<td>5</td>
<td>9</td>
<td>14</td>
<td>Current consultant</td>
</tr>
<tr>
<td>10</td>
<td>56</td>
<td>Female</td>
<td>Migraine, TTH</td>
<td>12</td>
<td>5</td>
<td>20</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>11</td>
<td>48</td>
<td>Female</td>
<td>Migraine, history of CDH</td>
<td>2</td>
<td>10</td>
<td>6</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>12</td>
<td>41</td>
<td>Male</td>
<td>CDH</td>
<td>45</td>
<td>2</td>
<td>0</td>
<td>Lapsed consultant</td>
</tr>
<tr>
<td>13</td>
<td>24</td>
<td>Female</td>
<td>CDH</td>
<td>16</td>
<td>3</td>
<td>17</td>
<td>Current consultant</td>
</tr>
</tbody>
</table>

NB. Frequency- days per month, Severity- 0 (no pain) – 10 (pain as bad as it can be)
4.4.2. Management strategies

All participants described a range of management strategies and self-help measures that they had used in the past or were still using at the time of the interview. All participants used several strategies at any one time. The combination of strategies used was individual to every patient. Management strategies included such as medication, consultations with health care professionals, trigger detection and avoidance and gathering information from family and friends, the media and specialised organisations. The participants described their adoption, maintenance and cessation of their personal management strategies over time.

4.4.3. The 4 stages of decision-making

Through the patients' descriptions of their management strategies emerged their decision-making to adopt, maintain or discontinue management behaviours. Four stages of decision-making, that were linked in a cyclical process (Figure 4.1), were identified. The 4 stages were: headache severity, evaluation, decision and behaviour. Decision-making was a complex, dynamic and continuous process that developed over time and operated on a justification and consequence system. Every decision, behaviour and change in migraine severity added to the experience and perceptions of the patients. In the figure (Figure 4.1), the shadows represent the experience, illustrating the influences of previous decision-making. These experiences, perceptions and newly gathered information influenced the outcome of their next decision, behaviour and headache severity.
Figure 4.1: The patients' process of decision-making for headache (migraine and CDH) management

- **Headache severity**
  - Diagnosis
  - Impact
  - Changes over time

- **Behaviour**
  - Management strategies (active vs. passive)

- **Evaluation**
  - Awareness
  - Assessment
  - Balancing options with opinions

- **Decision**
  - Specific
  - Non-specific

New Information
4.4.3.1. Headache Severity

*Headache severity*, an objective and factual stage, comprised the diagnosis (symptoms, pain severity, frequency and duration) of migraine, CDH and TTH, the progressive nature of migraine during attacks and over the years and impact of the headaches. Pt8 described the progressive nature of migraine:

"...I would say that the migraines got noticeably worse in the last five or six years..."

Pt7 outlined the impact of migraines on work:

"...I'll have the days off for the migraines and then I tend to be not at full capacity the day after..."

The onset of the headaches and their severity were the starting point of decision-making. Pt6 explains how the pain severity induces her to rely on medication:

"...the thing that really affects my working efficiency and just generally affects me, is the pain. Obviously I want to relieve the pain, so therefore I'm taking painkillers..."

However, *headache severity* was also an end-point as it served as an outcome measure to assess the efficacy of the management strategies. Pt13 explains how headache severity served as outcome measure:

"...try avoiding food, I gave up chocolate, cheese and red wine for three months... they made no difference, I still got headaches, even when I wasn't taking it and then when I re-introduced it..."

4.4.3.2. Evaluation

*Evaluation* was the most active, involved and complex stage of decision-making. It comprised 3 steps including awareness, assessment and balancing options with perceptions. Awareness was when the patients' stopped believing that their migraines
or headaches will not come back and they started thinking about how to deal with the problem.

The patients progressed to assess their headache severity, their experiences of headache management and the outcome and limitations of the previously employed strategies. Pt2 recognised the limitations of his own ideas for headache management and resorted to a GP consultation:

"...the initial ideas came from me, but there were some things, obviously without medical knowledge; I don’t have medical knowledge, so I thought the GP could certainly say “this is possibly a cause, you haven’t thought of this’...”.

The participants described options for pharmacological and non-pharmacological treatment. Knowledge about management strategies was acquired through the participants’ own and other people’s experiences and through information gathering. New management strategies were learnt by actively seeking and/or spontaneously receiving information and advice from other people (health professionals, family and friends), the media and specialised migraine organisations. The patients balanced treatment options with their individual perceptions to underpin their decisions. For example for Pt6, the severity of migraines did not justify prophylaxis:

"...although migraines are bad, I don’t know if I’d want to take medication every day...”.

Pt13 opted against acupuncture due to personal preference:

"...the GP did mention acupuncture, but I don’t believe in acupuncture, so I didn’t choose that...”.

Perceptions, included preferences, satisfaction, expectations, beliefs, and attitudes. They were influenced by the participants’ personality and their and other people’s
experiences of health care, particularly migraine management, and the health care
system. Based on her satisfaction with her GP generally, Pt6 chooses to consult:

"... the doctor I've got is very good and he's very understanding and he
does listen and discuss things with you. So I thought it would be
interesting to have his opinion on them [migraines], to see if there is
anything that he could suggest..."

Difficulties with evaluation, and the patients' subsequent decisions, arose with
misconceptions, when the management outcome was not clear or when there was
conflict between the patients' preferences and the management approach. Pt1
outlines how her beliefs about treatments influenced her consultation behaviour:

"... I didn't really think that there were particularly effective treatments.
And if I don't expect there to be anything for me... [consulting the GP] is
a waste of time..."

Other people influenced the participants' evaluations and sometimes convinced or
hindered the participants to take action. Pt12 was encouraged by his wife to try
various treatments:

"...A [wife] is now pushing me to have reflexology, which apparently
some people say is good for migraine... so I'm now considering that..."

As the central figure, the migraineurs felt that they knew best and the final decision
was theirs, as Pt13 explained:

"...[the GP] couldn't argue with me, because that was my opinion..."

4.4.3.3. Decision

Evaluation served as justification for the decisions these patients made for their
headache management. Pt7 assessed the type of headache and accordingly selected
treatment to achieve the best outcome:
“...you work out what you think it’s going to turn into and therefore taking the drugs that you will think will best suit it...”.

Decision was an active stage that described the patients’ choices for management. Decision, the outcome of evaluation, was often a compromise between their options and perceptions. Decisions were specific and non-specific. Specific decisions were those related to a specified management strategy, whereas non-specific decisions were general decisions to headache management. Non-specific decision were described as follows by Pt 2:

“...I want to move forward and try and deal with the problems...”;

A specific decision was outlined by Pt 13:

“... I told him [GP] that I was going to the chiropractor and that I didn’t want to take the drugs [beta-blockers]...”.

4.4.3.4. Behaviour

Following their decisions, the participants adopted, maintained or discontinued behaviours to manage their headaches acutely or prophylactically. Behaviour, which could be active or passive, outlined the participants’ past and current management strategies (trials and errors), as well as their individual management combinations. Pt 2 relied on the combination medication and lying down for acute treatment:

“...the only way I can deal with the pain is to obviously take medication, but really to commit myself to bed...”

Pt 7 talked about her past experience with alternative therapies:

“...I’ve tried Feverfew as well, I didn’t like the smell of those...and I have tried massaging smelly oils in my forehead, which didn’t really help...”.

Chapter 4: Patients’ decision-making for migraine and chronic daily headache management
Chapter 4: Patients’ decision-making for migraine and chronic daily headache management

Depending on the failure or success of a behaviour, a change occurred in the headache severity, thus making the theme of headache severity an outcome measure and also adding further to experience on which to base their subsequent decisions. Pt13 described how unsatisfactory headache relief motivated her to trying a variety of medications:

“...I went to the nurse and she gave me, I was taking Ibuprofen, but she gave me Co-codamol. And I was on maximum dose of that and it didn’t touch it. And then I went on maximum dose of Ibuprofen and Co-codamol together. That didn’t touch it. And then I was prescribed Diclofenac and that didn’t have any effect either. So after that I pretty much decided that if that couldn’t kick it, then I couldn’t do anything...”

4.5. Discussion

The main finding was that these patients were actively involved in managing their migraines or CDH, through both their decision-making or their behaviours. The patients were the central or key figure of migraine and CDH management and decision-making. Four stages of decision-making were identified: headache severity, evaluation, decision and behaviour. As illustrated by Figure 1, these 4 stages were linked in a cyclical process that developed over time through experience gained from previous decisions, behaviours and new information. Similar illustrations have been proposed for general decision-making (MacPhail-Wilcox and Bryant, 1988), the self-management of asthma (Clark and Nothwehr, 1997), and decision-making for taking sumatriptan (Ivers et al., 2000).

---

1 Patient defined headache severity including changes in headache frequency, duration, symptoms, and pain severity.
Ivers et al. (2000) described the decision-making process for taking sumatriptan based on symptom monitoring, evaluation outcome, treatment decision-making, health behaviour and final outcome. However, the sumatriptan decision-making model was limited to decisions about one drug for acute treatment for migraine. The results of this study add further to decision-making in headache management by bringing acute and preventive decision-making about different types of headache.

The findings of this study reveal the complexity and provide a more holistic picture of migraine management, which brings a new perspective on quantitative findings. Migraine patients have been described as being passive and as having a fatalistic attitude (Michel et al., 1996). This may be true if migraine management or health care behaviours are studied in isolation. However, in this study, all the participants were active in managing their migraines and CDH, despite not relying on all the available options as for example physicians’ consultations. The role of these participants went beyond playing an active role in their management. As the key decision-makers for headache management, the patients integrated their knowledge with their experiences and perceptions to make decisions and adopt behaviours that suited their individual expectations and preferences. Furthermore, self-management strategies, based on the patients’ experiences and preferences and input from other people, were found to play an important role in the patients’ perceptions of the management of high impact headaches.

Chronic disease has become the principal medical problem and it is thought that the patient must become a partner, who contributes at almost every decision and action level (Holman and Lorig, 2000). The doctor provides the general information and the patients provide individual information to achieve effective management (Holman...
and Lorig, 2000). Initiatives that have been taken to improve migraine care, such as disability assessment tools (Edmeads et al., 2001; Garber et al., 2001), stratified care (using information available at the initial consultation to choose treatment) (Lipton et al., 2000b) and headache management guidelines (Dowson et al., 2000) are aimed at physicians. Although an important step in improving migraine care, these initiatives may overlook the migraineur as an essential resource of migraine management. Patients want to be informed of their treatment options and they want to be involved in decisions when more than one alternative treatment exists (Michel et al., 1996). The active role the participants adopted in decision-making and behaviours in this study illustrates the extent to which migraine and CDH patients want to be involved in the management of their condition. The chronic features of migraine and particularly CDH, the patients’ desire of involvement and the fact that headache control is best when patients play an active role in their treatment (Silberstein et al., 2000) demand the patients’ input into headache management.

4.6. Conclusion

The study aimed to gain insight into the patients’ perspective of migraine and CDH management. The descriptive results showed the holistic picture of management. Due the qualitative methodology these findings cannot be generalised. However, they can be used to inform headache researchers and clinicians about the patients’ perspective of migraine and CDH management. Furthermore, these results can be used to generate future quantitative work, from which broader conclusions can be drawn.
Chapter 4: Patients' decision-making for migraine and chronic daily headache management

In addition to describing the holistic picture of the topic under study, qualitative research aims to understand, explain and reveal processes. This study showed how headache patients use their and other people's experiences to justify, explain and generalise their decisions and behaviours. Health care problems can only be addressed if the user's perspective is understood and if health care professionals and patients co-operate (Edwards and Staniszewska, 2000). By raising headache researchers' and clinicians' awareness of the patients' involvement in their own migraine and headache care, the results of this study can be used to educate and empower the patient and to make headache research and clinical practice more patient-centred and relevant to the headache patient.
4.7. References


Chapter 4: Patients’ decision-making for migraine and chronic daily headache management


Headache Classification Committee of the International Headache Society 1988, "Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain", *Cephalalgia*, vol. 8, pp. 1-96.


Chapter 4: Patients' decision-making for migraine and chronic daily headache management


Vydelingum, V. 1998, 'We treat them all the same'. *The experiences of nursing staff and of South Asia patients in a general hospital*, Ph.D. thesis, University of Southampton.
Chapter 5: The patients' perceptions of migraine and chronic daily headache: a qualitative study.

Based on: M. Peters; H. Huijer Abu-Saad; V. Vydelingum; A. Dowson; M. Murphy. 2003, “The patients’ perceptions of migraine and chronic daily headache. A qualitative study.” Submitted.
5.1. Abstract

Purpose: The purpose of this study was to gain insight into the management of migraine and chronic daily headache from the patients' perspective. This chapter outlines the patients' experiences, perceptions and their management of migraine and chronic daily headache.

Methods: Thirteen semi-structured interviews were carried out with patients suffering from IHS migraine. Five patients, due to their headache frequency of more than 15 headache days per month, were classed as CDH patients. The data were transcribed verbatim and analysed in accordance with the grounded theory methodology.

Main findings: Three main themes were identified: 1) headaches, 2) impact and 3) headaches in relation to health issues. The participants described their headaches, including their pain and symptoms, how they differentiated between their headaches and how their perceptions of their headaches influenced their management. They also described the impact of headaches on their lives, in terms of headache-related disability and put headaches into the wider picture of health in general.

Conclusion: The patients' perceptions of migraine and chronic daily headache were sometimes conflicting and influenced the patients' management behaviours. The qualitative methodology used in this study may help to inform doctors, other healthcare professionals and headache researchers about the patients' perspective and possibly develop future headache research, care and education.
5.2. Introduction

High-impact headaches such as migraine and Chronic Daily Headache (CDH) affect 12% (Breslau and Rasmussen, 2001) and 3.2-5% (Castillo et al., 1999; Lu et al., 2001) respectively of the general population. These headaches can cause disability and impair quality of life (QoL). Over 70% of migraine patients reported at least some disability, with about 30% of the migraineurs reporting severe disability (Stewart et al., 1994). QoL is significantly reduced in migraineurs when compared to healthy controls (Lipton et al., 1995). CDH has an even greater impact than migraine (Monzón and Láinez, 1998). QoL is more severely reduced in patients with CDH than in patients with episodic migraine (Meletiche et al., 2001).

Few studies have been published on the patients’ perceptions of migraine and even fewer data are available on the patients’ perceptions of CDH. Gaining better understanding of the patients’ beliefs and attitudes is important as beliefs and attitudes may have an influence on the patients’ consultation behaviour. Similarly to the study of patients’ management behaviours, the study of patients’ beliefs and attitudes has focused on clinical practice and medication and predominantly used survey designs. Of migraine patients who had never consulted, 17% believed that their doctor would not treat their migraine seriously enough, 76% said that they did not need a doctor’s opinion to treat their migraines, 52% reported that their headaches were not that bad and 50% said that they had a treatment option that worked (Dowson and Jagger, 1999). However, 42% of those with headaches in the US said that there was nothing the doctor could do, 41% said that seeing a doctor was too inconvenient and 32% said that seeing a doctor was too expensive (Lipton and Stewart, 1999). The lapsed consulters (65%) said they had not seen a doctor
Chapter 5: The patients’ perceptions of migraine and CDH

within the last year, because the prescribed treatment was working and 59% said that their headaches had improved. Conversely, 26% had lapsed because they thought there was nothing the doctor could do for their migraines, 20% said that their doctor did not help them and 15% said that their doctor was not interested in headache (Lipton and Stewart, 1999). Another study showed that reasons not to seek medical advice included statements like the following: “it’s only a headache” (28%), “OTC treatments work for me” (32%), “the doctor would not be able to do any more for me” (10%) or “previous visit to a doctor was unsatisfactory/ treatment did not work” (6%) (MacGregor et al., 2003). Sixty-five percent of migraine sufferers from the US, the UK, Germany, France and Italy believe that not enough is being done to help them (Brandes, 2002). A focus group study in the US found that migraine patients are interested in understanding their condition and in securing relevant information about migraines, as well as obtaining pain relief. Furthermore, the patients desired collaborative relationships and wanted a team approach to treatment that involved both patient and doctor (Cottrell et al., 2002).

These studies have predominantly been based on a survey (quantitative) design and little opportunity has been given to migraineurs or CDH patients to freely express their points of view. Qualitative research addresses these limitations by increasing understanding of the headache patients’ world. The data presented in this chapter are part of a study, which aimed at gaining insight into the patients’ perspective of migraine and CDH and their management. The aim of this chapter is to shed more light on patient’s perceptions and their experiences.
5.3. Methods

Recruitment, data collection and analysis were carried out simultaneously by the researcher (MP), unless stated otherwise, in accordance with the grounded theory methodology (Glaser and Strauss, 1967). Ethical approval was obtained from the University of Surrey Ethics Committee.

5.3.1. Sampling

A purposive sample of adult patients, who had suffered from migraine according to International Headache Society (IHS) criteria (Headache Classification Committee of the International Headache Society, 1988), were recruited in Surrey (UK) by theoretical sampling (Coyne, 1997). Participants were recruited through personal contacts (the researcher, MM), posters in 2 local supermarkets, and letters to 20 members of the Migraine Action Association. Thirty-nine patients had been in contact with the researcher to obtain a final sample of 15 patients, who all suffered from IHS migraine. Due to the high frequency of their headaches (frequency >15 days per month), 5 patients were classed as suffering from CDH. Dissimilar cases were recruited to reflect a range of patients’ characteristics based on the patients’ gender, socio-demographics, age, headache-related disability and consultation status. The patients’ characteristics are described in Table 4.3 (Chapter 4, page 131).

5.3.2. Data collection and analysis

Data were collected by semi-structured, individual and tape-recorded interviews (n=14). Based on recent migraine literature, a flexible interview guide was devised (initial interview questions are described in Table 4.1, Chapter 4, p.123). As part of
the verification procedure, the interview guide was further developed to include
previously raised issues and emerging concepts (Glaser and Strauss, 1967).

Interviews were arranged to the participants' convenience, at their home, work
place or the University of Surrey. Interviews lasted up to 2 hours with recording time
averaging 1 hour (range 50-90 minutes). The first interview served as a pilot
interview and was not included in the analysis. HAS and VV read interviews to
assess interview technique and content. Interviewing finished with data saturation.

Interviews were transcribed verbatim and prepared for analysis in QSR NUD*IST5,
a qualitative software package. All authors and an independent researcher were
involved in the analysis to reduce bias of the coding and the emerging taxonomy. A
coding guide devised by the researcher and HAS, was used to standardise coding for
triangulation. To begin analysis, the first 5 interviews were summarised (by the
researcher, HAS VV and an independent researcher). Secondly, the interviews were
coded sentence by sentence to give an initial coding scheme (the researcher, VV and
an independent researcher). No notable differences were found between the coding
of the different researchers. The third stage of analysis involved comparing similar
and different codes to group the codes into a hierarchical taxonomy to form concepts
and theories. These concepts and theories were based on theoretical memos and
discussions between the authors. The remaining 8 interviews were used to verify the
coding scheme and refine the emerging taxonomy and concepts. First, a summary of
the concepts and later detailed definitions, descriptions and interpretations of the
main concepts were discussed by the researcher and her supervisors.
5.4. Results

Three main themes were identified from the interviews: 1) headaches, 2) headache impact and 3) headache as a health issue. The theme entitled ‘headaches’ was further divided into ‘pain and other symptoms’, ‘differentiating between different types of headaches’ and ‘perceptions of headaches as barriers and facilitators to care’. The patients’ perceptions of headache are described in relation to these four themes. These perceptions were not static, but evolved over time, depending on the participants’ experiences of headache and treatment.

5.4.1. Headaches

This theme focused on the patients’ perceptions of their pain and other symptoms, their differentiation between different types of headaches and the influence of their perceptions on management. This theme illustrated the severity of the participants’ headaches and particularly migraines.

5.4.1.1. Pain and other symptoms

For most participants, pain was the dominant feature of their headaches. To help assess the severity of pain the participants explained their pain severity, their experience of the pain and how the pain developed over time (within an attack) and changed over the years (between attacks). Pain and migraines could be present upon waking up in the morning or could gradually build up during the day. Pt 10 frequently woke up with a migraine:

“...the first thing that I am aware of, it’s like somebody’s put an knife through my head. The pain is so intense that for several seconds I don’t ever open my eyes, in the hope that I’m just dreaming about it...”.
Chapter 5: The patients’ perceptions of migraine and CDH

Symptoms, other than pain, were also perceived as distressing and sometimes as more upsetting than the headache pain. Pt 12 described:

“...the thing that upsets me the most in a really bad one [migraine], I lose all coherency. I actually don’t know who I am or what anything is and just sounds and colours and brightness then really upset you...”

5.4.1.2. Differentiating between different types of headaches

The participants all suffered from IHS migraine, and 9 participants also had other headaches, such as daily or near-daily headaches (n=5) or tension-type headaches (n=3). The participants outlined the differences between those headaches. Knowing the difference between headache types was an important factor in the decision-making for treatment. Migraines were mostly associated with severe, throbbing pain, nausea and aura symptoms. Other headaches were described as not interfering with daily activities and as being treatable with simple painkillers, which migraines frequently were not. Pt 2 said that with a headache:

“...there is not a wide variety of symptoms as with the migraine. There seems to be less symptoms with the headache. It affects [me] less, so obviously the severity is less. And the way that the headache develops, I would say is different to the way the migraine develops...The migraine almost always begins at the back of my skull and works up and forward into my eyes. The headache...just materialises on the top of my head and stays there, it doesn’t really affect anything else. It can usually be dealt with in half an hour to three-quarters of an hour with painkillers...”

Most, but not all of the participants felt confident about differentiating between their headaches. Pt 13 was not sure about her diagnosis:

“...I’m not very good at necessarily differentiating between the migraine and the bad tension headaches... I always think ‘oh, no I don’t suffer from migraine’, but the doctor seemed to think that the way I was describing them that it was more migrainous. I guess I have never been a hundred percent certain of the differentiation between the two...”
5.4.1.3. Perceptions of headache as barriers and facilitators to management

The type of headache and particularly pain severity were often perceived as a cue for using pharmacological treatment, thus constituting a facilitator to care. When the pain and its severity were the type of pain and severity experienced during previous migraines, the participants took medication to stop the migraine from developing to its maximum severity. Pt 3 explained how she had learned to adapt her management behaviour based on her past experience of pain:

"...I can keep it quite moderate, if I get the tablets quick enough... I've learned to carry the tablets with me. If I know it's going to be a migraine and I'll take the tablets quickly. But I do get them really very bad..."

However, the participants' perceptions of their pain and other symptoms also sometimes constituted a barrier to management. The participants sometimes did not accept or doubted some of the characteristics of headaches, such as headaches recurring monthly or even near-daily, or headache severity. These participants expressed hope or optimism that the headaches would not return or resolve without active treatment (for example without relying on medication). Pt1, who has never consulted for her migraines, believed that her migraine may not recur:

"...I think 'oh, I haven't had a migraine for two weeks, maybe they won't come back', optimism..."

Pt13 described how her doubts about her headache severity influenced her consultation behaviour:

"...when I don't have any pain, I then start disbelieving whether it was really as bad as I thought it was... because I could just get on with life and have a couple of weeks and I think 'yeah, fine no problem'. And then it would hit me again, and I would think 'oh yeah, it really is that bad'... it was almost like I was disbelieving myself that I was ill or that it was a serious enough problem to look into it..."
Chapter 5: The patients’ perceptions of migraine and CDH

In contrast to the participants who were in denial about their headaches, some participants experienced worry and even fear. Worry occurred at the onset of the headaches and was related to a sudden onset, the lack of understanding of symptoms or the worry of a more sinister condition. Participants who were familiar with migraine symptoms, either through a family member or friend, rarely expressed worry. Pt7 outlined her fear:

“...my vision’s going, it’s scary and I don’t understand...”.

Similar to denial, worry influenced the participants’ management behaviour. Worried patients searched for reassurance by consulting other people, most often their general practitioner, for a diagnosis and explanation of the problem and treatment. Thus, whereas denial frequently induced passive behaviour, worry on the other hand induced active behaviour. Pt7 explained that she consulted the doctor because:

“...it was just reassuring, to find out if he could explain what I had, why it was doing it, sort of reassure me that other people had [it]. There are sort of ways in managing it, controlling it, and there [are] either preventatives or over the counters that you can take. Yeah, and mostly sort of reassurance I think, ‘cause it’s just so unknown, at the time it was unknown...”

5.4.2. Headache impact

The participants’ perceptions of impact illustrated suffering and put the magnitude of suffering into the context of the participants’ lives. Headache impact was mainly described in terms of disability, i.e. the participants’ inability to carry out their everyday tasks. All aspects of the participants’ lives had been affected by their headaches, including their work, family and social lives (leisure activities, holidays). Disability was personal to the patients, and referred to limitations to the participants’ everyday activities, such as work and family life, because of headaches. Pt 10 described:
“...last year I was to go to an open-air concert, it’s was Mozart, who is my favourite composer. I woke up that morning with migraine and I just couldn’t believe it. And I thought I’m going... if I have to crawl there on all fours. I did go and I sat listening to this music with my head pounding. I’d been terribly sick in the morning. But I just could not miss it, but in the interval, I admitted defeat and my sister drove me home...”

Headache-related disability went beyond the impact on the headache sufferers. The participants explained that their headaches also had an impact on other people, including their families, friends and work colleagues. These people have to help out when the patients were unable to carry out their tasks. Pt1 described the impact of her migraines on work and family:

“...there is this fear that if I get [a migraine] I’m gonna have to dive off [work] and I won’t be able to fulfil duties. It’s a disaster at home, because I just can’t do anything... I just have to lie down and the children just have to play and crawl around me... Mummy just can’t deal with them or do any housework or do anything... My husband just pitches in when I get one...”

Impact was a relative concept that was influenced by pain severity and headache frequency. More painful headaches usually led to greater physical disability, and less painful, but more frequent headaches usually were more distressing as described by Pt14:

“...I get really long drawn out ones as well. But they are the ones that bother you the most because you feel like that all the time and you just get sick of it... I have the constant thing all the time. But at such a level that it doesn’t affect me working...”

The relativity of impact was further demonstrated when patients with similar pain severity and headache frequency did not describe the same impact. The participants’ perceptions of impact varied depending on the participants’ commitments (work and family), their belief in their ability to cope and their ability to fit their lives around their headaches. Participants, who believed that they were able to cope and who were able to fit their lives around their headaches, perceived less disruption to their
everyday lives and activities and tended to be more accepting toward their headaches. Pt14 describes how he adapted his life to his headaches:

“...I've made my own little world and I'm so busy and it’s all in one place. I haven’t had to face it [getting treatment]... I put up with the stress it [headaches] caused me...”

5.4.3. Headache as a health issue

The theme of headache as a health issue related to what headaches meant in terms of health. The participants assessed what headaches meant as a health problem, as well as the meaning of headache within a wider health context. Headache was perceived to be a health issue, although not necessarily an illness. The refusal of some participants to acknowledge headaches as a problem or an illness meant that the participants perceived headaches as a low priority health issue. This denial often occurred before or soon after onset of the headaches or when headaches were believed to have little impact.

By comparing headaches to other illnesses, the participants put headaches into a wider health context. The participants related their experience of headaches to their own experiences of illnesses other than headaches, other people’s experiences of illness or illness in general. Mostly, participants related headaches to illnesses that they perceived as more serious, and consequently they played down headaches and headache impact. This made it easier for the participants to accept their headaches. Pt 9 felt lucky for ‘only’ suffering from headache:

“...a friend of ours had a stroke. I’m amazed really, I got to sixty and I’ve not had anything like that... So I’m really lucky in lots of ways. I just have a few headaches, that’s nothing...”

Not acknowledging headaches as a problem already indicated that the participants gave low priority to headaches as a health issue. This finding was reinforced by the
participants' beliefs that headaches were less serious or important than other health problems. Perceiving headaches as low priority influenced the participants' management behaviours, as outlined by Pt 1:

"...If I had a breast lump or something like that, something like that, I'd go straight there [GP], because I know what it is and it needs sorting out. But migraine doesn't fit into that category of absolutely needing sorting out desperately..."

Still, some participants had other views and they considered their suffering related to headaches worse than their suffering related to other illnesses, even life-threatening illnesses such as cancer, as described by Pt 10:

"...when people say to me 'oh my goodness me, you've had breast cancer, how awful'. I said 'it was nothing, it was nothing in comparison to my migraines'..."

5.5. Discussion

Three main themes had emerged from the interview data: 1) headaches, 2) headache impact and 3) headache as a health issue. The theme entitled 'headaches' was further divided into 'pain and other symptoms', 'differentiating between different types of headaches' and 'perceptions of headaches as barriers and facilitators to care'. This study adds to the current literature by giving insight into the patients' perspective of headache and by highlighting the influence of the patients' perceptions on their management behaviour.

Within the theme of headache, the participants revealed their perceptions of their headaches and how these perceptions influenced their management. Participants, who suffered from more than one type of headache, described how they differentiated between various types of headaches. The assessment of whether a headache was a migraine or not was important in the patients' decision-making for
treatment. Other factors involved in the patients’ decision-making for management were the headache pain (type and severity) and other symptoms. These findings were in line with the findings of another qualitative study. Aiming to investigate the decision-making of migraine patients taking sumatriptan, it was found that at the onset of head pain, participants actively compared their symptoms with a ‘migraine template’ that they had developed from past experiences (Ivers et al., 2000). Factors included in this personalised and complex ‘template’ that aided the participants in judging whether a headache was indeed a migraine were the nature, intensity, location and course of pain, the exposure to migraine triggers, presence of associated symptoms and presence of associated cognitive factors.

The patients’ descriptions of their headaches, and particularly headache severity, and headache impact indicate that patients perceive their migraine and CDH as a serious problem. However, the patients’ perceptions of headaches within wider context of health conflicted with the patients’ perceptions of headaches. The participants perceived headaches as less serious than other illnesses and gave low priority to headaches as a health problem. These perceptions may help to explain the low levels of consultations for migraine (Lipton et al., 1998), despite the high levels of disability (Holmes et al., 2001). Patients may think that their headaches are severe and disruptive to their lives, but at the same time not a serious enough problem to bother the doctor with.

The results of this study show the high impact of migraine and CDH on the patients’ lives, through the participants’ descriptions of their disability. Impact emerged as a relative concept in relation to other diseases, pain severity and headache frequency, as well as social and work commitments. In terms of areas of life affected, a focus
group study in the US revealed the areas of life that migraine patients perceive as most problematic in living with their headaches (Cottrell et al., 2002). The participants described effects on social functioning, family functioning, work and relationships. Similarly in this study, the participants described disability in relation to work, family and social lives. Quantitative findings confirm that migraine and CDH have a great impact on the sufferer due to disability (Lipton et al., 1995; Clarke et al., 1996; Holmes et al., 2001). The majority of migraine patients suffer at least some disability (Holmes et al., 2001) and patients with transformed migraine suffer even higher levels of disability than patients with episodic migraine (Meletiche et al., 2001).

The findings of this study indicated that the patients’ perceptions of headache influence headache management. Another study revealed that the patients’ perceptions of their abilities to control headaches (self-efficacy) and the patients’ belief that factors that influence headaches are within their control (locus of control) independently explained the variance in headache-related disability in a sample of headache patients (French et al., 2000). Patients who believed they could prevent and manage their headache (higher self-efficacy) believed that the factors influencing their headaches were potentially within their control (higher locus of control). Also, self-efficacy scores were positively associated with the use of positive psychological coping strategies to prevent and manage headaches and negatively associated with anxiety. Positive coping strategies were for example attempts to reduce muscle tension, cognitive restructuring or coping self-statements. Thus, self-efficacy was appeared to be a determinant of the patients’ efforts to cope with headaches and headache-related disability. However, the patients within this study were all tension-
type headache sufferers (90% of which suffered more than 15 headache days per month), and 29% of patients had an additional diagnosis of migraine.

Headaches remain under-diagnosed and under-treated (Lipton et al., 2001). Strategies have been proposed to improve headache management. Disability tools, such as MIDAS (Migraine Disability Assessment) (Stewart et al., 2001) and HIT (Headache Impact Test) (Garber et al., 2001) have been developed and a care approach based on disability assessment (stratified care) (Lipton et al., 2000) has been tested. Although shown to be useful, these strategies act at the clinical level, and the majority of patients do not consult their doctor about headaches (Lipton et al., 1998). Thus, it is necessary to gain insight into the patients' actions outside physician consultations. The findings of this study increase understanding of the patients' perceptions of migraine and CDH and it shows how the patients' perceptions influence their management behaviours. Management of migraine and CDH can only be improved in collaboration with the patients. Patient involvement in the care in their chronic illnesses, and patient-doctor collaboration are viewed as a strategy for managing chronic diseases in the 21st century (Department of Health, 2001). Education of headache patients has been shown to positively improve quality of life (Allen et al., 2000). Thus education programmes to influence the patients' perceptions of headache (by minimising the barriers and maximising the facilitators) may be a suitable approach to improve migraine and CDH management.
5.5.1. Strengths and weaknesses of methods

The strengths of qualitative methods include researching people in their natural settings and achieving deeper understanding of the participants' world. Allowing greater flexibility, qualitative studies give a more realistic view of the world by allowing patients to speak freely (Soafer, 1999) rather than addressing issues predetermined by the researcher. Few qualitative studies have been conducted in headache research and the use of qualitative research to address this gap has been advocated to better understand the headache patients' perspectives (Peters et al., 2002).

The findings of this qualitative study cannot be generalised. Qualitative research does not seek to be generalisable (Mays and Pope, 2000), but opens a window to insider perspectives that is not always achievable by quantitative methods. If research only focused on what can be quantified reliably, then factors that are significant in explaining important realities and complexities may be ignored.

Health care problems can only be meaningfully addressed through understanding the patients' perspective and the co-operation of health care professionals and patients (Edwards and Staniszewska, 2000). The findings of this study can be applied to generate quantitative research that is based on the patients' perspective rather than the researchers' point of view. Furthermore, the results of this study can be used to inform doctors and headache researchers and to increase understanding about the patients' perspective of migraine and CDH. This may help to identify headache patients as competent persons who cope with their illness, at least partly independent from doctors. Such an understanding may help to develop a more patient-centred health practice (Faltermayer, 1997), which is the preferred approach of primary care.
patients (Little et al., 2001) and to empower and educate patients to have the necessary knowledge and skills to seek help and to manage their headaches effectively (Diener et al., 2000).

5.6. Conclusion

This study reveals the patients’ perceptions of their migraine and CDH. The participants gave descriptions of their headaches that indicated the seriousness of their condition, as well as the impact these headaches have to their lives. However, in the wider context of health, the participants mostly found their headaches a less serious problem than other health issues. The study also showed how the patients’ perceptions influence their management behaviours. Patients may need to be educated and empowered to maximise the patients as a resource to management and to bring about the maximum benefit from the patients’ efforts.
Chapter 5: The patients' perceptions of migraine and CDH

5.7. References


Headache Classification Committee of the International Headache Society 1988, "Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain", *Cephalalgia*, vol. 8, pp1-96


Chapter 5: The patients’ perceptions of migraine and CDH


Chapter 6: The patients' perceptions of migraine and chronic daily headache management

Based on: M. Peters; H. Huijer Abu-Saad; V. Vydelingum; A. Dowson; M. Murphy. 2003, "The patients’ perceptions of migraine and chronic daily headache management." Submitted.
6.1. Abstract

Objectives: To gain insight into the patients' perceptions of migraine and chronic daily headache (CDH) management.

Methods: Thirteen, semi-structured interviews with 7 migraine and 5 CDH patients were carried out and analysed in QSR NUD*IST5, using a grounded theory methodology.

Results: The participants described using five areas of management: 1) health care use; 2) medication use; 3) alternative therapies; 4) social support; and 5) life-style and self-help. The participants described their expectations, preferences, worries and (dis)satisfaction in relation to these 5 areas of management. The participants adapted headache management to suit their needs and preferences, making migraine and CDH management highly individual and giving the headache patient a central role within their own care.

Conclusion: Health care is changing towards a greater involvement of the patients in their own care. Therefore it is important to increase understanding of the patients' perspective of chronic diseases, including migraine and CDH. The results from this study inform health care professionals of the range of their patients' needs and preferences. This knowledge can be used to shape clinical practice, to develop patient education programmes and to further research efforts into issues that are important to the headache patient.
6.2. Introduction

Migraine and chronic daily headache (CDH) affect 12% (Breslau and Rasmussen, 2001) and 3.2% (Lu et al., 2001) of the general population respectively. Migraine and CDH are chronic conditions that significantly reduce the sufferers’ quality of life (QoL), with QoL being more severely reduced in CDH patients than in migraine sufferers (Lanteri-Minet et al., 2003; Meletiche et al., 2001). Differences in QoL have also been observed within different CDH diagnoses, with transformed migraine (TM) patients having a lower quality of life than chronic tension-type headache (CTTH) patients (Wang et al., 2001a).

In chronic illness, patient self-management is inevitable and patients make decisions about their condition everyday, which introduces a new chronic disease paradigm: the patient and health care professional relationship involving collaborative care and self-management education (Bodenheimer et al., 2002). This paradigm implies that the health professional is the expert about the disease, whereas the patients are the experts about their own lives. Patients are empowered, i.e. they accept responsibility to manage their own condition and are encouraged to solve their own problems with information, but not orders, from health professionals.

Patients indirectly express their choices by behaving in a certain way, for example by choosing to take or not to take their medication (Kravitz and Melnikov, 2001). Investigating the patients’ perspective of the migraine and CDH management is the first step to understanding the patients’ current involvement in their own care, to identify areas for patient education and to involve the patients as a resource in managing their headaches. Multiple management strategies, such as health care consultations, medication and alternative therapies, are available to treat and prevent
Chapter 6: The patients' perceptions of migraine and CDH management

Migraine and CDH. Data are available on the patients' use of the management strategies for the management of headache including migraine and CDH. The main focus of these studies are the use of health care (general practice, specialist care and emergency services) and/or medication for migraine (Linet et al., 1991; Edmeads et al., 1993; To and Wu, 1995; Michel et al., 1996; Dowson and Jagger, 1999; Adelman et al., 2000; Wang et al., 2001b; Lavados and Tenhamm, 2001; Lipton et al., 2001) and for CDH (Lu et al., 2001). Two Canadian studies have investigated consultations rates with other health professionals (Edmeads et al., 1993; To and Wu, 1995). Some studies have investigated strategies other than health care and medication use, such as triggers (Dowson and Jagger, 1999), social support (Michel et al., 1996) and the use of behavioural responses for headache (migraine and TTH) relief (Pavão Martins and Parreira, 2001). One recent international study has focused on the broader picture of migraine management by investigating the patients' use of self-help strategies (such as bed rest, trigger avoidance and stress management) and alternative therapies (MacGregor et al., 2003).

Most of the studies to date have been carried out in migraine sufferers, and little attention has been given to the patients' management of CDH. Furthermore, studies have been based on survey designs, wherein the patients answered standardised and pre-determined questions (usually about health care and medication use). To understand the patients' involvement in their own care, it is important for health service providers to receive feedback from the patients about the care that is offered (Edwards and Staniszewska, 2000). Qualitative research allows the patients to speak, not merely to respond (Edwards and Staniszewska, 2000) and deals with the participants' unique experiences and their interpretation of these experiences to gain access to the respondent's perspective (Soafer, 1999).
Thus, a qualitative methodology would permit headache patients' to speak unrestrictedly about their experience and perceptions of headache management. Only one study has used a qualitative methodology, using focus groups, to investigate the perceptions and needs of migraine patients (Cottrell et al., 2002). This US study focused on migraine impact and the patients' preferred type of physician's assistance and gave some insights into the patients' perceptions of management. However, this study did not address patients' perceptions of the holistic picture of migraine management, nor did it investigate CDH management.

The study described in this chapter was part of a larger, qualitative study, which focused on the patients' perspective of migraine and CDH, and the management of these headaches. This chapter presents the patients' perceptions of migraine and CDH management.

6.3. Methods

Ethical approval was obtained from the University of Surrey Ethics Committee. Recruitment, data collection and analysis were carried out simultaneously by the researcher (unless stated otherwise), in accordance with the grounded theory methodology.

6.3.2. Recruitment

Based on theoretical sampling, a convenience sample was recruited in the Guildford (Surrey, UK) area. To be included in the study, the participants had to be aged 18-65 years and had to suffer from migraine according to the International Headache Society (IHS) criteria (Headache Classification Committee of the International Headache Society, 1988). Patients with co-existing headaches or patients who had...
developed CDH were not excluded. For the purpose of this study, CDH was defined as headaches occurring at a frequency above 15 days per month. Participants were recruited through a combination of personal contacts of the researcher and her supervisors, posters in 2 local supermarkets and letters to 20 members of the Migraine Action Association. A total of 39 patients had been contacted and 15 dissimilar cases were recruited. Of the 15 participants, one woman withdrew before the interview and the first interview, with a female migraine sufferer, served as a pilot interview. Thus the interviews of 13 participants (9 women and 4 men) were included in the analysis.

All 13 participants suffered from IHS migraine. Three patients also suffered from tension-type headache (TTH) and based on their headache frequency, 5 patients were classed as suffering or having from CDH. CDH patients experienced higher frequency and lower severity headaches, as well as full migraine attacks. One patient had suffered from CDH in the past, but had been effectively treated and did not suffer from CDH at the time of the study. One participant (Pt 1) had never consulted for migraine, 6 participants had not consulted within the last 12 months and 6 participants were had consulted within the last year. Four participants (1 lapsed and 3 current consulters) had consulted either a headache specialist or a neurologist. Levels of headache-related disability ranged from no disability to severe disability (as assessed by the Migraine Disability Assessment (MIDAS) questionnaire). The patients' characteristics are described in Table 4.3 (Chapter 4, p.132).

6.3.3. Data Collection

Interviews were semi-structured, individual and tape-recorded. A flexible interview guide was devised by the researcher and her supervisors based on recent migraine
Chapter 6: The patients' perceptions of migraine and CDH management

literature to comprise opening and more specific follow-on or clarifying questions and prompts. Initially the interviews focused on migraine experience, physician consultations and treatments for migraine and CDH (Table 4.1, Chapter 4, p.123). As interviewing and the analysis progressed, the interview guide was further developed to include previously raised issues and emerging concepts. Additional questions concentrated on patients' preferences, choices and decisions and a more holistic approach to management.

Interviews were arranged to the participants' convenience, at their home, workplace or at the University of Surrey. The participants, who all signed the consent form, were interviewed once. Interviews lasted up to 2 hours with recording time averaging 1 hour (range 50-90 minutes). Interviewing finished with data saturation. Interviews were transcribed verbatim.

6.3.4. Analysis

Interviews were prepared for analysis and coded using QSR NUD*IST5 (N5), a qualitative software package. To reduce bias of the coding scheme and emerging taxonomy and concepts, the researcher and her supervisors, as well as an independent researcher, were involved in different stages of the analysis. A guide was devised (by the researcher and HAS) to standardise the coding procedure for triangulation. One by one, the first 5 interviews were summarised (by the researcher, HAS, VV and an independent researcher). Then the interviews were coded sentence by sentence to give an initial coding scheme (the researcher, VV and independent researcher). No notable differences were found between the coding of the different researchers. Codes were grouped into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and
discussions between the authors. The last 8 interviews, coded according to the same technique, were used to verify the coding scheme and refine the emerging taxonomy and concepts. First, a summary of the concepts and later detailed definitions, descriptions and interpretations of the main concepts were discussed by the researcher and all her supervisors.

6.4. Results

6.4.2. The patients' use of management strategies

The participants described the management strategies they had used to treat and prevent their headaches. The management strategies employed fitted into five areas of management: 1) health care use; 2) medication use; 3) alternative therapies; 4) social support; and 5) life-style and self-help (Figure 6.1). Health care use involved consultations with doctors, predominantly the GP, neurologists and other health care professionals. Medication use related to the pharmacological agents used for the acute and prophylactic treatment of headaches. Alternative therapies comprised consultations with alternative therapists (such as osteopaths, chiropractors or acupuncturists) and the use of herbal and homeopathic remedies. Social support involved seeking and receiving advice for headache management from family, friends, work colleagues and other headache patients; the media and headache support groups such as the Migraine Action Association. Life-style and self-help dealt with non-pharmacological management such as trigger detection and avoidance, bed rest, relaxation and stress management and healthy life-style such as healthy eating and exercise.
Chapter 6: The patients’ perceptions of migraine and CDH management

Figure 6.1: Areas of migraine and CDH management

Management strategies

Health care use
- General Practitioner
- Neurologist
- Headache specialist
- Other (nurse, physiotherapist, pharmacist)
  - Acute
  - Over the Counter
    - Prescription
  - Prophylaxis

Medication use

Alternative therapies
- Acupuncture
- Chiropractic
- Homeopathy
- Osteopathy
- Reflexology

Social support
- Family
- Friends
- Work colleagues
- Other headache patients
- Headache support groups
- Media

Life-style and self-help
- Non-pharmacological management
  - Triggers
  - Stress management
  - Relaxation
  - Bed rest
  - Life-style
    - Healthy eating
    - Exercise
Chapter 6: The patients’ perceptions of migraine and CDH management

6.4.3. The patients’ perceptions of management strategies for headaches

6.4.3.1. Health care use

The participants’ descriptions of health care use mainly focused on consultations with doctors and mainly the GP, although consultations with other health care professionals, such as nurses and pharmacists were also described. As far as general practice consultations were concerned, some participants had low expectations and questioned the GPs ability and interest to treat headaches, to the extent that they did not consult for headaches. Pt 5, who was not consulting for his migraines, thought the following:

“...nothing has ever indicated to me that anybody is interested and that there is any medical help...”

Participants, who had consulted a neurologist for their headaches, described higher expectations and often a preference for specialist consultations. They were, however, not necessarily more satisfied. Pt 7 described her reasons for preferring a consultation with a specialist clinic:

“...GPs are very good at general practice. That’s what they are qualified to do. They know a limited amount about a lot of different illnesses, symptoms, problems. Going to a specialised clinic, they are specialist, they spend their working day dealing purely with headaches, they can also [do] diagnostic tests, whatever. It’s that additional sort of support. The GP can only do one to one discussion of what your symptoms are. Whereas if you go to a specialist clinic you can go along for scans or x-rays and see if there is anything in your head that is causing the headaches or the migraines. That was the theory..."
Independent of their consultation status, the participants thought that general practice consultations, and consequently the role of the GP, mainly revolved around pharmacological treatments. The GP’s role was to advise on Over the Counter (OTC) medications or to give out prescriptions to treat symptoms. Little attention was given to issues, such as uncovering the causes of the headaches, finding a cure and discussing the impact of headaches or non-pharmacological and alternative therapies. However, these were issues that the participants would have liked to discuss with their GPs. For example, Pt 13 was interested in the causes of her headaches, rather than the use of medication:

"...I thought I don’t want to be on these [drugs] long-term. I want to find... if there is a cause to these headaches. I’d rather get to the bottom of it, rather than just taking drugs to deal with the symptoms..."

Pt 12 would have liked to talk about the impact of headaches, rather than only receive medication:

"...it’s [GP consultations] orientated by drugs, it seems to me. It wasn’t about ‘how do you feel’, ‘how does this affect you’, ‘what are you experiences with diet, whatever’. It was “yeah ok, we’ve got Inderal, that will slow you heart down, we’ve got [diazepam], will make you calmer, we’ve got Imigran, will squash it when it happens, we’ve got Parannax to stop you vomiting”. It’s almost sort of like, they’re not looking at the cause and possibly just trying to treat the symptom...”

When issues other than medication were discussed during consultation and the participants were encouraged to return for further consultations, the GP was perceived as helpful and interested in the participants’ headaches. Consequently, the participants were more likely to be satisfied with the consultations and to return for follow-up consultations. Pt 9 had different experiences with doctors and described how the doctor’s attitude influenced her consultation behaviour:
Chapter 6: The patients’ perceptions of migraine and CDH management

"...I think they [GPs] are concerned and they do, they are very sympathetic. And they all want to do the best, you know, for you. I think if they were the other way you wouldn’t go, would you? I don’t think if you got the ‘oh don’t bother me with this’. I did have a lady doctor years ago and I have been to her with the headaches... She used to turn around to me and say ‘well, you’re like my father, my father used to get them at weekends, because he was relaxing’”. And that’s the only sympathy I got, so I thought ‘alright, if that’s all I am going get’, she never gave me anything...so I didn’t go and see her...”

6.4.3.2. Medication

The participants’ perceptions of the medications ranged as widely as the number and types of medications they had used. Despite expressing preferences for not taking any medication, all 13 participants had relied on medication for their headaches in the past. Some participants had only used OTC drugs, whereas other participants had also used prescription medication, including prophylaxis. Generally, the participants found using acute medications more acceptable than using prophylactic drugs, as outlined by Pt 6:

"...although migraines are bad, again I don’t know if I’d want to take medication every day and there might be side effects..."

Despite all having used acute medication for headaches, some participants had low expectations of and low satisfaction with medication. Frequently these patients had only tried OTC medications and had experienced unsuccessful pharmacological treatment. Pt 6 found painkillers and Migraleve, which was recommended by her GP, ineffective and concluded that there was no effective treatment:

"...although it is very disabling really to have a migraine [pause] somehow, you know you just think, you should; it’s just a headache and nothing is going to help it really. If painkillers don’t work, then there is probably nothing else that is going to work. Once I’ve tried Migraleve, I thought that was it, obviously the treatment he [GP] suggested to me and then it didn’t work..."
Chapter 6: The patients' perceptions of migraine and CDH management

Based on these low expectations and the worry of side effects, some patients preferred to cope without medication (Pt 10) or restricted their medication use. Pt 5 frequently opted against taking acute medication, because he was convinced he would suffer from side effects:

"...I know it's impossible to take any form of medication without having side effects, it's impossible that's the way it works. So therefore if you're going to take some then you have to balance it with the side effects. If you can get through whatever your problem is without taking any drugs, then you've got no side effects..." 

Other patients had found an effective drug and shared the view of Pt 7, who preferred taking medication to having a migraine. Pt 3 went as far as describing Sumatriptan as 'her lifeline'. Still, the participants, who used medication regularly, did not use them lightly. They had specific views on taking medication and on why and when to take the different types of medication. The reasons to take medication included pain control, restoring the ability to function or the prevention of headaches. However, different medications served different purposes, for example triptans were for 'severe migraines' only, not for 'headaches'. Overall, it was the triptans that the participants used the most carefully. Pt 8 described his reasons for using Zomig sparingly:

"...the trouble that I was getting with Zomig is, they advise that really you take it as soon as you think it's a migraine coming. And the two problems with that is, one you don't always know that it's not just going to be a bad headache. So I was reluctant to take Zomig and then just find that it's going to be a bad headache...I only had, I think I only had about six of them [Zomig] I think. It was a struggle to get the doctor to prescribe them anyway, because they're quite expensive..."

Pt 7 used Imigran for her severe migraines, otherwise she relied on OTC drugs. She also limited her use of Imigran because of the cost, but her personal costs of a prescription rather than the cost to the health service:

"...recently, well since '98, I've been on Imigran, so if I do get a severe one, I tend to take that. It actually does seem to work better than the
Migraleve, but the Imigran is very expensive, it's a prescription drug. So I tend to rely quite heavily on Migraleve... In terms of finances it's better to take Migraleve, because it's cheaper...

Similarly, although the participants preferred not to take drugs every day, prophylaxis became acceptable in certain situations. Pt 4, after one particularly severe migraine attack, accepted to try beta-blockers:

"...I can remember an incident last year. In fact I went to the doctor's. And it was three, four days, I had this terrible headache. And I just couldn't get rid of [it], I just felt dreadful. And it was up; across my face and then it was just lodged on one side and I felt that I couldn't bear the light etc. And I was just on painkillers, the maximum dose and possibly a bit more, which is very silly. I went to the doctor's in the end on the fourth or fifth day. And they prescribed beta-blockers, which helped..."

But when she experienced side effects (hence the circumstances changed), she discontinued the treatment.

"...beta-blockers made me feel quite light headed..., a little bit disorientated I suppose, because I had no sense of urgency or purpose about anything. I felt a little bit sort of dizzy. But dizzy in; I don't mean off balance, but just not quite with it... Because to be totally unaware of the police chasing you for three miles with a great big siren, just indicates how spaced out I was... But anyway, they [beta-blockers] did help the headaches, but I couldn't carry on like that because I was out of touch with life. So I gave them up..."

6.4.3.3. Alternative therapies

Although not all the participants had consulted an alternative therapist (such as osteopath or chiropractor), they generally expressed an interest in what alternative therapies had to offer. Frequently it was cost that prevented the participants from trying alternative therapies. The participants, who had consulted alternative therapists, compared these consultations to the traditional medical consultations. They gave little descriptions on how effective they found alternative therapy, but they expressed satisfaction with the time and advice offered by alternative therapists.
Chapter 6: The patients’ perceptions of migraine and CDH management

Pt 13 described her consultations:

...varying [laughter], some people were really helpful, like I found the chiropractor pretty helpful. And I guess met my need very much at the time and continued to kind of look at a more holistic care, you know, thinking of lots and lots of things, like exercise stretching exercise, diet, stress, you know, the whole lot. As did the doctor, the second GP. The first GP I felt was very narrow minded and I [was] very much put off by him, if you get the gist. The neurologist was ok, I guess kind of what I expected, but quite impersonal...”

Pt 12 also expressed his satisfaction with his alternative therapy consultations:

“...the homeopath and the cranial chap [osteopath] were trying to get to the cause, whether it was psychological, physical or a bit of both. They addressed that and then tailored what they did to that, rather than the other way around. So that’s why I feel I made more progress with them...”

The participants also used homeopathic and herbal remedies to treat and prevent their headaches. These remedies were compared to the pharmacological agents, and were rated as ‘natural’, ‘safer’ and as ‘not leading to side effects’, as Pt 5 reported:

“...I would try those [herbal remedies] you know, so long as they; it was natural vegetation and not a drug as such. ...I don’t think they have any negative effects...”

Satisfaction or dissatisfaction with homeopathic and herbal remedies was expressed less often, and depended on the individual’s perspective. Pt 7 was not impressed by alternative therapy:

“... I did try a homeopathic thing once, but that didn’t do anything...I’ve tried Feverfew as well, I didn’t like the smell of those...”

Pt 9, however, had found acupuncture helpful:

“...it certainly helped me for a little while, ‘til I stopped. You’ve got to keep these things up...”
6.4.3.4. Social support

The use of social support was an adjunct to the other management strategies and was used to complement or further improve the participants’ headache management. The participants received social support from their families, friends, work colleagues and other headache patients. Having people to talk to about headaches, and particularly other headache patients, was considered enjoyable and interesting, as described by Pt 3:

“...I’ve been down to my doctor’s, because I had a bit of blood pressure. I’ve been seeing a nurse and I was talking to her. And she suffers with them, migraines. And she has the same tablets, she has Imigran and she says that’s her lifeline. She feels the same as me... It’s very interesting, because you know you think ‘oh’ you know, ‘I seem to be the only one suffering from headache’...”

Talking to people allowed the participants to give and receive support and understanding and to exchange information and gain insights into other management strategies. For example Pt 10 said:

“...I’ve just met a new person, who suffers with headaches. She’s not had migraines, but she’s had very bad headaches. We just spent a whole hour chatting to one another, and giving one another different ideas. And afterwards it was just so nice, she said to me ‘you’ve helped me such a lot’...”

Also family and friends helped the participants to be more active in their own headache management and provided support when the participants had an attack. P 4 decided to consult her GP, on her husband’s insistence:

“...my husband said ‘oh you must go to the doctor and sort it out’....

Gaining new information about headaches to learn to better deal with them was considered important by the participants. New information was sought through various sources of social support such as family and friends, work colleagues, other
headache patients and the media. Particularly charities, such as the Migraine Action Association were thought to be useful, since they gave access to the latest developments, as outlined by Pt 6:

"...They [Migraine Action Association] might have new treatments that have been successful with other sufferers, because obviously they are in touch with a number; a much larger number of people than probably the GP is. So they might have more idea of different treatments that can be used and possibly support for the sufferer..."

Although expressing interest in information about migraines, not all the participants, however, benefited from social support. Pt 5 for example was not aware of an association that can provide information for migraine and said the following:

"...it's just one of those areas where it's tucked to one side, there is probably something going on in pockets, but for the population as a whole; they're not aware of anything going on, where to go, is there anything for it? You know if you had asthma, there are societies for asthma and the doctor can put you in touch...You can actually take it as far as you want to take it, can't you. You can stay with the problem and just research it. But I am not aware of anything like that for migraine..."

### 6.4.3.5. Self-help and life-style

Not only did the analysis reveal the patient as having a central role in their management, the patients perceived themselves as an essential resource to management. The participants often thought it was their responsibility to deal with their headaches through self-help and life-style changes. Pt 9 believed that headache management was:

"...a matter of doing most of the work yourself..."

As social support, self-help and life-style were described as adjunctive management strategies to health care and medication use. Self-help involved taking initiatives and contributing to their own headache management, by gaining information about treatments, selecting their own prescription drugs, and convincing their GPs to
Chapter 6: The patients’ perceptions of migraine and CDH management

prescribe the drugs. Pt 8 explained how he influenced the outcome of his GP consultations:

“...The only way they [migraines] got better was really by me sort of making them better, you know, sort of talking about Zomig... I just said [to the GP] I’d heard about these [Zomig] ‘what do you think of them’?... She looked them up ... and said ‘oh, yes’. So I don’t think she’s heard of them before and said ‘yeah, we can try these if you like’...”

Self-help often revolved around triggers and analysis of their own headaches to help find a cause and possibly a cure. Pt 2 described looking for a cause of his headaches by examining his everyday behaviours:

“...I got to the stage where it got so bad I just had to look at everything that I was doing in a day. So, where are you in a day? What are you doing in a day? Now can this be a cause? No, ok let’s move on to the next thing...”

The participants’ life-style management strategies revolved around stress control, getting enough sleep and dietary changes. But changes in life-style could be as extreme as changing jobs to help control the migraines, as outlined by Pt 8:

“...I’ve sort of resigned myself almost to the fact that it’s now up to me to get out of my job and the shift work to stop my migraines...”

6.5. Discussion

The interviews revealed the wide range of strategies that the participants used to manage their headaches. The sampling aimed to recruit dissimilar patients and therefore the study gave access to many different perspectives and perceptions of migraine and CDH management. The participants adapted headache management to suit their needs and preferences, making migraine and CDH management highly individual. The participants predominantly talked about the traditional medical system, including consultations with doctors and medication use. They reported both
unsatisfactory and satisfactory consultations with doctors and concerns with medications, including low expectations, sometimes low satisfaction, decisions about which type of medication to use and worries about medication side effects and costs. Similar concerns were revealed in another qualitative study, which used focus group to study the perceptions and needs of migraine patients (Cottrell et al., 2002). Problems included the implementation of treatment, even when effective treatment had been prescribed, dissatisfaction with emphasis on drug treatments (especially among women), worries about (long-term) side effects from taking medication and the costs of medication.

Poor communication between the doctor and the patient is thought to be one of the underlying causes of migraine under-treatment (Lipton et al., 1994). The participants, particularly the lapsed consulters and unsatisfied consulters, in this study reported that doctors were not interested enough. The participants were more satisfied with consultations when management was shaped to their needs and preferences, and when they felt that they were listened to and their concerns were understood by the health professional. However, concerns such as low expectations of treatments and the worry of side effects were rarely addressed within consultation and dissatisfied patients chose not to consult again. Gaining insight into these issues is important to help health professionals to better understand the needs of headache patients and to communicate more effectively with headache patients. This may contribute to improving consultations and consequently treatment of migraine and CDH. Also, better understanding of the patients’ preference for treatment may encourage further research into management strategies that the patients express a preference for.
Chapter 6: The patients’ perceptions of migraine and CDH management

In view of the new chronic disease paradigm (Bodenheimer et al., 2002), the most important finding of the study was the central role the participants assigned to their involvement (self-management) in their headache care, including their role in during health care consultations and decisions about medication use. Chronic disease has become the principal medical problem and it is thought that the patient must become a partner, who contributes at almost every decision and action level (Holman and Lorig, 2000). The results presented in this chapter and further results from this study (Peters et al., 2003) showed how the patients’ perceptions of themselves as a resource to management; and their expectations, preferences and satisfaction with management strategies influence their choices for management. They express their willingness to be involved indirectly through their actions and directly through their interest in learning more about headaches through their social support network.

6.6. Conclusion

Health care is changing towards a greater involvement of the patients in their own care. The Department of Health (UK) advocates the ‘Expert Patient’ as a new approach to chronic disease management for the 21st century (Department of Health, 2001). Therefore it is important to increase understanding of the patients’ perspective of chronic diseases, including migraine and CDH. Qualitative research, although limited in its generalisability, is suitable to gain insight into the migraine and CDH patients’ perspective. The results from qualitative studies can be used to inform health care professionals of the range of their patients needs and preferences, to shape clinical practice, to develop patient education programmes and to further research efforts (both qualitative and quantitative) into issues that are important to the headache patient.
6.7. References


Headache Classification Committee of the International Headache Society 1988, "Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain", *Cephalalgia*, vol. 8, pp. 1-96.


Chapter 6: The patients' perceptions of migraine and CDH management


Chapter 6: The patients' perceptions of migraine and CDH management


Chapter 7: Phase II research design: Survey methods
7.1. Rationale

The literature review (Chapter 2) has described the high prevalence of migraine and chronic daily headache (CDH) (12% (Breslau and Rasmussen, 2001) and 3.2% (Lu et al., 2001) respectively). It has also described that migraine and CDH patients have reduced quality of life (QoL), with CDH patients being more severely affected than patients suffering from episodic migraine (Meletiche et al., 2001).

Migraine patients have been criticised for having a fatalistic attitude towards the treatment of their migraines (Henry et al., 1992), and migraine remains under-diagnosed and under-treated (Lipton and Stewart, 1994). The qualitative study had aimed at gaining insight into the patients' management from the holistic perspective. The 13 participants described their active involvement in their headache care. The interviews also revealed that the participants' management strategies included and went beyond the traditional health care consultations and medication use. However, the qualitative methodology is limited in its generalisability, and a postal survey was conducted to study and compare the holistic management used by migraine and CDH patients.

To prepare for designing the survey, previous studies using a survey design to investigate the migraine and CDH patients’ use of management strategies were identified. These studies were summarised (Appendix 1) to identify which type of headache had been studied, which factors had been included and excluded, and which time frames and instruments (questionnaires vs. interviews vs. diaries) had been used. These issues were used as a guideline for the designing the questionnaire used in this study.
Chapter 7: Phase II research design: Survey methods

Twenty-four studies, using a survey design, have been carried out between 1991 and 2003 on the management behaviours employed by migraine and CDH patients. Six surveys have used a postal questionnaire only. Seven surveys have used telephone interviews and 5 studies have used face-to-face interviews. Only two studies used diaries, one of which had used diaries additionally to interviews. A large number of studies (n=10) did not specify time frame used, but the most common time frame was 12 months (n=9). The studies had been carried out in a variety of countries. The largest number of studies have been conducted in the US (n=9). Two studies have been carried out in the UK. One international study also included the USA and the UK in their sample.

The Summary Table (Appendix 1) also presents the results of these studies (the number of patients using the studied strategies). Most studies focused on the use of health care (general practice, specialist care and emergency services) and/or medication for migraine (Linet et al., 1991; Edmeads et al., 1993; To and Wu, 1995; Michel et al., 1996; Dowson and Jagger, 1999; Adelman et al., 2000; Wang et al., 2001; Lavados and Tenhamm, 2001; Lipton et al., 2001) and for CDH (Lu et al., 2001). Predominantly management strategies have been studied in isolation, apart from the combined studies on health care and medication use. Some studies investigate other migraine management strategies, but usually these remain limited to one additional strategy for example triggers (Dowson and Jagger, 1999), social support (Michel et al., 1996) and the use of behavioural responses for headache (migraine and TTH) relief (Pavão Martins and Parreira, 2001). One recent international study has focused on a wider range of issues including consultations with doctors, alternative health care use and self-help strategies such as bed rest and trigger avoidance (Brandes, 2002; MacGregor et al., 2003).
Comparisons of health care behaviours have been drawn between migraine patients and controls (To and Wu, 1995; Michel et al., 1996; Lipton et al., 2001). Other studies compared management of patients with different headache diagnoses. Most comparisons between diagnoses were drawn between migraine and tension-type headache (Edmeads et al., 1993; Lavados and Tenhamm, 2001; Pavão Martins and Parreira, 2001). One study compared 4 headache groups: migraine, probable migraine, tension-type headache and other headache (Linet et al., 1991). A further survey compared migraine patients with non-migraine headache sufferers (Wang et al., 2001). Comparisons between migraine and CDH are limited to one study that investigated the differences in coping, but not the use of management strategies, in migraine and CDH patients (Siniatchkin et al., 1999).

To summarise, few studies have focused on the management strategies employed by migraine sufferers. Previous studies on the migraine patients’ management have focused on consultations with doctors and medication use. Data on CDH management from the patient perspective is even more limited. Furthermore, to date, no study has drawn a comparison between the management behaviours employed by migraine and CDH patients. Also, the preliminary qualitative study showed that migraine and CDH management is more than physicians’ consultations and pharmacological treatment.

It is thought that headache management is best when the patient is actively involved (Silberstein et al., 2000). Through their use of management, patients indirectly express their views on preferences and choices (Kravitz and Melnikov, 2001). The limited amount of data on the patients’ behaviours suggests that headache patients are often disregarded as a resource to effective management. Increased knowledge of
the patients' behaviours, particularly between the different headache types, may help to better understand patients' preference and decision-making.

Therefore, to increase knowledge about the patients' use of management and to make the qualitative findings more useful for explanation and prediction, a postal survey was carried out. The following chapter sets out to describe the aims and research questions and design, data collection and analysis of the questionnaire.

7.2. Aim and research questions

The aim of the survey was to investigate and compare the management strategies used by patients suffering from migraine (M), migraine with aura (MWA) or CDH. The survey aimed to compare three groups, rather than the 2 groups (migraine and CDH) used for the qualitative phase, because the qualitative data indicated that patients with different headache diagnoses and increasing headache severity managed their headaches differently. Also, migraine diagnosis has been shown to be more likely when certain symptoms are present, including aura and increasing disability (Lipton et al., 2001).

The 2 main research questions were formulated according to this aim and were as follows:

- Which management strategies do M, MWA and CDH patients use to treat and prevent their headaches?

- What are the differences in management employed by M, MWA and CDH patients to treat and prevent their headaches?
7.3. Development of the questionnaire

The questionnaire was developed through the collaboration of the student and her supervisors, based on the findings of the qualitative methodology and on the literature. As previously described, the studies on the patients' use of management strategies are mainly based on telephone and mail questionnaire surveys. Due to time limitations and cost, a mail questionnaire was selected as a method of data collection. Also a mail questionnaire allowed a wider spread sample and it permitted people to confer with other people or think about their answers, which was important in view of the retrospective approach of the survey. The questionnaire collected data on the management behaviours of migraine and CDH patients in the year prior to the study.

The literature was searched to identify previous studies investigating migraine and CDH management from the patients' perspective. Few data on the patients' management of headache were available. No studies investigating the holistic picture of either migraine or CDH management (i.e. comprising the 5 themes identified in the qualitative study) were identified. Furthermore, there were no comparisons between the management of migraine and CDH. Since, past questionnaires to study certain aspects of management were either not available or did not exist in English, a new questionnaire was developed.

In previous publications, patients' input into the questionnaire development was not described. Only one questionnaire to study the patients' preferences for migraine therapy was based on qualitative findings (Caro et al., 1998). Therefore, it can be assumed that the surveys, although investigating the patients' behaviours, are developed by headache researchers. The questionnaire used in this survey was developed with the patients' input, based on the previous qualitative findings, as well
as expert validation by other researchers and pilot work with migraine and CDH patients.

7.4. Content

No previous questionnaire had investigated either the holistic management of migraine or CDH from the patients’ perspective. Therefore, a new questionnaire was developed. The questionnaire contained 4 main parts: 1) headache information (section 1), 2) the management strategies (sections 2 to 6), 3) the patients’ opinions and beliefs (sections 7 and 8) and 4) biographical information. These four sections will be described below in more detail. A copy of the questionnaire can be found in Appendix 11.

7.4.2. Headache information

No validated diagnostic tool in English was available to diagnose the volunteers as suffering from migraine, migraine with aura or CDH patients. Therefore, a diagnostic tool was designed to be included in the questionnaire. This tool was based on the IHS criteria (for migraine and migraine with aura) and on the (Silberstein et al., 1994) criteria for CDH.

7.4.3. Management Strategies

Management strategies included in the questionnaire were identified from the current literature (Chapter 2) and the preliminary qualitative study. Five main areas of management had been identified and were included in the questionnaire: 1) health care use, 2) medication use, 3) alternative therapies, 4) social support and 5) lifestyle and self-help (Table 7.1)
Table 7.1: The five areas of management for migraine and CDH and their definitions, according to the qualitative study.

<table>
<thead>
<tr>
<th>Area of management</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care use</td>
<td>Consultations with health care professionals within the National Health Service, including GPs, neurologists, doctors specialising in headache, nurses, pharmacists, physiotherapist and psychologists</td>
</tr>
<tr>
<td>Medication use</td>
<td>The use of pharmacological agents, including Over the Counter and prescription medication, and acute and prophylactic treatments</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>Consultations with alternative therapists, including chiropractors, osteopaths and homeopaths</td>
</tr>
<tr>
<td></td>
<td>The use of herbal or homeopathic remedies, such as Feverfew or butterbur</td>
</tr>
<tr>
<td>Social Support</td>
<td>Support sought and given by family, friends and work colleagues, support groups.</td>
</tr>
<tr>
<td></td>
<td>Information from the media such as the internet, newspapers, magazines, books and television.</td>
</tr>
<tr>
<td>Self-help and lifestyle</td>
<td>Trigger avoidance, avoidance of aggravating stimuli, exercise, healthy eating, massage and cold/hot treatment,</td>
</tr>
</tbody>
</table>

These 5 areas of management were rearranged to reflect 4 other themes of management: 1) consultations, 2) the use of acute and prophylactic medication and herbal/homeopathic remedies, 3) acute and prophylactic general management and 4) social support.
7.4.4. Opinions

Two sections of the questionnaire (6 and 7) dealt with the patients' opinions. Section 6 related to the patients' opinions about management strategies for dealing with their headaches and section 7 related to the patients' beliefs and attitudes about headaches as a health issue.

7.4.5. Biographical information

This section of the questionnaire asking for biographical information reflected the data set of the last National Census, which was downloaded from the Internet.

7.5. Design of the questionnaire

To increase response rate, the questionnaire was laid out to be simple and to appear personal by the use of coloured paper and by directly addressing the respondents. It included a blank page for further comments, any other information that patients might feel that was relevant.

7.6. Cover letter and information sheet

The cover letter and information sheet were designed to appear personal and to motivate headache patients to take part in the study. The information sheet was printed on University of Surrey headed paper. The cover letter was also printed on University of Surrey headed letter paper for the letters sent to the respondents of the advertisements. The cover letter sent via the Migraine Action Association was printed with the Migraine Action Association logo, to demonstrate that the Migraine Action Association was supporting the study. A copy of the cover letter can be found in Appendix 12 and the information sheet can be found in Appendix 13.
7.7. Ethical approval

Ethical approval had been obtained from the University of Surrey Ethics Committee (Appendix 14).

7.8. Pilot testing

7.8.2. Experts opinion

The questionnaire was developed by the researcher and in collaboration with her supervisors, who commented on the design and content of the questionnaire. Furthermore, two independent researchers with expertise in questionnaire design assessed the lay out and feasibility of the questionnaire. The information provided was used to revise the questionnaire.

7.8.3. Patients' pilot study

The questionnaire was administered to 10 headache patients to test the content validity and feasibility of the questionnaire. The 10 patients were given an evaluation form (Appendix 15) to assess the Headache Management Questionnaire, the cover letter and information sheet. None of the 10 patients had any problems of filling the questionnaire in. These 10 patients were selected through personal contacts and through a Headache Clinic.

7.8.4. Diagnostic Tool- Validity

A further initiative was taken to test the validity of the diagnostic tool within the questionnaire. Working together with the research nurse at the Headache Clinic, the 9 questions relating to the diagnosis were sent to 30 patients who had previously been diagnosed by the clinic’s headache specialist. The questionnaire contained a
code, which allowed the research nurse to identify the patient for comparison of the diagnosis. The patients were also sent a letter explaining the procedure (Appendix 16), and a stamped and self-addressed envelope to return the questions to the researcher. Twenty-six (87.7%) questionnaires were returned. The diagnosis was made by the researcher and compared to the clinician’s diagnosis (Appendix 17). The questionnaire diagnosis and clinician’s diagnosis concurred in 22 out of 26 cases. Thus the validity between the questionnaire and the clinician’s diagnosis was 84%.

7.8.5. Changes to the questionnaire

Following the experts’ input and the patients’ pilot study, only minor changes had been made to the questionnaire. Spelling and labelling mistakes were corrected. Also, in accordance with the experts’ opinion, the section on biographical information was moved to the end of the questionnaire.

7.9. Data Collection/ Administration

7.9.2. Mailing

The volunteers were sent a copy of the questionnaires together with an information sheet and a stamped (second class) and self-addressed envelope. The volunteers were asked to return the questionnaire within two weeks. Depending on the response rate, a follow up letter was to be sent 3 weeks after mailing the questionnaire. However, due to the high response rate, it was not necessary to send follow up letters. Envelopes were stamped with the University of Surrey address, and the researcher’s name.
7.9.3. Recruitment

**7.9.3.1. Advertisements**

Two advertisements were placed (Appendix 18) to recruit volunteers to complete the questionnaire. First, an advertisement was placed on the Migraine Action Association web-site (http://migraine.org.uk). This advertisement led to few responses and therefore as a second step, the same advertisement was placed in the October 2003 issue of the Migraine Action Association Newsletter. Although this increased the response rate, the sample size of 400 questionnaires had not yet been achieved. A total of 87 responses to the advert on the internet and in the Migraine Action Association Newsletter had been achieved. All questionnaires had been given a unique identification number to verify which questionnaires had been returned and to send follow up letters if necessary.

**7.9.3.2. Mailing the questionnaire to members of the Migraine Action Association**

Since the advertisement had not led to the desired response rate, it was decided to mail the questionnaire to a random sample of the members (n=800) of the Migraine Action Association. Due to the high response rate that the Migraine Action Association achieves when they mail questionnaires to their members, it was decided that mailing 800 questionnaires would be sufficient to achieve the desired sample of 400. A list of the respondents to the adverts was sent to the Migraine Action Association to prevent members being asked to fill the questionnaire in twice.

An adapted version of the cover letter was used for mailing the 800 questionnaires. The cover letter was jointly written by the researcher and director of the Migraine
Chapter 7: Phase II research design: Survey methods

Action Association. The letter was signed by the director of the Migraine Action Association. The information sheet was printed on University of Surrey headed paper, the same as for the mailings in response to the advertisement.

The 800 questionnaires, cover letters, information sheets and stamped and self-addressed envelopes were put into prepared envelopes (second class stamp and University of Surrey address). These 'packages' were boxed and sent by Parcel Force to the Migraine Action Association for mailing to 800 members.

7.10. Questionnaire processing

For the questionnaires that were returned in response to the advertisement, the identification number was checked and deleted from the address database.

The questionnaires returned from the mailing to Migraine Action Association members, were given a unique identification number upon receipt. The identification numbers were entered into SPSS to facilitate data checking at a later stage.

7.11. Data checking

7.11.2. Eligibility

Upon receipt the questionnaires were checked for eligibility (age and diagnosis) by the first author. If a definite diagnosis of IHS migraine (with or without aura) or CDH were given, the questionnaire (n=422) was entered into the statistics package. To check the reliability of the diagnosis, a 10% (n=42) random sample were selected and re-diagnosed independently by a headache clinician to assess the reliability of the diagnoses. Diagnoses concurred in 40 cases (95.2%).
Based on this data checking, 65 questionnaires were excluded from analysis, due to absence of headaches in the last 12 months (n=9), the respondent being over the age limit of 65 years (n=39), missing biographical data (n=5) or missing diagnostic data (n=12). The diagnosis of further 50 questionnaires could not be established and was discussed between with the headache clinician. This led to the exclusion of further 34 questionnaires, based on the headaches being unclassifiable (n=7) or the patients suffering from headaches other than migraines (with or without aura) or CDH (n=27). The remaining 16 questionnaires were entered for data analysis. Thus, 438 questionnaires were included in the data analysis.

7.12. Analysis

The questionnaire data were entered into SPSS 10.1 for analysis. The non-numerical data was coded for entry into SPSS. First, codes were assigned for the closed questions. Data from open-ended questions were entered as open data initially and the coding was developed after the answers had been read and evaluated.

Data were analysed by descriptive statistics to compare the three groups (M, MWA and CDH). Chi-square tests were used for to test differences of categorical variables, including consultations, medication use. Kruskal-Wallis tests were used for ordinal data, including frequency of medication use, general acute and prophylactic management and social support. Analysis of variance (ANOVA) and post-hoc Scheffe tests were used for continuous variables including headache frequency, pain severity, impact and total scores for the use of general acute and prophylactic management and social support. The level of significance was set at p<0.05.
7.13. References


Chapter 7: Phase II research design: Survey methods


Chapter 8: Patients' management of migraine and chronic daily headache: A survey

Based on: M. Peters; H. Huijer Abu-Saad; I. Robbins, V. Vydelingum; A. Dowson; M. Murphy. 2003, “Patients’ management of migraine and chronic daily headache: A survey.” Submitted
8.1. Abstract

Objectives: This study aimed to compare headache management between migraine (with and without aura) and chronic daily headache (CDH) patients over the last 12 months. Management strategies from 4 areas were studied, including health care consultations, medication and alternative remedies, general (acute and prophylactic) strategies and social support. The patients’ beliefs and attitudes were also investigated and compared.

Methods: A postal questionnaire was sent to members (n=887) of the Migraine Action Association. The response rate was 61.2% (n=543), and 438 questionnaires were included in the analysis. M (n=117) and MWA (n=239) patients were classed according to the IHS (International Headache Society) criteria. CDH (n=83) was diagnosed when patients suffered more than 15 headaches days per month. Descriptive tests, ANOVAs, Chi-square and Kruskal-Wallis tests were used for statistical analysis (p<0.05).

Results: Significant differences in the use of management strategies were found in consultations with headache specialists (p=0.002) and neurologists (p=0.004), the number and types of acute medications (e.g. triptans, p=0.002), the use of antidepressants (p=0.004) and some acute and prophylactic avoidance techniques. Although, no significant differences between the groups were found in the use of other health professionals (e.g. GP), alternative health professionals, general acute management and the use of social support, they all actively used these strategies. Overall, CDH patients were more active than M and MWA patients. For the management strategies where no significant differences were found, there was a trend towards a greater level of use of management strategies by CDH sufferers.
Patients with CDH also had more negative beliefs and attitudes than M and MWA sufferers.

Conclusion: All the respondents were actively involved in their headache management, with CDH patients being more active. Given the initiatives towards higher involvement of the patients in the care of their chronic conditions, this reveals M, MWA and CDH sufferers as patients who are willing to be involved in their own care. The high level of suffering of the respondents suggests the need for more effective headache management and that the patients may be used as a resource to management. Therefore, patient education programmes should be developed to help the patients to maximise their efforts to achieve the maximum benefit.
8.2. Introduction

Migraines (with and without aura) affect 12% (15-18% of women and 6% of men) of the general population (Breslau and Rasmussen, 2001). On average, migraine patients suffer one attack per month, but the condition can progress to higher frequency headaches. Headaches with a frequency above 15 days per month, are clinically recognised as chronic daily headache (CDH). CDH affects 2.98% (Lanteri-Minet et al., 2003) to 4.1% (Scher et al., 1998) of the general population. Migraine and CDH adversely affect the patients’ quality of life, with CDH patients being more severely affected than episodic migraine patients (Meletiche et al., 2001).

The chronic nature of migraine and CDH require these high impact headaches to be managed over a prolonged period of time. The major responsibility for management lies with the patient, as most attacks are managed by the patient, in the absence of health care professionals. However, few studies have been carried out to investigate the migraine patients’ involvement in their headache care and even fewer data are available on CDH patients’ self-management. A qualitative study showed the migraine and CDH patients’ involvement in their own headache care and decision-making for their care (Peters et al., 2003a), but the view that migraine patients are passive in their headache management prevails.

It is recognised that headache management is best when the patient is actively involved (Silberstein et al., 2000) and that facts known by the physician need to be supplemented by facts that are only known by the patients (Sullivan, 2003). Therefore, gaining knowledge about the migraine and CDH patients’ perspective is important to make research and health care practice more patient-centred and focused on the issues that are important to the patients (Sullivan, 2003). This study aimed to
investigate and compare the management used by migraine (with and without aura) and CDH patients in the last 12 months, to gain further understanding of the involvement of headache patients in their own care.

8.3. Methods

8.3.2. Questionnaire

No previous questionnaire had investigated the holistic management of migraine or CDH from the patients' perspective. Therefore, based on the findings of a preliminary qualitative study (Peters et al., 2003b), a new questionnaire was developed to include 4 areas of management: 1) consultations, 2) acute and prophylactic medication and herbal/homeopathic remedies, 3) acute and prophylactic general management and 4) social support. Further sections included headache information (symptoms and impact) and biographical data.

The questionnaire was developed through collaboration by the authors. Two independent researchers with expertise in questionnaire design assessed the layout and feasibility of the questionnaire. To test content validity and feasibility, the questionnaire was administered to 10 headache patients. To test the validity and reliability of the diagnostic tool within the questionnaire, 30 patients who had previously been diagnosed by a headache clinician (AD) were asked to complete the questions relating to diagnosis. The first author made the diagnosis based on the returned questionnaires (n=26). The questionnaire diagnosis and clinician's diagnosis concurred in 22 cases (84%).
8.3.2.1. Respondents and recruitment

The questionnaire was targeted at adult headache patients (aged 18-65) who had either suffered from IHS migraine (M), IHS migraine with aura (MWA) or CDH (headache frequency >15 days per month) in the last 12 months. Only UK residents were included in the sample. Ethical approval was obtained from the University of Surrey Ethics Committee.

The respondents were recruited through the Migraine Action Association in the UK. The questionnaire was sent to a total of 887 patients and 543 questionnaires (61.2%) were returned.

8.3.2.2. Data preparation

Upon receipt the questionnaires were checked for eligibility (age and diagnosis) by the researcher. If a definite diagnosis of IHS migraine (with or without aura) or CDH were given, the questionnaire was entered into the statistics package. Of these 422 questionnaires, a 10% (n=42) random sample were selected and re-diagnosed independently by a headache clinician (AD) to assess the reliability of the diagnoses. Diagnoses concurred in 40 cases (95.2%).

Based on this data checking, 65 questionnaires were excluded from analysis, due to absence of headaches in the last 12 months (n=9), the respondent being over the age limit of 65 years (n=39), missing biographical data (n=5) or missing diagnostic data (n=12). The diagnosis of further 50 questionnaires could not be established and was discussed between the researcher and headache clinician (AD). This led to the exclusion of further 34 questionnaires, based on the headaches being unclassifiable (n=7) or the patients suffering from headaches other than migraines or CDH (n=27).
The remaining 16 questionnaires were entered for data analysis. Thus, 438 questionnaires were included in the data analysis.

**8.3.2.3. Analysis**

The questionnaire data were entered into SPSS 10.1 for analysis. Data were analysed by descriptive statistics to compare three groups: migraine (M), migraine with aura (MWA) and CDH. Descriptive statistics, chi-square Kruskal-Wallis, analysis of variance (ANOVA) and post-hoc Scheffe tests were used for statistical analysis. The level of significance was set at $p<0.05$.

**8.4. Results**

**8.4.2. Respondents**

Based on headache symptoms and headache frequency, of the 438 patients 117 (109 women and 8 men) were diagnosed as M patients, 238 (211 female and 27 male) as MWA patients and 82 (72 female and 10 male) as CDH patients. There were no significant differences in gender, marital status, ethnicity, level of education, work status, age, age of onset of headaches and years of headache experience between the three groups (Table 8.1).

**Table 8.1: Characteristics of the respondents by diagnosis**

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>49.9 (8.86)</td>
<td>48.3 (9.66)</td>
<td>49.9 (9.02)</td>
</tr>
<tr>
<td>Mean age at headache onset</td>
<td>21.58 (10.66)</td>
<td>19.26 (10.07)</td>
<td>18.88 (10.83)</td>
</tr>
<tr>
<td>Years of headache experience</td>
<td>28.63 (12.23)</td>
<td>28.94 (12.34)</td>
<td>30.99 (13.16)</td>
</tr>
</tbody>
</table>
8.4.3. Headache symptoms

The majority of respondents reported unilateral and pulsating or throbbing pain, aggravation of pain by physical activity, photophobia, phonophobia and nausea/vomiting (Table 8.2). The mean pain severity was 6.84 (sd 1.64) for M, 7.02 (sd 3.70) for MWA and 6.70 (sd 1.81) for CDH. No significant differences were found for pain severity, location of the headache, type of headache pain, aggravation of headache by physical activity and headache duration with medication between the 3 groups. Headache duration without medication was significantly longer for CDH than for M and MWA (p=0.016). Frequency of headaches (days per month) was significantly higher for CDH than for M and MWA (p=0.000), with CDH patients suffering a mean of 21.9 (sd 5.50) headache days vs. 6.84 (sd 1.64) days for M and 5.53 (sd 3.70) days for MWA patients. As far as associated symptoms were concerned, only phonophobia differed significantly (p=0.017), with CDH patients being more affected than M and MWA patients.

Table 8.2: Percentage of M, MWA and CDH patients reporting symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache location</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unilateral</td>
<td>93.2</td>
<td>88.7</td>
<td>85.4</td>
</tr>
<tr>
<td>Bilateral</td>
<td>6.8</td>
<td>11.3</td>
<td>14.6</td>
</tr>
<tr>
<td>Type of headache pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulsating or throbbing</td>
<td>56.5</td>
<td>53.7</td>
<td>44.9</td>
</tr>
<tr>
<td>Steady ache</td>
<td>35.7</td>
<td>30.4</td>
<td>43.6</td>
</tr>
<tr>
<td>Tight band</td>
<td>7.8</td>
<td>15.9</td>
<td>11.5</td>
</tr>
<tr>
<td>Aggravation by physical activity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Photophobia</td>
<td>94.9</td>
<td>85.6</td>
<td>92.6</td>
</tr>
<tr>
<td>Phonophobia</td>
<td>85.5</td>
<td>90.0</td>
<td>86.3</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>83.5</td>
<td>81.8</td>
<td>78.1</td>
</tr>
<tr>
<td>Aura symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual disturbance</td>
<td>-----</td>
<td>75.8</td>
<td>38.3</td>
</tr>
<tr>
<td>Speech disturbance</td>
<td>-----</td>
<td>59.8</td>
<td>45.6</td>
</tr>
<tr>
<td>Numbness</td>
<td>-----</td>
<td>41.1</td>
<td>38.3</td>
</tr>
<tr>
<td>Dizziness</td>
<td>-----</td>
<td>45.5</td>
<td>61.0</td>
</tr>
</tbody>
</table>
8.4.4. Headache impact

Overall headache impact, rated on a scale of 0-10 (no impact to a lot of impact), significantly differed (p<0.001) between the 3 groups. The mean impact was 5.53 (sd 2.29) for M, 5.51 (sd 2.40) for MWA and 7.16 (sd 1.13) for CDH. Post-hoc analysis (Scheffe test) showed that CDH patients were significantly more affected than M (p<0.001) and MWA patients (p<0.001). In terms of areas of life affected (Figure 8.1), between 64 and 90% of patients reported headache impact on paid work, housework, leisure activities, and family and social lives. Fewer patients reported an impact on career and education. Apart from paid work, more CDH patients reported impact than M or MWA on specific areas, but significant differences were only found in the impact on housework (p=0.021) and career (p=0.013). The total number of areas of life affected by headaches was significantly different between M, MWA and CDH. The post-hoc Scheffe test showed that CDH was significantly different from M (p=0.043) and MWA (p=0.03).

Figure 8.1: Impact reported by M, MWA and CDH patients
8.4.5. Consultations

8.4.5.1. Consultation rates

The total number of health professionals consulted significantly differed between groups (p=0.001). On average, M patients consulted 1.71 (sd 1.19) health professionals, compared with 1.84 (sd 1.65) for MWA and 2.53 (sd 1.81) for CDH. The post-hoc Scheffe test showed that CDH patients had consulted a significantly higher number of health professionals than M (p=0.002) and MWA (p=0.004) patients. The three groups had consulted a variety of health professionals, including medical professionals and alternative therapists (Figure 8.2). The highest consultation rates occurred with general practitioners. The pharmacist was the second most consulted health professional, whereas psychologists were the least consulted. No significant differences were found for the consultations with most health professionals, apart from higher consultations rates for CDH with headache specialists (p=0.027) and neurologists (p=0.002).

Figure 8.2: Consultations by M, MWA and CDH patients
Further significant differences in consultations were found when examining the consultation frequency of the three groups. Significant differences in the consultation frequency were found for consultations with the GP (p<0.001), the neurologist (p<0.001), the osteopath (p=0.018) and the psychologist (p=0.011). The mean consultation rates for every health professional are presented in Table 8.3 and the post-hoc Scheffe test revealed the following differences between the groups. CDH patients consulted GPs significantly more frequently than M (p=0.001) and MWA (P<0.001). Furthermore, CDH patients had consulted neurologists significantly more often than M (0.005) and MWA (p=0.001). The frequency of consultation with the osteopath was significantly different between CDH and M patients (p=0.019). Consultations with the psychologist were significantly more frequent for CDH patients than for M (p=0.036) and MWA patients (p=0.017).

Table 8.3: Frequency of consultations for M, MWA and CDH

<table>
<thead>
<tr>
<th>Health professional</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncturist</td>
<td>0.42</td>
<td>1.32</td>
<td>1.36</td>
<td>10.12</td>
</tr>
<tr>
<td>Chiropractor</td>
<td>0.19</td>
<td>0.78</td>
<td>1.28</td>
<td>7.91</td>
</tr>
<tr>
<td>Headache specialist</td>
<td>0.22</td>
<td>0.80</td>
<td>0.24</td>
<td>0.80</td>
</tr>
<tr>
<td>GP</td>
<td>2.00</td>
<td>2.05</td>
<td>1.93</td>
<td>2.59</td>
</tr>
<tr>
<td>Homeopath</td>
<td>0.17</td>
<td>0.93</td>
<td>0.43</td>
<td>2.05</td>
</tr>
<tr>
<td>Neurologist</td>
<td>0.18</td>
<td>0.60</td>
<td>0.17</td>
<td>0.51</td>
</tr>
<tr>
<td>Nurse</td>
<td>0.07</td>
<td>0.37</td>
<td>0.27</td>
<td>1.09</td>
</tr>
<tr>
<td>Osteopath</td>
<td>0.23</td>
<td>1.05</td>
<td>0.51</td>
<td>2.13</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>0.40</td>
<td>1.09</td>
<td>0.47</td>
<td>1.20</td>
</tr>
<tr>
<td>Psychologist</td>
<td>0.03</td>
<td>0.28</td>
<td>0.04</td>
<td>0.25</td>
</tr>
</tbody>
</table>
When analysing only the data of consulters (those who have had at least one consultation with a specified health professional in the last 12 months), consultation frequency only significantly differed for GP consultations \((p<0.001)\). The post-hoc Scheffe test showed that the frequency of GP consultations for consulters was significantly different in CDH patients \((\text{mean } 4.72, \text{sd } 4.55)\) when compared to M \((\text{mean } 2.58, \text{sd } 1.99)\) \((p<0.001)\) and MWA \((\text{mean } 2.95, \text{sd } 2.70)\) \((p=0.001)\).

8.4.6. Medication use

8.4.6.1. Acute medication

The majority of the patients (99.1% M, 99.6% MWA and 98.7% CDH) had used acute medication in the last 12 months. Acute medication use included the use of Over the Counter medications (OTCs) and prescription medications (Table 8.4). The use of OTCs differed between the 3 groups (69% M, 75.9% MWA and 81.7 CDH patients), but this difference was not significant. However, significantly more \((p=0.003)\) of M (86.2%) and CDH patients (82.7%) relied on acute prescription medication when compared to MWA (71.4%).

Table 8.4: Percentage of M, MWA and CDH patients using medication and other remedies

<table>
<thead>
<tr>
<th>Remedy</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>OTC medication</td>
<td>69.0</td>
<td>75.9</td>
<td>81.7</td>
</tr>
<tr>
<td>Acute prescription medication*</td>
<td>86.2</td>
<td>71.4</td>
<td>82.7</td>
</tr>
<tr>
<td>Prophylactic medication</td>
<td>45.2</td>
<td>38.6</td>
<td>48.1</td>
</tr>
<tr>
<td>Homeopathic/ herbal remedies</td>
<td>31.6</td>
<td>30.0</td>
<td>40.2</td>
</tr>
<tr>
<td>Vitamins/ minerals</td>
<td>17.4</td>
<td>20.3</td>
<td>27.5</td>
</tr>
</tbody>
</table>

NB. Significant difference \(p=0.003\)
The patients’ use of OTCs and prescription drugs already indicates that most patients had used more than 1 type of acute medication. Indeed, 71.7% M patients, 59.9% MWA sufferers and 79.0% CDH patients had treated their headaches with one or more types of medication. In terms of number of acute medications used, MWA patients had used an average of 1.92 (sd 0.97) types of medication, M patients had used 2.22 (sd 1.12) types and CDH had used 2.43 (sd 1.22) types. The number of medications used by MWA sufferers in the last 12 months was significantly lower than the mean number of medications used by M (p=0.046) and CDH patients (p=0.001).

CDH patients used both OTC and prescription medication more often than M and MWA patients (Table 8.5). Reflecting the difference in number of headaches days per month, the frequency of use of acute medications significantly differed for prescription (p<0.001) and OTC medication (p<0.001). The median frequency of use for OTCs was ‘once a week’ for M and MWA patients, and ‘2-4 times per week’ for CDH patients. The median frequency of use for prescription medication was ‘once a week’ for M, ‘every 2-3 weeks’ for MWA and ‘2-4 times per week’ for CDH.

Table 8.5: Frequency of use of OTC and prescription medication by M, MWA and CDH patients

<table>
<thead>
<tr>
<th>Frequency of use of OTCs</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>2.64</td>
<td>2.54</td>
<td>4.18</td>
</tr>
<tr>
<td>SD</td>
<td>1.34</td>
<td>1.43</td>
<td>1.12</td>
</tr>
<tr>
<td>p</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of use of prescription medication</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>2.52</td>
<td>2.17</td>
<td>3.70</td>
</tr>
<tr>
<td>SD</td>
<td>1.32</td>
<td>1.51</td>
<td>1.35</td>
</tr>
<tr>
<td>p</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NB. Level of significance (p) according to Kruskal Wallis test.
0= ‘less than once a month’; 1= ‘once a month’; 2= ‘every 2-3 weeks’; 3= ‘once a week’; 4= ‘2-4 times per week’ and 5= ‘5-7 times per week’.
Chapter 8: The Patients' Management of Migraine and Chronic Daily Headache

In terms of specific acute medications, combination medications (including caffeine-combinations, codeine-combinations, caffeine and codeine combinations and other combination medications) and triptans had been most widely in the last 12 months (Figure 8.3). Combination medications (p=0.026), and more specifically codeine combinations (p=0.040) and caffeine-codeine combinations (p=0.047) were used by significantly more CDH than M and MWA patients. Significantly more M and CDH patients (p=0.002) used triptans when compared to MWA patients.

8.4.6.2. Prophylactic medication

Although more CDH patients used prophylactics (Table 8.4), no significant differences were found between the 3 groups. Beta-blockers were used most frequently for prophylaxis in M (21.7%) and MWA (17.2%). A comparable number of CDH patients (19%) used beta-blockers, but the most common prophylactic used for CDH were anti-depressants (25.3%). Of the specific medications, only the use of anti-depressants significantly (p=0.004) differed between the groups.

The three groups also relied on herbal/homeopathic remedies and vitamins/minerals for prophylaxis, but these were used less often than prescription prophylactics (Table 8.4). Homeopathic/herbal remedies were used by 31.6% of M, 30% of MWA and 40.2% of CDH patients, with Feverfew being the most common remedy used. Vitamin/minerals were used by 17.4% of M, 20.3% of MWA and 27.5% of CDH patients, with magnesium being the most commonly used. Although more CDH patients used herbal/homeopathic remedies and vitamins and minerals, there were no significant differences in the use of either of these strategies or in the type of remedy.
Figure 8.3: Types of acute medication used by M, MWA and CDH patients
Figure 8.4: Types of prophylactic medication used by M, MWA and CDH patients
8.4.7. General management

8.4.7.1. Acute general management

Acute general management strategies included avoidance techniques, disability behaviours and active management strategies (Table 8.6). All three groups used acute general management strategies to treat headaches (Table 8.7). Avoidance techniques and disability behaviours were used by the majority of patients. Although still used at least sometimes by a substantial proportion of patients, active acute management strategies were used by fewer patients. Relaxation was the most used active strategy, whereas biofeedback was rarely used. Although all three groups used these strategies, no significant differences were found in the respondents’ level of use (Table 8.8).

Table 8.6: Areas of acute general management strategies

<table>
<thead>
<tr>
<th>Areas of acute management</th>
<th>Specific acute management techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidance techniques</td>
<td>Avoid alcohol, avoid bright light, avoid certain foods, avoid exercise, avoid head movement, avoid noise and avoid tea/coffee.</td>
</tr>
<tr>
<td>Disability behaviours</td>
<td>Avoid housework, leave social events, leave work, lie down and slow down.</td>
</tr>
<tr>
<td>Active acute management</td>
<td>Biofeedback, cold treatment, heat treatment, massage and relaxation</td>
</tr>
</tbody>
</table>
Table 8.7: Percentage of M, MWA and CDH patients using acute general management strategies at least sometimes

<table>
<thead>
<tr>
<th>Acute general management strategy</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid alcohol</td>
<td>91.2</td>
<td>89.9</td>
<td>93.6</td>
<td>91.6</td>
</tr>
<tr>
<td>Avoid bright light</td>
<td>84.1</td>
<td>94.3</td>
<td>91.5</td>
<td>90.0</td>
</tr>
<tr>
<td>Avoid certain food</td>
<td>75.6</td>
<td>78.8</td>
<td>82.6</td>
<td>79.0</td>
</tr>
<tr>
<td>Avoid exercise</td>
<td>72.9</td>
<td>69</td>
<td>72.4</td>
<td>71.4</td>
</tr>
<tr>
<td>Avoid head movement</td>
<td>74.2</td>
<td>80.8</td>
<td>87.5</td>
<td>80.8</td>
</tr>
<tr>
<td>Avoid housework</td>
<td>72</td>
<td>70.6</td>
<td>71.6</td>
<td>71.4</td>
</tr>
<tr>
<td>Avoid noise</td>
<td>86.8</td>
<td>87.1</td>
<td>90.3</td>
<td>88.1</td>
</tr>
<tr>
<td>Avoid tea/coffee</td>
<td>64.6</td>
<td>68.4</td>
<td>56.9</td>
<td>63.3</td>
</tr>
<tr>
<td>Leave social events</td>
<td>79.8</td>
<td>78.4</td>
<td>81.5</td>
<td>79.9</td>
</tr>
<tr>
<td>Leave work</td>
<td>62</td>
<td>65</td>
<td>56.9</td>
<td>61.3</td>
</tr>
<tr>
<td>Lie down</td>
<td>92.2</td>
<td>90.1</td>
<td>86.5</td>
<td>89.6</td>
</tr>
<tr>
<td>Slow down</td>
<td>92.9</td>
<td>92.6</td>
<td>95.1</td>
<td>93.5</td>
</tr>
<tr>
<td>Biofeedback</td>
<td>4.4</td>
<td>8.0</td>
<td>5.7</td>
<td>6.0</td>
</tr>
<tr>
<td>Cold treatment</td>
<td>48.8</td>
<td>43.2</td>
<td>51.8</td>
<td>47.9</td>
</tr>
<tr>
<td>Heat treatment</td>
<td>37.7</td>
<td>33.8</td>
<td>38.7</td>
<td>36.7</td>
</tr>
<tr>
<td>Massage</td>
<td>50.9</td>
<td>42.2</td>
<td>45.6</td>
<td>46.2</td>
</tr>
<tr>
<td>Relaxation</td>
<td>67.3</td>
<td>69.1</td>
<td>65.4</td>
<td>67.3</td>
</tr>
</tbody>
</table>
### Table 8.8: The level of use of acute general management strategies by M, MWA and CDH patients

<table>
<thead>
<tr>
<th>Acute general management strategy</th>
<th>M</th>
<th>SD</th>
<th>MWA</th>
<th>SD</th>
<th>CDH</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid alcohol</td>
<td>3.32</td>
<td>1.21</td>
<td>3.23</td>
<td>1.24</td>
<td>3.37</td>
<td>1.08</td>
</tr>
<tr>
<td>Avoid bright light</td>
<td>2.88</td>
<td>1.20</td>
<td>3.17</td>
<td>1.01</td>
<td>3.04</td>
<td>0.96</td>
</tr>
<tr>
<td>Avoid food triggers</td>
<td>2.48</td>
<td>1.47</td>
<td>2.65</td>
<td>1.40</td>
<td>2.70</td>
<td>1.34</td>
</tr>
<tr>
<td>Avoid exercise</td>
<td>2.38</td>
<td>1.42</td>
<td>2.22</td>
<td>1.39</td>
<td>2.23</td>
<td>1.30</td>
</tr>
<tr>
<td>Avoid head movement</td>
<td>2.52</td>
<td>1.45</td>
<td>2.45</td>
<td>1.24</td>
<td>2.56</td>
<td>1.18</td>
</tr>
<tr>
<td>Avoid housework</td>
<td>2.30</td>
<td>1.43</td>
<td>2.14</td>
<td>1.38</td>
<td>2.20</td>
<td>1.21</td>
</tr>
<tr>
<td>Avoid noise</td>
<td>2.90</td>
<td>1.22</td>
<td>2.72</td>
<td>1.17</td>
<td>2.87</td>
<td>0.97</td>
</tr>
<tr>
<td>Avoid tea/coffee</td>
<td>2.16</td>
<td>1.52</td>
<td>2.27</td>
<td>1.46</td>
<td>1.85</td>
<td>1.50</td>
</tr>
<tr>
<td>Leave social events</td>
<td>2.28</td>
<td>1.09</td>
<td>2.16</td>
<td>1.02</td>
<td>2.28</td>
<td>0.95</td>
</tr>
<tr>
<td>Leave work</td>
<td>1.85</td>
<td>1.20</td>
<td>1.85</td>
<td>1.14</td>
<td>1.72</td>
<td>1.07</td>
</tr>
<tr>
<td>Lie down</td>
<td>2.74</td>
<td>0.97</td>
<td>2.72</td>
<td>0.99</td>
<td>2.57</td>
<td>1.04</td>
</tr>
<tr>
<td>Slow down</td>
<td>2.90</td>
<td>1.01</td>
<td>2.85</td>
<td>0.99</td>
<td>2.87</td>
<td>0.96</td>
</tr>
<tr>
<td>Use biofeedback</td>
<td>0.18</td>
<td>0.59</td>
<td>0.24</td>
<td>0.65</td>
<td>0.30</td>
<td>0.62</td>
</tr>
<tr>
<td>Use cold treatment</td>
<td>1.42</td>
<td>1.47</td>
<td>1.24</td>
<td>1.31</td>
<td>1.48</td>
<td>1.44</td>
</tr>
<tr>
<td>Use heat treatment</td>
<td>1.11</td>
<td>1.35</td>
<td>0.88</td>
<td>1.13</td>
<td>1.13</td>
<td>1.29</td>
</tr>
<tr>
<td>Use massage</td>
<td>1.39</td>
<td>1.22</td>
<td>1.13</td>
<td>1.08</td>
<td>1.23</td>
<td>1.12</td>
</tr>
<tr>
<td>Use relaxation</td>
<td>1.81</td>
<td>1.17</td>
<td>1.78</td>
<td>1.14</td>
<td>1.83</td>
<td>1.22</td>
</tr>
</tbody>
</table>

NB. No statistically significant differences were found, using the Kruskal Wallis test.

0 = 'never'; 1 = 'rarely'; 2 = 'sometimes', 3 = 'often' and 4 = 'always'.

8.4.7.2. Prophylactic general management

Prophylactic general management strategies, including avoidance techniques and healthy lifestyle (Table 8.9), were used less often, but apart from avoiding exercise, more than 50% of patients used these strategies at least sometimes (Table 8.10). Eating regularly to prevent headaches was the most commonly used management strategy, whereas avoiding exercise was the least commonly used prophylactic strategy. Significant differences in the level of use of prophylactic strategies were found between the groups (Table 8.10) for avoidance of bright light (p=0.007), exercise (p=0.011), avoidance of noise (p=0.004) and food triggers (p=0.025). Avoidance of bright light, exercise and noise were used more frequently by CDH patients than M and MWA patients. The avoidance of food triggers was used less often by M patients than by MWA and CDH patients.

Table 8.9 Prophylactic general management strategies

<table>
<thead>
<tr>
<th>Areas of prophylactic management</th>
<th>Specific prophylactic management techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoidance techniques</td>
<td>Avoid bright light, avoid exercise, avoid noise, avoid stress, avoid food triggers and avoid non food triggers</td>
</tr>
<tr>
<td>Healthy lifestyle</td>
<td>Eat regularly, sleep regularly, prophylactic exercise and relaxation</td>
</tr>
</tbody>
</table>
Table 8.10 Percentage of M, MWA and CDH patients using prophylactic general management at least sometimes

<table>
<thead>
<tr>
<th>Prophylactic general management strategy</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid bright light</td>
<td>56.6</td>
<td>66.8</td>
<td>77.2</td>
</tr>
<tr>
<td>Avoid exercise</td>
<td>25.9</td>
<td>33.4</td>
<td>52.4</td>
</tr>
<tr>
<td>Avoid noise</td>
<td>52.0</td>
<td>53.9</td>
<td>78.5</td>
</tr>
<tr>
<td>Avoid stress</td>
<td>72.3</td>
<td>71.9</td>
<td>77.6</td>
</tr>
<tr>
<td>Avoid food triggers</td>
<td>64.8</td>
<td>78.7</td>
<td>76.0</td>
</tr>
<tr>
<td>Avoid non-food triggers</td>
<td>70.5</td>
<td>94.5</td>
<td>82.2</td>
</tr>
<tr>
<td>Eat regularly</td>
<td>95.6</td>
<td>95.9</td>
<td>98.7</td>
</tr>
<tr>
<td>Sleep regularly</td>
<td>93.0</td>
<td>92.8</td>
<td>92.5</td>
</tr>
<tr>
<td>Prophylactic exercise</td>
<td>64.3</td>
<td>69.1</td>
<td>64.6</td>
</tr>
<tr>
<td>Relaxation</td>
<td>67.2</td>
<td>70.2</td>
<td>66.2</td>
</tr>
</tbody>
</table>

Table 8.11: Level of use of prophylactic general management strategies by M, MWA and CDH patients

<table>
<thead>
<tr>
<th>Prophylactic general management strategy</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
<th>Kruskal Wallis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid bright light</td>
<td>1.72</td>
<td>1.30</td>
<td>2.03</td>
<td>2.35</td>
</tr>
<tr>
<td>Avoid exercise</td>
<td>0.87</td>
<td>1.04</td>
<td>0.96</td>
<td>1.12</td>
</tr>
<tr>
<td>Avoid noise</td>
<td>1.54</td>
<td>1.28</td>
<td>1.56</td>
<td>1.30</td>
</tr>
<tr>
<td>Avoid stress</td>
<td>1.90</td>
<td>1.04</td>
<td>1.92</td>
<td>1.08</td>
</tr>
<tr>
<td>Avoid food triggers</td>
<td>2.00</td>
<td>1.41</td>
<td>2.58</td>
<td>1.39</td>
</tr>
<tr>
<td>Avoid non-food triggers</td>
<td>2.08</td>
<td>1.34</td>
<td>2.40</td>
<td>1.26</td>
</tr>
<tr>
<td>Eat regularly</td>
<td>3.35</td>
<td>0.92</td>
<td>3.32</td>
<td>0.91</td>
</tr>
<tr>
<td>Sleep regularly</td>
<td>3.09</td>
<td>1.04</td>
<td>3.11</td>
<td>0.99</td>
</tr>
<tr>
<td>Exercise</td>
<td>1.83</td>
<td>1.24</td>
<td>1.97</td>
<td>1.19</td>
</tr>
<tr>
<td>Relaxation</td>
<td>1.78</td>
<td>1.05</td>
<td>1.92</td>
<td>1.11</td>
</tr>
</tbody>
</table>

NB. 0 = 'never'; 1 = 'rarely'; 2 = 'sometimes'; 3 = 'often' and 4 = 'always'.

227
The individual prophylactic strategies were grouped to give an overall score for avoidance strategies and lifestyle strategies. The use of prophylactic avoidance techniques was significantly different between the groups (p<0.001). Of a maximum score of 24, the mean scores were 9.91 (sd 5.24) for M, 11.36 (sd 5.10) for MWA and 13.14 (sd 5.17) for CDH. Post-hoc analysis showed, that CDH used significantly more general prophylactic strategies than M (p<0.001) and MWA patients (p=0.043).

The use of prophylactic general management, consisting of the total score of 10 strategies (score range 0-40), was significantly different (p=0.003) between groups. The mean score was 19.62 (sd 6.69) for M, 21.67 (sd 6.60) for MWA and 23.01 (sd 6.48) for CDH. Post-hoc analysis showed that M patients had significantly lower scores than CDH (p=0.005) and MWA patients (p=0.039).

8.4.8. Social support

Using social support was the least used management strategy, but most (apart from patient support groups and charity help-lines) strategies were used at least sometimes by more than 30% of the patients (Table 8.12). No significant differences were found in the level of use of social support between the three groups. Social support focused on 3 areas: media (internet, magazines, newspapers, scientific articles and television); family and friends (family, friends and work colleagues) and patient support (charity publications and telephone/email help-line, other headache patients and support groups). Other headache patients and reading, including charity publications, magazines, newspapers and scientific articles, were used at least sometimes by over 50% of patients. Charity telephone/email help-lines and support groups were used the least often.
Table 8.12: Percentage of M, MWA and CDH patients using social support at least sometimes

<table>
<thead>
<tr>
<th>Source of social support</th>
<th>M (%)</th>
<th>MWA (%)</th>
<th>CDH (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity publications</td>
<td>73.1</td>
<td>80.7</td>
<td>79.9</td>
</tr>
<tr>
<td>Charity telephone/ email help-line</td>
<td>7.5</td>
<td>8.6</td>
<td>14.6</td>
</tr>
<tr>
<td>Family</td>
<td>40.5</td>
<td>40.0</td>
<td>31.1</td>
</tr>
<tr>
<td>Friends</td>
<td>48.6</td>
<td>47.6</td>
<td>40.5</td>
</tr>
<tr>
<td>Internet</td>
<td>39.3</td>
<td>30.8</td>
<td>44.3</td>
</tr>
<tr>
<td>Magazines</td>
<td>72.7</td>
<td>72.8</td>
<td>77.2</td>
</tr>
<tr>
<td>Newspapers</td>
<td>70.7</td>
<td>72.4</td>
<td>74.7</td>
</tr>
<tr>
<td>Other patients</td>
<td>60.0</td>
<td>58.7</td>
<td>60.8</td>
</tr>
<tr>
<td>Support groups</td>
<td>10.6</td>
<td>12.4</td>
<td>15.3</td>
</tr>
<tr>
<td>Scientific articles</td>
<td>44.8</td>
<td>53.5</td>
<td>57.1</td>
</tr>
<tr>
<td>Television</td>
<td>31.9</td>
<td>33.4</td>
<td>35.1</td>
</tr>
<tr>
<td>Work colleagues</td>
<td>34</td>
<td>31.8</td>
<td>23.9</td>
</tr>
</tbody>
</table>

8.4.9. Patients' opinions

The patients' rated their level of agreement with 18 statements on headaches and headache management. The table shows the respondents mean level of agreement (and standard deviation) with each statement. Significant differences between the 3 groups were found for 11 of the 18 statements (Table 8.13). Overall, CDH patients had a more negative attitude towards headaches and their management, for example they found consultations with the doctor significantly less helpful and were significantly less satisfied with their headache management. Even in the statements for which no significant differences were found, the trend was towards a more negative attitude of the CDH patients.

In terms of effectiveness of management strategies, medication was perceived as the most effective way to manage headaches. Self-help, although not considered as effective as medication, was thought more effective than alternative therapies.
Receiving advice from friends and family was not thought as helpful as reading about headaches. Interestingly, reading about headache was considered more helpful than talking to the doctor or other health professionals. Satisfaction with management was low and patients wanted better management for their headaches. The respondents knew that headaches are not curable and believed that headache treatment had improved in the last 10 years. M and MWA patients tended to agree that headaches could be treated successfully, whereas CDH patients tended to disagree with this statement.
Table 8.13: M, MWA and CDH patients’ opinions about headache and headache management.

<table>
<thead>
<tr>
<th>Opinion</th>
<th>M</th>
<th>MWA</th>
<th>CDH</th>
<th>Kruskal Wallis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication is effective to manage my headaches</td>
<td>2.86</td>
<td>2.56</td>
<td>2.20</td>
<td>0.001</td>
</tr>
<tr>
<td>Self-help (such as avoiding triggers) is effective to manage my headaches</td>
<td>2.30</td>
<td>2.54</td>
<td>2.05</td>
<td>0.001</td>
</tr>
<tr>
<td>Alternative therapies (such as osteopathy) are effective to manage my headaches</td>
<td>1.64</td>
<td>1.81</td>
<td>1.54</td>
<td>0.019</td>
</tr>
<tr>
<td>Receiving advice from friends and family is helpful to manage my headaches</td>
<td>1.60</td>
<td>1.72</td>
<td>1.35</td>
<td>0.013</td>
</tr>
<tr>
<td>Reading about headache is helpful to manage headaches</td>
<td>2.65</td>
<td>2.63</td>
<td>2.42</td>
<td>0.99</td>
</tr>
<tr>
<td>I am satisfied with my headache management</td>
<td>1.95</td>
<td>1.97</td>
<td>1.40</td>
<td>0.001</td>
</tr>
<tr>
<td>Talking to the doctor about my headaches is helpful</td>
<td>2.16</td>
<td>2.05</td>
<td>1.77</td>
<td>0.050</td>
</tr>
<tr>
<td>Talking to health professionals other than the doctor about my headaches is helpful</td>
<td>2.18</td>
<td>2.14</td>
<td>1.87</td>
<td>0.98</td>
</tr>
<tr>
<td>I know how to manage my headaches effectively</td>
<td>2.18</td>
<td>2.21</td>
<td>1.80</td>
<td>0.008</td>
</tr>
<tr>
<td>I would like better management for my headaches</td>
<td>3.16</td>
<td>3.00</td>
<td>3.38</td>
<td>0.002</td>
</tr>
<tr>
<td>Headaches can be treated successfully</td>
<td>2.29</td>
<td>2.21</td>
<td>1.91</td>
<td>0.97</td>
</tr>
<tr>
<td>Headaches are curable</td>
<td>1.47</td>
<td>1.53</td>
<td>1.35</td>
<td>0.98</td>
</tr>
<tr>
<td>Headache treatment has improved in the last 10 years</td>
<td>2.96</td>
<td>2.90</td>
<td>2.65</td>
<td>0.045</td>
</tr>
<tr>
<td>Headaches make life difficult</td>
<td>3.71</td>
<td>3.65</td>
<td>3.74</td>
<td>0.47</td>
</tr>
<tr>
<td>Headaches are a misunderstood condition</td>
<td>3.54</td>
<td>3.62</td>
<td>3.78</td>
<td>0.42</td>
</tr>
<tr>
<td>Taking medication always leads to side effects</td>
<td>2.48</td>
<td>2.53</td>
<td>2.73</td>
<td>0.97</td>
</tr>
<tr>
<td>Everybody gets headaches like I do</td>
<td>0.61</td>
<td>0.74</td>
<td>0.62</td>
<td>0.83</td>
</tr>
<tr>
<td>Headaches are a serious health problem</td>
<td>3.00</td>
<td>2.58</td>
<td>2.91</td>
<td>1.19</td>
</tr>
</tbody>
</table>

NB 0=strongly disagree; 1=disagree; 2= neither agree, nor disagree; 3= agree; 4= strongly agree
8.5. Discussion

Focusing on the holistic management of M, MWA and CDH, this study shows that patients are actively involved in their headache management. Furthermore, management is based on a combination from 4 areas including consultations, use of medication and alternative remedies, general (acute and prophylactic) management and social support. Strategies were highly used, with most strategies being used by over 50% of patients. The level of use for some management strategies was dependent on the headache diagnosis, whereas other management strategies were equally used by the 3 groups.

It was mainly the behaviour of CDH patients that differed from the behaviour of M and MWA patients. CDH patients tended to be more active in their management. These differences were not always significant, but for the non-significant results there was a trend towards a higher level of activity in CDH patients. This indicates that the higher frequency of CDH makes these patients more active in their headache management. However, the high headache frequency and the high headache impact suggest that, despite the patients’ efforts, CDH management is not effective and/or not appropriate. Indeed, the high use of medication is cause for concern. In this study, most CDH patients used acute medication several times a week. Since the majority of transformed migraine patients (62.5%) reported that medication provided the main headache improvement factor (Galego et al., 2002), CDH patients may believe that using medication is the best approach to treat headaches. In this study, CDH patients most strongly agreed that medication was effective to manage their headaches, whereas they found self-help and alternative therapies less effective. However, over-use of medication may be a contributory factor in the development of
CDH (Diener and Katasarva, 2001). Therefore, acute medication use should be limited and more emphasis should be put onto prophylaxis. In this study, only 48.1% of the CDH patients were using prophylactics. Since the majority of CDH patients (75.6%) have consulted their GP within the last 12 months, there is scope to prescribe prophylactic medication to these patients and to educate CDH patients about the implications of medication over-use in the development of their CDH.

As far as the respondents’ beliefs and attitudes were concerned, it was also mainly CDH patients who differed from the other two groups. Overall, CDH patients had a more negative attitude than M and MWA patients. CDH patients disagreed more strongly that medication, self-help and alternative therapies were effective to manage headaches. Also, they found receiving advice from friends and family, reading about headaches and talking to the doctor, less helpful than M and MWA patients. CDH patients were more dissatisfied with their management and reported that they knew less well how to manage their headaches effectively. Accordingly, CDH patients expressed a stronger desire for better headache management. The CDH patients’ negative beliefs and attitudes, particularly towards the effectiveness of management strategies, may be a barrier towards self-management and lead to passive behaviour.

Indeed, in the qualitative phase (Chapter 6), low expectations and failed experiences with management strategies were barriers to adopting or maintaining a given management strategy. However, the quantitative findings show that the CDH patients’ beliefs and attitudes did not stop CDH sufferers to be actively involved in their headache management. Indeed, CDH patients were more active in their management than M and MWA patients, who reported less negatives beliefs and attitudes. This may mean that CDH patients benefit from their management behaviours, despite their negative beliefs and attitudes. However, this remains
speculative since the study design does not allow drawing conclusions on the effectiveness of self-management on the patients' outcomes. Another possible explanation may be found within the qualitative data (Chapter 6), which showed that headache severity, in terms of symptoms and perceived suffering, influenced the management behaviours of migraine and CDH patients. Thus it may be that the patients' perceptions of headaches have a stronger influence on management behaviour than the patients' perceptions of management strategies. The influences of the patients' perceptions on management behaviour, and predictors for management behaviour, are areas of self-management that need further investigation.

In terms of the level of use of individual management strategies, previous studies have predominantly focused on health care and medication use in migraine. In this study, the GP was the most frequently consulted health professional, both in terms of consultation rates and consultation frequency. In comparison to previous studies, more patients in this study relied on consultations with family physicians. Migraine studies have shown physician consultation rates of 50% in the US (Brandes, 2002) (Lipton and Stewart, 1999) and 29% (family physician) in Taiwan for migraine, versus consultation rates with GPs of 67.7% for M and 78.0% for MWA. CDH studies have shown consultation rates of 41% with family physician (Wang et al., 2001) a substantially lower rate than the 75.2% consultation rate found in this study. However, neurologist consultation rates for CDH have been reported at the same level (28%) (Wang et al., 2001) than those found in this study.

As far as consultations with health professionals other than physicians are concerned, few data are available and they focus on migraine. The available data do not give all the necessary details or the health professionals under investigation differ from those
in this study. Edmeads and colleagues (1993) reported that many headache patients consulted chiropractors, acupuncturists, masseuses, homeopaths and nutritionists. However, the authors did not give any details on consultation rates and thus no comparisons can be drawn to this study. A further Canadian study revealed that 1.51% of migraine patients reported consulting a nurse, 71.4% had consulted a dental practitioner, 42.5% an optician, 23.9% a pharmacist, 6.9% a physiotherapist, 14.8% a chiropractor and 11.7% a psychologist, social worker or other counsellor (To and Wu, 1995). In this study, consultations with a nurse were higher than those found by To and Wu (5.3% M, 11.3% MWA and 10.0% CDH patients). Consultations with pharmacists were comparable for M and MWA patients (17.7% and 24.4% respectively), but higher rates were reported by CDH patients (30.5%). Consultations with a chiropractor were reported by 7.8% M, 12.1% MWA and 21.4% of CDH patients. Consultations with the psychologist were reported by 0.9% of M, 2.6% of MWA and 6.4% of CDH patients. However, due to its design, the study by To and Wu did not allow to conclude whether these visits were for migraine.

The number of patients using medication have both been reported at similar and at lower levels. In this study, over 98% of patients reported to have used acute medication in the last 12 months. This corresponds to the levels of medication use (94%) by migraine patients in the UK (Dowson and Jagger, 1999). Other studies showed lower levels of medication use, such as 72% of French patients using medication (Michel et al., 1996). The use of prescription medication (over 70%) was also substantially higher in this study, than in a US study (41%) (Lipton et al., 2001). In terms of specific medications, triptans were of particular interest, as they were used by the majority of patients (57.7% MWA, 75.2% M and 67.8% CDH). In
previous studies, only 10-18% (Dowson and Jagger, 1999; Brandes, 2002; Lipton et al., 2003) of migraine patients had used triptans.

In this study MWA patients had used fewer types of acute medication and few MWA patients used prescription medication and triptans. This was surprising as a previous study showed that symptoms such as aura influence the diagnosis of migraine (Lipton et al., 1992) and the use of prescription medication (Celentano et al., 1992).

The lower use of prescription medication and triptans in this study may be explained by the patients' opinions. MWA patients were more likely to report self-help and alternative therapies as effective for the management of their headaches.

The higher use of GP consultations and medication in this study population may be related to the respondents' membership of the Migraine Action Association. The newsletter, which Migraine Action Association members receive four times a year, provides information about migraine management, including consultations and new treatments. The respondents found reading more helpful in the management of their headaches than consultations with the doctor and other health professionals. Thus, through their reading, the respondents may be better informed about treatment availability, which may make them more pro-active and assertive in their pursuit of finding effective treatment. A study in the Netherlands found that 58% of headache patients attributed their reduction in headache impact to social support strategies such as the support by the Dutch Society of Headache Patients (Vos and Passchier, 2003).

The Migraine Action Association newsletter also reports on other strategies, such as alternative therapies and general management. Thus the high levels of use of other management strategies may also be higher in this study population than in the general population.
This study shows that there is a large group of M, MWA and CDH patients, who are actively involved in their headache management. Furthermore, since the majority of respondents have reported to use social support strategies, this study shows the benefits of using patient charities and the media in educating the patients about headache management in terms of achieving higher levels of activity for the management of M, MWA and CDH. Indeed, having better information may have been an incentive to consult, since more lapsed (60%) and non-consulters (65%) than current consultants (42%) felt that they did not have most current information (Adelman et al., 2000). Given that most of the patients in this study, and particularly CDH patients, still suffered from high frequency headaches, it is important that the patients’ efforts to manage their headaches are maximised and optimised. The differences in management found in this study, in relation to diagnosis, need to be taken into consideration when educating patients about headache management.

8.6. Conclusion

This study shows that M, MWA and CDH patients are actively involved in their headache management and that management is a combination of 4 areas including consultations, use of medication and alternative remedies, general management and social support. Most strategies were used by over 50% of patients and the level of use was dependent on the headache diagnosis for some, but not all, strategies. Overall, CDH patients were more active in their headache management than M and MWA patients. Also, CDH patients had more negative attitudes and beliefs towards headaches and their management, as well as their own ability to manage headaches effectively.
Health care is changing towards a greater involvement of the patient in his/her own care. The new chronic disease paradigm, in which the health professional provides the expertise about the disease and the patient provides the knowledge about his/her life and experience (Bodenheimer et al., 2002; Holman and Lorig, 2000), can only be implemented if the patients are willing to be involved. The patients’ high level of involvement in their own care indicates the headache patients’ willingness to participate in their care. The high levels of suffering experienced by the respondents of this study suggest that these patients’ headache management is not as effective as it could be. Education programmes are needed to maximise the patients’ efforts towards gaining the greatest benefit for the patients, in terms of reducing headache impact and improving quality of life.
8.7. References


description of chronic daily headache in the general population in France", *Pain*, vol. 102, pp. 143-149.


Chapter 8: The Patients' Management of Migraine and Chronic Daily Headache


Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods.

Based on: M. Peters; H. Huijer Abu-Saad; I. Robbins, V. Vydelingum; A. Dowson; M. Murphy. 2003, “The patients’ involvement in migraine and chronic daily headache management: A study combining qualitative and quantitative methods.”

Manuscript in preparation.
9.1. Abstract:

Aim: The aim of this study was to investigate the patients' perspective of migraine and chronic daily headache (CDH) management.

Methods: The study was conducted in two phases in the UK. The sample for both phases included adult (aged 18-65) headache patients, who suffered either from migraine according to the International Headache Society criteria or from CDH (headache frequency >15 days per month). First, a qualitative phase was conducted, using semi-structured interviews that were analysed according to the grounded theory methodology. Secondly, a quantitative phase was carried out, based on a postal survey that was administered to migraine, migraine with aura and CDH patients, who were members of the Migraine Action Association (UK).

Findings: The qualitative findings revealed the patients' decision-making for their headache management, their perceptions of headache and headache management and the complete set of management strategies used to treat and prevent headaches. Patients were highly involved in their headache management and perceived themselves as key resource to management.

The survey showed the proportion of patients using management strategies from 4 areas of management including health care consultations, medication use, general management and social support. The survey also showed the differences in use of the management strategies. Overall, CDH patients were more active in their headache management, but not all these findings were statistically significantly different.
Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

Conclusion: Both the qualitative and quantitative findings showed the patients’ high level of involvement in their headache care. Combining the two methodologies helped to confirm and reinforce the findings. The results of this study can be used to inform and educate health professionals, including headache clinicians and researcher to make research and clinical practice more patient-centred, to set up education programmes for patients and to maximise the patients’ efforts to achieve successful headache outcome.
9.2. Introduction

With chronic disease having become the principal medical problem, the approach to the management of chronic disease has evolved to put more emphasis on the patients’ involvement. In the UK, the Department of Health advocates the expert patient as a new approach to chronic disease management (Department of Health, 2001). It is time for the patient to become a partner and expert in care and to create a new generation of patients who are empowered to take action to improve their own health (Donaldson, 2003). In chronic disease, patient self-management is inevitable and patients make decisions about their condition everyday (Bodenheimer et al., 2002). The patient must become a partner, who contributes at almost every decision and action level (Holman and Lorig, 2000). Based on these factors, a new chronic disease paradigm has been introduced: the patient and health care professional relationship involving collaborative care and self-management education (Bodenheimer et al., 2002; Holman and Lorig, 2000).

The chronic disease paradigm implies that the health professional is the expert about the disease, whereas the patients are the experts about their own lives. Facts known by the physician need to be supplemented by facts that are only known by the patients to make research and health care practice more patient-centred and focused on the issues that are important to the patients (Sullivan, 2003). When the patient and health care professional recognise and respect the other’s area of expertise, they can work together to pool their knowledge and choose the way forward (Kennedy, 2003).

Affecting 12% (Breslau and Rasmussen, 2001) and 3.2% (Lu et al., 2001) of the general population respectively, migraine and CDH are chronic diseases that need to
be managed over a prolonged period of time. It is recognised that headache management is best when the patient is actively involved (Silberstein et al., 2000). Headaches generally occur in the absence of the doctor and patients have to make their own decisions for management. Patients indirectly express their choices by behaving in a certain way, for example by not taking their drugs (Kravitz and Melnikov, 2001). Therefore, gaining knowledge into the patients’ involvement in their migraine and CDH management is important. However, little is known about the patients’ management of CDH. As far as migraine is concerned, studies have focused on doctors’ consultations and medication use. Consultation rates for migraine remain low (Lipton et al., 1998) and migraine is under-diagnosed and under-treated (Lipton et al., 1992; Lipton et al., 2000), with patients predominantly using Over the Counter (OTC) medications (Lipton et al., 2001). Thus it has been suggested that migraine sufferers learn to cope and live with their disease, rather than actively seek effective treatment (Michel et al., 1996).

To understand the patients’ involvement in their own care, it is important for health service providers to receive feedback from the patients about the care that is offered (Edwards and Staniszewska, 2000). Thus, if migraine and CDH patients are to become a resource to headache management, it is important to understand the patients’ current involvement in headache care. Gaining insight into the patients’ perspective may help to identify areas for patient-centred research and health care, patient education and self-management. This study aimed to investigate the migraine and CDH patients’ perspective of headache management. Four research questions had been formulated:

1. How do migraine and CDH patients perceive headaches and headache care?
2. Which management strategies do migraine and CDH patients use?

3. What are the differences in the use of management strategies between different types of headache patients (migraine, migraine with aura and CDH)?

4. What is the patients' involvement in their migraine and CDH care?

Combining qualitative and quantitative research is required to investigate and enhance the study of long-term chronic illnesses (Casebeer and Verhoef, 1997). Therefore, this study used a combination of qualitative and quantitative methods to address the research aim and questions.

**9.3. Qualitative phase**

**9.3.1. Rationale**

A qualitative methodology was chosen for the first part of the study, since qualitative methods deal with gaining insight into the participants' unique experiences and their interpretation of these experiences (Soafer, 1999). In qualitative studies, the participants are allowed to speak freely (Edwards and Staniszewska, 2000), thus qualitative methods gain access to the participants' perspective, particularly their perceptions, beliefs and attitudes. Also qualitative research is suitable to investigate areas that have previously little attention (Pope and Mays, 1995). Qualitative studies have been under-used in headache research, but could make an important contribution to gaining insight into headache (Peters et al., 2002). Based on the research aim and questions, the qualitative phase aimed:

- To gain access into the patients’ perceptions and experiences of headache and its management.
Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

- To identify which management strategies headache patients use.

- To identify the patients' involvement in their headache care.

The qualitative phase was carried out according to the grounded theory methodology, including theoretical sampling and simultaneous data collection and analysis. Thus the aim of the qualitative phase was to gain understanding of the patients' behaviours and to help develop the survey. The aim of the survey was to measure the patients' level of activity in their own headache management and to make the qualitative findings applicable to a wider sample. Ethical approval had been obtained by the University of Surrey Ethics Committee.

9.3.2. Methods

9.3.2.1. Recruitment and participants

Based on theoretical sampling, a convenience sample was recruited through personal contacts, posters in 2 local supermarkets and letters to 20 members of the Migraine Action Association. To be included in the study, the participants, had to be aged 18-65 years and had to suffer from migraine according to the International Headache Society (IHS) criteria (Headache Classification Committee of the International Headache Society, 1988). Patients with co-existing headaches or patients who had developed CDH were not excluded. A total of 39 patients had been contacted and 15 dissimilar cases were recruited. Of the 15 participants, one woman withdrew before the interview and the first interview, with a female migraine sufferer, served as a pilot interview. Thus the interviews of 13 participants (9 women and 4 men) were included in the analysis.
Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

All 13 participants suffered from IHS migraine. Three patients also suffered from tension-type headache (TTH) and based on their headache frequency (> 15 days per months) 5 patients were classed as suffering or having from CDH. CDH patients experienced higher frequency and lower severity headaches, as well as full migraine attacks. One patient had been effectively treated for CDH and did not suffer from CDH at the time of the study. One participant (Pt 1) had never consulted for migraine, 6 participants had not consulted within the last 12 months and 6 participants were had consulted within the last year. Four participants (1 lapsed and 3 current consulters) had consulted either a headache specialist or a neurologist. Levels of headache-related disability ranged from no disability to severe disability (as assessed by the Migraine Disability Assessment (MIDAS) questionnaire). The patients’ characteristics are presented in Table 4.3. (Chapter 4, p.132).

9.3.2.2. Data collection

Data were collected by semi-structured, individual and tape-recorded interviews. The researcher and her supervisors had devised a flexible interview guide based on recent migraine literature. Initial questions focused on migraine experience, physician consultations and treatments for migraine and CDH. As interviewing and the analysis progressed, the further questions were included in the interview guide to collect further data on previously raised issues and emerging concepts. These questions concentrated on patients' preferences, choices and decisions and a more holistic approach to management (such as alternative therapies, life-style and self-management).
Interviews were carried out to the participants' convenience, at their home, workplace or at the University of Surrey. The participants, who all signed the consent form, were interviewed once. Interviews lasted up to 2 hours with recording time averaging 1 hour (range 50-90 minutes). Interviewing finished with data saturation.

9.3.2.3. Data analysis

Interviews were transcribed verbatim. The transcripts were coded in QSR NUD*IST5 (N5), a qualitative software package. To reduce bias of the coding scheme and emerging taxonomy, the researcher, her supervisors and an independent researcher, were involved in the analysis. A coding guide was devised (by the researcher and HAS) to standardise the procedure for triangulation. One by one, the first 5 interviews were summarised (by the researcher, HAS, VV and independent researcher). Then the interviews were coded sentence by sentence to give an initial coding scheme (the researcher, VV and independent researcher). No notable differences were found between the coding of the different researchers. Codes were grouped into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and discussions between the authors. The last 8 interviews, coded according to the same technique, were used to verify the coding scheme and refine the emerging taxonomy and concepts. First, a summary of the concepts and later detailed definitions, descriptions and interpretations of the main concepts were discussed by the researcher and all her supervisors.

9.3.3. Qualitative findings

The qualitative findings fitted into 3 main categories, which all played a role in the patients' headache management: 1) the patients' decision-making (Peters et al.,
Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

2003a) (Chapter 4, p.117), 2) the patients' perceptions of headache (Chapter 5, p.147) and 3) the patients' perceptions of headache management (Chapter 6, p.168). Underlying these three categories were the management strategies used by the patients including 1) health care use, 2) medication use, 3) alternative therapies, 4) social support and 5) lifestyle and self-help (Table 7.1, Chapter 7, p.198) (Peters et al., 2003b). The 13 participants described using or having used a various and usually multiple management strategies and self-help measures. The combination of strategies used was individual to every patient.

9.3.3.1. Patients' decision-making

Patients' decision-making was one of the main three categories that emerged from the qualitative data. The participants explained their reasons for using or not using certain strategies (Peters et al., 2003a). To make decisions about management, the participants relied on and generalized from their subjective experiences, which they perceived as significant. From the participants' descriptions emerged 4 stages of decision-making: headache severity, evaluation, decision and behaviour (Figure 4.1, Chapter 4 p.134).

Headache severity comprised the diagnosis of migraine, CDH and TTH, the progressive nature of migraine during and between attacks and headache impact. Headache severity, particularly at the onset of the headaches, was the starting point of decision-making. It also served as an end-point, since the participants used it as an outcome measure to assess the efficacy of the management.

Evaluation was the most active, involved and complex stage of decision-making and comprised 3 steps including awareness, assessment and balancing options with
Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

perceptions. Awareness was when the patients’ stopped believing that their headaches will not recur and they started thinking about how to deal with the problem. The patients progressed to assess their headache severity, their experiences of headache management and the outcome and limitations of the previously employed strategies. The third part of evaluation was balancing options with perceptions. The participants learned about management options, which they balanced with their individual perceptions (preferences, satisfaction, expectations, beliefs, and attitudes) to underpin their decisions.

Based on their evaluation, the participants made their decisions for management, both for being active or passive in relation to a specific management strategy. Decision was often a compromise between the participants’ options and perceptions.

Behaviour, the final stage of decision-making, described the outcome of the participants’ decisions. The participants adopted, maintained or discontinued management behaviours to treat and prevent their headaches. Behaviour, which could be active or passive, outlined the participants’ past and current management strategies (trials and errors), as well as their individual management combinations.

Decision-making was a complex, dynamic and continuous process that developed over time and operated on a justification and consequence system. Every decision, behaviour and change in migraine severity added to the experience and perceptions of the patients. Drawing on their experiences and perceptions, the patients were the key decision-makers for the management of their headaches and thus demonstrated their involvement in their headache care.
9.3.3.2. Patients’ perceptions of headache

The patients’ perceptions of headache was the second main category found from the qualitative interviews (Chapter 5, p. 147). Three main themes were identified from the interviews: 1) headaches, 2) headache impact and 3) headache as a health issue.

The theme entitled ‘headaches’ was further divided into ‘pain and other symptoms’, ‘differentiating between different types of headaches’ and ‘perceptions of headaches as barriers and facilitators to care’. For most participants, pain was the dominant feature of their headaches. To help assess the severity of pain the participants explained their pain severity, their experience of the pain and how the pain developed over time (within an attack) and changed over the years (between attacks).

The participants assessed their symptoms to differentiate between headaches. Migraines were mostly associated with severe, throbbing pain, nausea and aura symptoms. Other headaches were described as not interfering with daily activities and as being treatable with simple painkillers.

The participants’ perceptions of their headaches, including pain and other symptoms, acted as barriers and facilitators to management. The type of headache and particularly pain severity were often perceived as a cue for using pharmacological treatment. Thus, differentiating between different types of headaches was important in the participants’ decision-making for treatment. Participants who did not accept certain headache characteristics (such as headache recurrence or headache severity), participants expressed hope or optimism that the headaches would not return or resolve without active treatment.
Impact illustrated the patients' perceptions of suffering and put the magnitude of suffering into the context of the participants' lives. Headache impact was mainly described in terms of disability. All aspects of the participants' lives had been affected by their headaches, including their work, family and social lives (leisure activities, holidays). Disability was personal to the patients, and referred to limitations to the participants' everyday activities, such as work and family life, because of headaches.

The theme of headache as a health issue related to what headaches meant in terms of health. Headache was perceived to be a health issue, although not necessarily an illness. By comparing headaches to other illnesses, the participants put headaches into a wider health context. The participants related their experience of headaches to their own experiences of illnesses other than headaches, other people's experiences of illness or illness in general. Mostly, participants related headaches to illnesses that they perceived as more serious. Consequently they played down headaches and headache impact, which gave a conflicting view with the participants' perceptions of headache pain and symptoms and headache-related impact.

9.3.3.3. The patients' perceptions of headache management

The third main category of the qualitative data was the patients' perceptions of headache (migraine and CDH) management (Chapter 6, p.167). Based on the participants' own, and other people's, headache and treatment experiences, the participants had developed expectations, preferences and satisfaction with management. The participants described their perceptions on all areas of
management: 1) health care use; 2) medication use; 3) alternative therapies; 4) social support; and 5) life-style and self-help (Figure 6.1., Chapter 6, p.176).

The theme of health care use mainly focused on consultations with doctors and mainly the GP. Some participants had low expectations of general practice consultations and questioned the GP’s ability and interest to treat headaches, to the extent that they did not consult for headaches. The participants thought that general practice consultations, and consequently the role of the GP, was focused on pharmacological treatments and that little importance was given to finding the cause of headaches, finding a cure or discussing impact and non-pharmacological management. Discussions of issues other than medication led to greater patient satisfaction and increased the likelihood of follow-up consultations.

The participants’ perceptions of the medications ranged as widely as the number and types of medications they had used. Despite expressing preferences for not taking any medication, all 13 participants had relied on headache medication in the past. Some patients, usually those who had only tried OTC medication and who had experienced treatment failures, expressed low expectations and low satisfaction with headache medications. Low expectations and the worry of side effects led to some participants strictly limiting their medication intake. Satisfied participants, however, preferred taking medication to suffering a migraine.

Interest was expressed in alternative therapies, although not all the participants had tried alternative health care. Patients who had consulted alternative therapists gave little information on efficacy of these treatments, but expressed satisfaction with the time and advice offered within alternative health care.
Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

Receiving social support was considered important to learn about new management strategies and to receive and give understanding about headaches from patients' with similar experiences. Social support was considered a valuable and helpful management strategy that was used by most of the participants.

Self-help and life-style focused on issues such as trigger control, dietary changes and stress management. This theme showed that the participants' viewed themselves as an essential resource to management. The participants believed they were heavily involved in their headache care, by learning about headache and headache treatments and by taking initiatives to obtain the treatments they wanted.

9.4. Quantitative phase

9.4.1. Rationale

The qualitative findings included the areas of management (holistic management) used by the patients, as well as their decision-making, perceptions of headache and management. The data from the interviews also showed that headache management was an individual and complex set of behaviours that was composed from five areas of management. Previous studies on the patients' management behaviours have predominantly focused on two of the management areas, i.e. doctors' consultations and medication use. The qualitative study showed that headache management goes beyond doctors' consultations and medication use. However, although the qualitative findings revealed which management strategies are used by the patients to manage migraine and CDH, the findings do not inform on how many patients use each management strategy. Furthermore, qualitative methods are limited in their generalisability, therefore a quantitative phase followed the qualitative phase to
Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

assess how many patients used any given management strategy and to make the qualitative findings relevant to a wider population.

The qualitative phase had also indicated that patients with different headache diagnoses and increasing headache severity managed their headaches differently (for example CDH patients rather than migraine patients had consulted their General Practitioner (GP) within the last 12 months). Migraine diagnosis has been shown to be more likely when certain symptoms are present, including aura and increasing disability (Lipton et al., 2001). Studies on migraine management from the patients’ perspective have not examined differences in behaviours of patients with different migraine diagnoses, neither has a comparison been drawn to CDH. Therefore, the quantitative phase aimed:

- To investigate which management strategies are used by migraine (M), migraine with aura (MWA) and CDH patients

- To compare the management used by M, MWA and CDH patients over the last 12 months.

9.4.2. Methods

9.4.2.1. Questionnaire

The quantitative phase was based on a postal survey. Since no previous questionnaire had investigated the holistic management of migraine or CDH from the patients’ perspective, the researcher and her supervisors developed a new questionnaire based on the 5 areas of management identified in the qualitative phase. The questionnaire included 4 sections of management: 1) consultations, 2) acute and prophylactic
medication and herbal/homeopathic remedies, 3) acute and prophylactic general management and 4) social support. Further sections included headache information (symptoms and impact) and biographical data.

Two independent researchers with expertise in questionnaire design assessed the layout and feasibility of the questionnaire. To test content validity, the questionnaire was administered to 10 headache patients. To test the reliability and validity of the diagnostic tool within the questionnaire, 30 patients who had previously been diagnosed by a headache clinician (AD) completed the questions relating to diagnosis. The researcher made the diagnosis based on the returned questionnaires (n=26). The questionnaire diagnosis and clinician’s diagnosis concurred in 22 cases (84%).

9.4.2.2. Respondents and recruitment

The questionnaire was targeted at the same age group as the qualitative interviews i.e. adults aged 18-65 years. The participants had to have suffered either from IHS migraine, IHS migraine with aura or CDH (headache frequency >15 days per month) in the 12 months prior to the study. Only UK residents were included in the sample. Ethical approval was obtained from the University of Surrey Ethics Committee.

The respondents were recruited through the Migraine Action Association in the UK. The questionnaire was sent to a total of 887 patients and 537 questionnaires (60.5%) were returned. Upon receipt the questionnaires were checked for eligibility (age and diagnosis) by the researcher. Questionnaires were excluded due to absence of headaches in the last 12 months (n=9), the respondent being over the age limit of 65 years (n=39), missing biographical data (n=5), missing diagnostic data (n=12), the
headaches being unclassifiable (n=7) or the patients suffering from headaches other than migraines or CDH (n=27).

A total of 438 questionnaires were analysed. A 10% (n=42) random sample of the questionnaires included in the analysis were selected and re-diagnosed independently by a headache clinician (AD) to assess the reliability of the researcher’s diagnoses. Diagnoses concurred in 40 cases (95.2%).

9.4.2.3. Data analysis

The data were entered into SPSS 10.1 for analysis. Data were analysed by descriptive statistics and comparisons were drawn between three diagnostic groups: migraine (M), migraine with aura (MWA) and CDH. Descriptive statistics, chi-square Kruskal-Wallis, analysis of variance (ANOVA) and post-hoc Scheffe tests were used for statistical analysis. The level of significance was set at p<0.05.

9.4.3. Quantitative findings

9.4.3.1. The respondents

Based on headache symptoms and headache frequency, of the 438 respondents, 117 (109 women and 8 men) were diagnosed as M patients, 238 (211 female and 27 male) as MWA patients and 82 (72 female and 10 male) as CDH patients. There were no significant differences in gender, marital status, ethnicity, level of education, work status, age, age of onset of headaches and years of headache experience between the three groups. The patients’ characteristics are presented in Table 8.1. (Chapter 8, p. 213).
9.4.3.2. Patients' use of headache management

9.4.3.2.1. Health care consultations

The total number of health professionals consulted significantly differed between groups (p=0.001). The post-hoc Scheffe test showed that CDH patients had consulted a significantly higher number of health professionals (2.53, sd 1.81) than M (1.71, sd 1.19) (p=0.002) and MWA (1.84, sd 1.65) (p=0.004) patients. The three groups had consulted a variety of health professionals, including medical professionals and alternative therapists (Figure 8.2., Chapter 8, p.216). The highest consultation rates occurred with general practitioners. No significant differences were found for the consultations with most health professionals, apart from more CDH patients consulting headache specialists (p=0.027) and neurologists (p=0.002).

Significant differences in the consultation frequency were found for consultations with the GP (p<0.001), the neurologist (p<0.001), the osteopath (p=0.018) and the psychologist (p=0.011) (Table 8.3., Chapter 8, p. 217). The post-hoc Scheffe test showed the differences between the groups. CDH patients consulted GPs significantly more frequently than M (p=0.001) and MWA patients (p<0.001). Furthermore, CDH patients had consulted neurologists significantly more often than M (0.005) and MWA (p=0.001). The frequency of consultation with the osteopath was significantly different between CDH and M patients (p=0.019). Consultations with the psychologist were significantly more frequent for CDH patients than for M (p=0.036) and MWA patients (p=0.017).
9.4.3.2.2. Medication use

The majority of the patients (99.1% M, 99.6% MWA and 98.7% CDH) had used acute medication (OTC and prescription) in the last 12 months. The use of OTC medications did not significantly differ between the groups, but significantly more (p=0.003) of M (86.2%) and CDH patients (82.7%) relied on acute prescription medication when compared to MWA (71.4%) (Table 8.4; Chapter 8, p.218). CDH patients used both OTC and prescription medication more often than M and MWA patients. Reflecting the difference in number of headaches days per month, the frequency of use of acute medications significantly differed for prescription (p<0.001) and OTC medication (p<0.001) (Table 8.5. Chapter 8, p.219). Combination medications (p=0.026), and more specifically codeine combinations (p=0.040) and caffeine-codeine combinations (p=0.047) were used by significantly more CDH than M and MWA patients. Significantly more M and CDH patients (p=0.002) used triptans when compared to MWA patients (Figure 8.3. Chapter 8; p221).

More CDH patients, than M or MWA patients, used prophylactics (pharmacological agent and herbal/homeopathic and vitamins/minerals), but no significant differences were found between the 3 groups (Table 8.4., p.218).

9.4.3.2.3. General management

The majority of respondents used acute general management strategies to treat their headaches at least sometimes (Table 8.7., Chapter 8, p.224), but no significant differences were found in the level of use between the groups (Table 8.8, Chapter 8, p.225). The majority of respondents used prophylactic general management...
strategies at least sometimes (apart from avoiding exercise) (Table 8.10., Chapter 8, p.227). Significant differences in the level of use of prophylactic strategies were found between the groups for avoidance of bright light ($p=0.007$), exercise ($p=0.011$), avoidance of noise ($p=0.004$) and food triggers ($p=0.025$) (Table 8.11., Chapter 8, p.227).

9.4.3.2.4. Social support

Social support was the least used management strategy, but most (apart from patient support groups and charity help-lines) strategies were used at least sometimes by more than 30% of the patients (Table 8.12., Chapter 8, p.229). No significant differences were found between the level of use of these strategies between the groups.

9.5. Discussion

The aim of the study was to investigate migraine and CDH management from the patients’ perspective. First, the qualitative methodology revealed the management strategies used by the participants, the patients’ decision-making for headache management, and the participants’ perceptions of headaches and headache management. Headache management emerged as a complex and individual process of decision-making and set of behaviours to treat and prevent headaches that evolved over time as patients gained new knowledge and experiences about headaches and headache management. In a second phase, the survey revealed that most management strategies, that had been described in the qualitative phase, were used by at least 50% of patients. Thus the quantitative findings reinforced the qualitative findings, by further confirming the patients’ high level of involvement in the headache care.
Furthermore, the interviews indicated that the participants' management behaviours differed according to diagnosis and severity of their headaches. Patients who perceived themselves as more severely affected were more likely to be self-directed in their headache management. Headaches were perceived as increasingly severe with increasing headache frequency. Findings from previous (quantitative) studies confirmed that headache severity and symptoms such as aura increase the likelihood of diagnosis (Lipton et al., 2001), thus the survey aimed to compare headache patients with different diagnoses. Overall, CDH patients were more active in their headache management. Significant differences in the management of CDH were found for a number of strategies. The use of other strategies was not found to differ between the groups, but mostly trend was towards a greater level of activity of CDH patients. For some management strategies, M patients were as active as CDH patients, such as the use of triptans. These findings showed that the patients' management of headache varies according to diagnosis. The greater level of activity of CDH patients within the survey confirmed the findings of the interviews and indicated greater need and willingness (self-direction) of CDH patients to be active in improving their headaches.

Taken together, both the qualitative and the quantitative study showed the high level of involvement of the patients in their headache management. This is contrary to the belief that migraine patients are passive and fatalistic in their headache management (Michel et al., 1996). Michel et al also concluded that patients want to be informed of their treatment options and they want to be involved in decisions when more than one alternative treatment exists (Michel et al., 1996), which is more in accordance with the findings of this study. The qualitative data showed the patients' involvement
in their care, through their decision-making, perceptions and behaviours. Indeed the participants perceived themselves as a key decision-maker and resource to management and the high level of use of management found in the survey confirmed the involvement of headache patients in their own care.

In this survey, despite their involvement in their care, the respondents continued to suffer from high frequency headaches. During the interviews, participants reported failed treatments and changing treatments due to lack efficacy and treatment side effects. Additional to the patients’ behaviours, the interviews also revealed that the participants were continuously trying to improve their headache management. However, due to the design of the survey, it is not possible to conclude how much if any improvement had been achieved through the patients’ management behaviours.

The considerable suffering of these patients indicates that their headache care is not optimal despite the patients’ efforts. Therefore, the importance of the findings rests with understanding the patients’ perspective and their willingness to be involved, as well as their current involvement in their care. Health care problems can only be addressed if the user’s perspective is understood and if health care professionals and patients co-operate (Edwards and Staniszewska, 2000). Understanding the patient may help to develop a more patient-centred health practice (Faltermaier, 1997) and to empower and educate patients to have the necessary knowledge and skills to seek help and to manage their headaches effectively (Diener et al., 2000). The change towards greater involvement of patients in their health care is only possible if the patients are willing to be involved. Understanding the patients’ current involvement helps to gain insight into the patients preferences, which they indirectly express.
through their choices; and may help to develop, implement and carry out patient-focused education, self-management programmes and research.

9.5.1. Combining qualitative and quantitative findings

Qualitative and quantitative methods can investigate a similar topic by addressing a different research question (Jones, 1995), collecting different types of data and producing different sorts of answers (Barbour, 1999). The aim of this study was to investigate the patients' perspective of migraine and CDH management. Four research questions had been formulated:

1. How do migraine and CDH patients perceive and experience headaches and headache care?

2. Which management strategies do migraine and CDH patients use?

3. What are the differences in the use of management strategies between different types of headache patients (migraine, migraine with aura and CDH)?

4. What is the patients' involvement in their migraine and CDH care?

Qualitative research is useful to explore areas that have received little previous attention (Pope and Mays, 1995). Few studies have been carried out on the headache patients' perspective and particularly the patients' perceptions. Furthermore, qualitative methods are suitable to answer questions such as "what is 'x'?", "how does 'x' vary in certain circumstances and why?" and "what is the purpose of 'x'?". Questions that concern meanings, experience, patterns, relationships and values are best addressed by qualitative methods (Miller and Crabtree, 1994). Thus, the research questions identifying the management strategies used by the patients and
questions dealing with the patients’ perceptions and experiences of migraine and CDH management were best answered by a qualitative design. The use of qualitative methods has added to knowledge by giving insight into the patients’ perceptions and decision-making, as well as the complete picture of the patients’ management practices.

The qualitative findings provide insight into the subjective reality of the participants. The researcher is the main instrument of data collection and analysis, which introduces bias into the research process. While objectivity is accepted as one of the weaknesses of and fundamentally rejected in qualitative research, objectivity is nonetheless an important feature of research. Objectivity is achieved through the standardisation of the research process (such as collecting data through a standardised questionnaire) and contributes to the study findings being relevant to a wider population group. In quantitative research, reality is objective, simple and positive and all members of society define reality in the same way. Objectivity is employed to minimise personal bias and to guarantee that reality will be presented as it is, rather than as it is interpreted by the researcher (Sarantakos, 1998).

The qualitative methods were not able to address all research questions that aimed to quantify the proportion of migraine and CDH patients using the described management strategies. Also, no comparison between the management behaviours of headache patients with a different diagnosis could be drawn from the qualitative findings. The primary focus of quantitative studies is to quantify and measure. To answer questions such as ‘how many’, ‘how much’, ‘what size’ or numerically measurable associations between factors, a survey is appropriate (Miller and
Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

Crabtree, 1994). Thus, the survey had been chosen as a means to address the research questions that could not be addressed by the qualitative methods.

In this study, using both qualitative and quantitative methods served several purposes. Qualitative research can be used as a prerequisite to quantitative methods to facilitate the development of the quantitative research by identifying the ‘correct’ terminology for inclusion in a survey questionnaire or generating hypotheses (Greene et al., 1989). In this study, the qualitative data was used to inform the design of the research questions. This contributed to the development of a valid questionnaire that was relevant to migraine and CDH patients. Thus, the respondents answered questions, which reflected their views, rather than the views of the researchers.

The second purpose of a combined methodology was methods triangulation. This involved comparing data collection through qualitative methods with data collected through quantitative methods (Patton, 1999). Due to the limited generalisability of qualitative data, the survey permitted to reliably quantify issues raised within the qualitative phase and to make the findings applicable to a larger population. The qualitative and quantitative findings both indicated that migraine (with and without aura) and CDH patients are active in the management of their headaches. Thus, the findings of one methodology confirmed the results of the other methodology. Additionally, the findings allowed to draw conclusions on how the patients’ management of their headaches (qualitative) as well as investigating and comparing the patients management behaviour (survey).

An increasing number of studies is using a combination of qualitative and quantitative methods, and the combination of qualitative and quantitative methods is recommended to enhance the study of chronic diseases (Casebeer and Verhoef,
Previous studies have shown that integrating qualitative and quantitative methods emphasise the findings (Clarke, 2003; Chan, 2001) or the interpretation of findings was facilitated by the simultaneous use of qualitative and quantitative methods (Etter and Perneger, 1997). Abu et al (2001) found that qualitative findings confirmed the quantitative results and suggest that a combined approach should be used in future studies of the patients' views of health care.

The use of combined methods allowed the researcher to approach the patients' involvement in their headache care from two different angles. This meant the study answered different research questions and provided a fuller picture of the patients' perspective. Similarly to the experiences in previous studies, it was found that the results from the two methodologies confirmed and enhanced each other. However, given the various strengths and weaknesses of qualitative vs. quantitative research, the researcher using different methods to investigate the same phenomenon should not expect that the findings generated by those different methods come together to produce some nicely integrated whole (Patton, 1999). The qualitative phase has raised issues that were beyond the scope of the questionnaire, but that were nonetheless important and require further investigation. The headache patients' perceptions and their decision-making are areas that have received little attention in headache research to date, but that are essential given the increasing importance that is given to patient expertise and patient-doctor collaboration in health care. Despite not being quantified, these findings are of importance for headache researchers and clinicians, and other health professionals to gain better understanding of headaches and headache patients.
9.5.2. Limitations and future research

Qualitative research is suitable to investigate new areas (Pope and Mays, 1995) and has been underused in headache research (Peters et al., 2002). Giving headache patients the opportunity to speak freely has raised many issues that were beyond the scope of the questionnaire, but that will need further investigation. The holistic management of migraine and CDH is a broad and complex topic and individual management strategies need to be studied in more detail to gain insight into the full picture of migraine and CDH management. The qualitative methodology has highlighted the importance of the patients’ perceptions in their headache management and how the patients use their perceptions to make management decisions. However, these findings cannot be generalised and quantitative research is necessary to identify any predictive power of the perceptions on management.

Migraine is more than a headache and the current endpoints of clinical trials need further development, as for example measuring headache relief as an endpoint alone does not capture the complete picture about the new treatments (Goadsby, 2000). The qualitative study has revealed the patients’ perceptions of the efficacy of treatments, but more research efforts need to focus on treatment outcome. Better understanding of the patients’ perceptions of treatments and their efficacy, to develop more patient-centred outcome measures for clinical trials.

The qualitative study revealed that multiple strategies were used for the treatment of individual headaches. Long-term, migraine and CDH management changed over time, depending on the patients (and other people’s) knowledge and experiences. The quantitative data was also able to show that patients had used multiple strategies.
within the last 12 months, but the study design did not permit to draw any conclusions on how management changed over time. Therefore, the changes within patient behaviour should be studied prospectively to identify those changes within a larger sample. Reasons that explain the changes in the patients’ management behaviour would be suitable for further qualitative investigation.

The studies to date on the patients’ management have been carried out in different countries, but predominantly the USA. This study has solely focused on the management used by headache patients who are residents within the UK. However, the health care systems between countries vary and may have an influence on the patients’ management behaviour. Therefore, it is important to carry out further studies on the holistic management of migraine on an international level to compare not only different types of headaches but also the influence of different health care systems and across cultures.

The questionnaire sample included only headache patients who are members of the Migraine Action Association in the UK. It is likely that these patients are more interested in their headaches, are better informed about headache management and are more pro-active in their treatments. Therefore the findings of this survey may not be applicable to the wider headache population and it would be advisable to conduct a survey on the patients’ holistic management within the general population. Still, the results of this study should not be dismissed, since the Migraine Action Association is a patient group with over 17000 members. If the members of the Migraine Action Association are indeed more active than headache patients within the general population, this may be due to the regular information they receive as part of their membership. Having better information may have been an incentive to consult in an
Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

international study, since more lapsed (60%) and non-consulters (65%) than current consulters (42%) felt that they did not have most current information (Adelman et al., 2000). Therefore, the patients’ management behaviour within this study may be an indication of the value of patient education, which may trigger further study into the patient as a resource to management and may be used to underpin the development of patient education programmes.

Finally, since the survey was conducted at only one point in time, it is not possible to ascertain how the patients’ management practices influence their headache development over time and whether the patients’ management practices are successful or unsuccessful in relieving and reducing headaches and headache-related impact. Furthermore, the study design does not allow to draw conclusions on which management strategies the patients perceive as most or least helpful. To address these questions, it would be necessary to collect a further data set, using the questionnaire, at a different point in time, as well as using additional questions (either within the questionnaire or as a qualitative study) to determine which strategies the patients find the most or the least helpful.

9.6. Conclusion

The aim of this study was to investigate the patients’ involvement in the headache (migraine and CDH) management. The study used both qualitative and quantitative methodologies to gain access to the patients’ perspective from two different viewpoints. Combining the methodologies was found to be useful, as the qualitative findings helped to develop a valid questionnaire that was relevant to the patients and helped to explain the quantitative findings. Furthermore, the quantitative findings
confirmed issues raised within the qualitative interviews and made the findings applicable to a wider population of headache patients.

The findings revealed that headache patients are actively involved in their headache management, both in terms of their decision-making for management and in their management behaviours. The qualitative data had indicated that patients who are more severely affected are more self-directed in their search for effective management. The comparison of M, MWA and CDH patients within the survey confirmed that CDH patients, who have higher frequency headaches than M or MWA patients are more active in their management.

The findings of this study can be used to inform headache researchers and clinicians of the patients' behaviours to lead to greater understanding of the patients' perspective. Furthermore, the patients' high level of involvement in their care, and particularly their perceptions of themselves as the key decision-makers of their headache care, indicates that headache patients are interested in being involved in medical decision-making. Thus, headache care should move towards the new chronic disease paradigm, which advocates the collaboration of the health care professional and the patient, by the health care professional providing the medical knowledge and the patients supplying personal expertise of the disease.
Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods

9.7. References


Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods


Headache Classification Committee of the International Headache Society 1988, "Classification and diagnostic criteria for headache disorders, cranial neuralgias and facial pain", Cephalalgia, vol. 8, pp 1-96


Chapter 9: The patients’ involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods


Chapter 9: The patients' involvement in migraine and chronic daily headache management: a study using qualitative and quantitative methods


Chapter 10: The contribution to knowledge
Chapter 10: The contribution to headache research, research methods and theory

10.1. Introduction

This study aimed to investigate the patients’ management of migraine and chronic daily headache (CDH). To achieve this, the study used a combination of qualitative and quantitative methods. This section discusses the contribution of this study to research methods in health care, the contribution to theory (including coping, the transtheoretical model, and models of problem-solving including Leventhal’s self-regulatory model) and the contribution of this study to knowledge and understanding of headache management.

10.2. Contribution to research methods

Few studies have used a combination of qualitative and quantitative methodologies. However, in the context of the study of health, the gap between qualitative and quantitative research is narrowing and the combination of methodologies is thought to be fruitful for the study of chronic disease (Casebeer and Verhoef, 1997). Recently more studies using a combined methodology have been published and these studies report positive experiences from using this approach to investigate health issues. (Etter and Perneger, 1997) reported that the interpretation of findings was facilitated by the simultaneous use of qualitative and quantitative methods. (Clarke, 2003) and (Chan, 2001) believe that integrating qualitative and quantitative methods emphasised their findings. Abu et al (2001) found that qualitative findings confirmed the quantitative results and suggest that a combined approach should be used in future studies of the patients’ views of health care.

Qualitative and quantitative methods can investigate a similar topic by collecting different types of data and producing different sorts of answers (Barbour, 1999) and addressing a different type of research question (Jones, 1995). Questions that concern
Chapter 10: The contribution to headache research, research methods and theory

meaning, experience, patterns, relationships and values are best addressed by qualitative methods and questions that concern numerically measurable associations between factors are appropriately addressed by a survey (Miller and Crabtree, 1994).

Patient management of a chronic health problem, including the management of migraine and CDH, is a topic, which can be studied by either qualitative or quantitative methods. However, each method is suitable to answer a certain type of research question. In view of the research questions formulated for this study (Chapter 1), a combined qualitative and quantitative approach was necessary to provide answers to all the research questions. Thus, combining the two methods allowed answering a wider range of questions relating to the headache patients' management behaviours, thus giving a deeper and broader understanding of the patients' perspective of headache management.

The qualitative findings gave insight into and provided explanation of migraine and CDH management. The qualitative methodology allowed the patients to speak openly and freely about their headache management to gain access to the patients' subjective reality in terms of their experiences of headache management and their interpretations of these experiences. Furthermore, the qualitative findings contributed to the design of a valid questionnaire that was relevant to headache patients. The survey added objectivity to the qualitative findings (the patients' use of management) and made the qualitative findings generalisable to a wider population.

10.3. Contribution to theory

Phase 1 of this study was based on grounded theory methodology, which aims to generate theory through comparative analysis of the data (Glaser and Strauss, 1967). From the findings of the qualitative phase, emerged the theory that migraine and CDH patients are highly involved in their headache management, and that this
management varies according to headache type, severity, impact and the patients' perceptions of headache and headache management. Thus, the qualitative findings revealed issues related to coping, the transtheoretical model of change and self-regulatory theory.

10.3.1. Coping

Coping has been defined as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman, 1984) or, in other words, 'the attempt to change a stressor or a stress response' (Kaplan et al., 1993). Methods of coping are important in migraine patients, since patients who employ more passive coping strategies, have been shown to have lower quality of life (Passchier et al., 2001). There are two main types of coping: problem-focused coping and emotion-focused coping (Cohen and Lazarus, 1979; Folkman and Lazarus, 1980; Folkman and Lazarus, 1980). Problem-focused and emotion-focused coping can be used together and the balance between problem-focused and emotion-focused coping depends on the demands of the stressful situation. In this study, migraine and CDH were the stressor that the patients had to cope with. The patients employed both problem-focused and emotion-focused coping to manage their headaches and the management behaviours used aimed at reducing headache severity (including pain severity, headache frequency and impact) to improve quality of life.

Problem-focused coping aims to reduce the demands of the stressful event or to expand the resources to deal with the stressful event. In this study, the migraine and CDH patients employed a wide range of management strategies, such as consultations with health professionals, using medication or social support. These management behaviours aimed to reduce their headache severity, either by the
patients attempting to change their stressor (headache severity) through employing a variety of management strategies or by patients expanding their resources to deal with their headaches, through seeking social support and educating themselves about headaches.

On the other hand, emotion-focused coping aims at controlling the emotional response to the stressor without attempting to change the stressful situation. Emotion-focused coping involves behavioural approaches, for example seeking social support, distracting attention from the problem, and cognitive approaches, such as changing the meaning of a situation, denying the problem (Sarafino, 1994). In this study, the patients employed emotion-focused coping in several ways. Either they denied their headaches and/or were optimistic that the headaches would not return. Alternatively, they came to terms with their headaches and accepted them, believing that there was nothing they could do to alleviate the burden of their headaches. Finally, the participants also changed the meaning of the situation. Although they described and acknowledged that their headaches were painful and caused disability; they also argued that suffering from headaches was not so bad, since other health conditions are more serious and threatening than headaches.

10.3.2. The transtheoretical model

The transtheoretical model was developed by Prochaska and DiClemente to describe and explain changes related to health-related behaviours (Prochaska and DiClemente, 1984; Prochaska et al., 1992). The model comprises five stages, which people seem to move through these stages at an orderly sequence at their own pace. Stage 1 (precontemplation) includes the people who are not seriously thinking about changing their health care behaviours. In stage 2, called contemplation, people are aware that a problem exists and they are seriously starting to consider changing their
Chapter 10: The contribution to headache research, research methods and theory

health-related behaviours. Preparation (stage 3) involves people pursuing a behavioural goal, within the next month or people who have tried to reach a goal within the last year without being fully successful. Stage 4 (action) spans over a period of time (usually 6 months), from start of the person's successful and active efforts to change behaviour. The last stage, maintenance, involves people working to maintain the successful changes in behaviour.

The qualitative findings revealed the patients' decision-making for the management of migraine and CDH (Chapter 4). The figure illustrating the patients' decision-making included 4 different stages: 1) headache severity, 2) evaluation (including perceptions), 3) decision and 4) behaviour. The decision-making process also revealed that the patients' perceptions and behaviours were not static, but evolved over time, influenced by a range of barriers and facilitators. The decision-making process helps to explain the management behaviours of migraine and CDH patients, thus the transtheoretical model and the decision-making process revealed in this study have been compared to outline their similarities and differences.

The migraine and CDH patients' process of decision-making is similar to the transtheoretical model, in that patients progress through the different stages at their own pace. The transtheoretical model is a linear model, although progression through the stages does not necessarily occur in a linear fashion. The model proposed in this research for decision-making about migraine and CDH management differs from the transtheoretical model, since it is a cyclical process. However, the two models share the patients' progress through the stages at their own pace and the fact that change in health behaviours continues to occur over time.

Furthermore, the stages within the two models are comparable. The perception of 'headache severity' could be compared to precontemplation, when the patients,
although suffering from headaches, have not adopted any health care behaviours yet to induce a reduction of headache severity. The ‘evaluation’ stage of the decision-making model includes features of ‘contemplation’ and ‘preparation’. At this stage, the patients weigh up the costs and benefits of a particular behaviour, or in case of the headache patients, they weigh up their preferences with the available headache management strategies to decide which strategies to adopt, maintain or discontinue.

The ‘decision’ stage within the decision-making model, does not have an explicit equivalent within the transtheoretical model. However, the stages of ‘preparation’ and ‘action’ imply that a decision has been made. Finally, ‘action’ and ‘maintenance’ of the transtheoretical model are reflected within the theme of behaviour of the decision-making model. Thus the decision-making model includes ‘action’ and ‘maintenance’ within one stage, thus not assessing whether the behaviours have been adopted over a prolonged period of time. The assessment of maintenance of behaviours may be more suitable in prophylactic behaviours (i.e. behaviours that are carried out over a prolonged period of time, such as trigger avoidance) rather than acute behaviours (i.e. behaviours when the patient suffers from headaches, such as taking painkillers).

10.3.3. Problem solving models and Leventhal’s self-regulatory model of illness cognitions

Traditional models of problem-solving include three stages: 1) interpretation, 2) coping and 3) appraisal (Ogden, 2000). In these models, it is assumed that given a problem, an individual will be motivated to solve the problem and reestablish normality. In case of the problem being an illness or a health issue, the person suffering from illness aims to re-establish health. This assumption applies in two ways to migraine and CDH patients. Firstly, when suffering from a headache (i.e. ...
Chapter 10: The contribution to headache research, research methods and theory

Acutely), migraine and CDH aim to become headache free. Secondly, patients suffering from chronic, recurring headaches, will also aim to prevent their headaches, thus trying to stop suffering from headaches even when they do not actually have a headache. The model of decision-making (Chapter 4) incorporates both the migraine and CDH patients' attempts to re-establish normality, both acutely and prophylactically. In terms of similarities between migraine and CDH patients' decision-making and traditional problem solving models, 'evaluation' relates to 'interpretation' and 'appraisal' and 'decision' and 'behaviour' relate to coping.

Leventhal's self-regulatory model is based on approaches to problem solving and suggests that illness/symptoms are dealt with by individuals in the same way as other problems. Additionally, the model incorporates description of illness cognitions as described by Leventhal and colleagues (Leventhal et al., 1980; Leventhal et al., 1985; Leventhal and Nerenz, 1985; Leventhal et al., 1997). Illness cognitions are defined as a patient's own implicit common sense beliefs about their illness. These cognitions provide the patients with a framework for coping with and understanding their illness and telling the patients what to look out for when they are becoming ill. Leventhal and his colleagues identified five cognitive dimensions: 1) identity (label given to an illness), 2) perceived cause of the illness (biological or psychosocial causes), 3) time line (patients' beliefs about how long illness will last), 4) consequences (patients' perceptions of possible consequences of their illness and 5) curability and controllability (patients' beliefs on whether the illness can be treated and cured and the extent to which the illness is controllable by themselves or others).

As far as migraine and CDH patients in this study were concerned, the patients described the importance of identifying their headache type, for example in terms of deciding which type of medication was appropriate and to assess whether their
headaches are serious enough to warrant a consultation with the doctor. The patients' perceived cause of illness mainly related to acute issues, meaning that they reported issues that had caused a particular migraine attack (such as stress), rather than describing their thoughts on why they suffered from chronic, recurring headaches. The 'time line' dimension, however, in these migraine and CDH patients related to the chronicity of migraine and CDH rather than their acute features, including denial and optimism ('I will not have any more of these headaches') or acceptance ('I will at some point have another headache'). In terms of 'consequences', the participants illustrated the effect that their headaches had on their lives. Headache-related impact varied between patients, even in patients with a similar degree of headache severity (frequency, pain severity and disability). Finally, 'curability and controllability' issues were apparent in the migraine and CDH patients’ perceptions of their headaches, as well as their more self-directed or accepting approaches to management behaviours to treat and prevent headaches.

10.4. Contribution to knowledge and understanding of migraine and CHD management

As outlined in Chapter 2, studies investigating the patients’ use of management have mainly focused on doctors’ consultations and medication use. These studies have shown that migraine is under-diagnosed and under-treated. The majority of patients do not consult their doctor about their condition. Migraine patients rely predominantly on Over the Counter (OTC) medications, rather than prescription medication, to treat their headaches. This has led to the theory that migraine patients are passive and fatalistic in their headache management (Michel et al., 1996). However, anecdotal information suggests that migraine patients use management strategies other than doctors’ consultations and medication use. The knowledge about
Chapter 10: The contribution to headache research, research methods and theory


the management used by CDH patients is even more limited. Therefore, this study aimed to investigate the patients’ perspective of migraine and chronic daily headache (CDH) management. The objectives were to gain insight into the patients’ perceptions of headache and headache management; to establish which management strategies were used and what proportion of patients used these management strategies; and to compare the management used by patients suffering from different types of headaches.

This study has contributed to knowledge and understanding about headaches in several ways. First, the qualitative phase revealed the holistic management of migraine and CDH. Previous studies have revealed the patients’ use of isolated management strategies (mainly doctors’ consultations and medication use), but they give limited information on the combination of management strategies used by migraine and CDH patients. Although it is useful to study management strategies in isolation; it is also important to study the patients’ management from an holistic perspective, to improve understanding of the complete picture of headache management. The findings of this study showed that migraine and CDH management goes beyond medical consultations and medication use, to also include alternative therapies, general acute and prophylactic management and the use of social support.

In this study, headache management was shown to be individual to the patient and was based on the patients’ combination of behaviours from the 5 areas of management (health care consultations, medication use, alternative therapies, general management and social support). This study showed that management behaviours were employed simultaneously to maximise the outcome and effectiveness and that although patients may be passive in terms of one specific management behaviour, they are likely to be using a wide range of other strategies for the treatment and prevention of their headaches.
Secondly, the qualitative findings gave insight into the patients' perceptions of headache and headache management. Few studies have focused on the headache patients' perspective, and those studies have predominantly used quantitative methods (Chapter 2 and Appendix 1). The patients’ descriptions of their headaches, and particularly headache severity, and headache impact indicate that patients perceive their migraine and CDH as a serious problem. Headache impact, as outlined in the review of the literature, has been an area of interest in headache research in recent years. This study confirms previous findings on headache impact, but additionally reveals the concept of relativity of headache impact. Furthermore, this study gives insight into the patients’ perceptions of headaches within wider context of health. The study also shows the patients’ dilemma in terms of the seriousness of headaches as a health problem. Migraines and CDH entail suffering and have a serious impact on the patients’ lives, but in comparison to other, potentially fatal, health problems, migraines and CDH are considered less serious and are given low priority. This dilemma may be an important contributor to the patients’ approach to management and may help explain the patients' self-medicating with OTC medications rather than seeking medical support.

Thirdly, the interview data explained the patients’ decision-making about migraine and CDH management, including how the patients’ experience, knowledge and perceptions influenced the participants’ management decisions and behaviours. Apart from one qualitative study on the decision-making for the use of sumatriptan (Ivers et al., 2000), no studies have focused on explaining how the patients choose their headache management. Ivers et al (2000) found that at the onset of head pain, participants actively compared their symptoms with a ‘migraine template’ that they had developed from past experiences. Factors, included in this personalised and complex ‘template’ that aided the participants in judging whether a headache was
indeed a migraine, were the nature, intensity, location and course of pain, the exposure to migraine triggers, presence of associated symptoms and presence of associated cognitive factors. The findings of this study also showed how the patients’ perceptions of their headaches influenced their headache management. Patients who perceived their headaches as more severe or as having a greater impact were more determined to find more effective management for their headaches. Patients who perceived migraines and CDH as less severe were more accepting towards their headaches and less pro-active in their search for effective treatment. Thus, the results of this study confirmed the findings of Ivers and colleagues (2000). At the same time, since this study investigated management decisions beyond the use of one type of pharmacological treatment, the findings of this study extend the findings by Ivers et al (2000) to give insight and understand about the patients’ decision-making of the complete picture of migraine and CDH management.

Grounded theory aims to generate theory (Glaser and Strauss, 1967) and from the qualitative findings emerged the theory that migraine and CDH patients are highly involved in their headache management, and that this management varies according to headache type, severity, impact and the patients’ perceptions of headache and headache management. The survey aimed to further investigate the patients’ behaviours, to validate part of the qualitative findings. Thus, the survey aimed to investigate the management behaviour (level of involvement) of different types of headache sufferers and to compare the management used by the different types of patients. Three headache types were included: migraine (M), migraine with aura (MWA) and CDH. M and MWA were included as separate headache types, as features such as aura symptoms and headache impact have previously been shown to influence migraine diagnosis (Lipton et al., 2001), which may influence the doctor’s recommendations and prescriptions for headache management. The quantitative
findings contributed to knowledge by revealing both the high level of involvement of M, MWA and CDH patients in their headache care, as well as differences in management depending on the headache diagnosis. The findings showed the proportion of headache patients using specific management strategies or their level of use of management strategies within the last 12 months. Thus, revealing a high level of management, these results confirmed the qualitative findings that M, MWA and CDH patients were highly involved in their headache management.

Additionally, the survey also aimed to compare the use of management strategies between different groups of headache patients. Previous surveys (Appendix 1) have predominantly focused on migraine patients, although not differing between migraine without aura and migraine with aura. Four surveys (Ferrari et al., 1997; Siniatchkin et al., 1999; Lu et al., 2001; Lanteri-Minet et al., 2003) have investigated the use of management by CDH patients, but 2 of those studies (Lu et al., 2001; Lanteri-Minet et al., 2003;) did not draw comparisons to other types of headache. Two studies have compared episodic and chronic headaches, but one of these focused on psychological coping strategies rather than the use of management strategies. In this study, the quantitative results showed that there was a difference in the use of management for some strategies (such as the use of prescription medication or the use of general prophylactic management). When such a difference was found, it was usually a larger number of CDH patients who reported using the strategy or CDH patients had a higher level of use of the strategy than either M or MWA patients or both. More similarities were found in the management behaviours of M and MWA patients. This finding further confirms that there is a difference in the patients’ management behaviour (as had been indicated by the qualitative results) and that this difference is related to headache diagnosis. The qualitative findings also indicated that it was the more severely affected patients who were more active in
Chapter 10: The contribution to headache research, research methods and theory

their management. This finding has been further confirmed by the survey, since it was CDH patients who were more active in their headache management.

Thus the main finding of this study was the high level of involvement of migraine and CDH patients in their headache care. Contrary to the belief that migraine patients are passive and fatalistic in their headache management (Michel et al., 1996), the patients perceived themselves to have a central role in their headache management, thus indicating the importance of patient self-management. Headache patients were willing to be involved and attributed a great importance to themselves, namely as a key resource to treat and prevent their headaches, through their perceptions, which influenced and shaped management and decisions for migraine and CDH management in a way that is unique and individual to every patient. The high use of management behaviours found in the survey further showed the patients' involvement in headache care and their willingness to manage their disease.

The patients' involvement in the care of chronic disease has been advocated in the UK by the Department of Health (Department of Health, 2001) and in the US by the Disease Management Association of America (Disease Management Association of America, 2002). Although, the Department of Health did not include headaches, migraine or CDH, within their report on the 'The Expert Patient: A New Approach to Chronic Disease Management for the 21st century'; migraine and CDH are conditions that are suitable for patient self-management. Due to their chronicity, migraine and CDH need to be managed over a prolonged period of time and most headaches need to be managed by the patients in the absence of health care professionals. These facts, taken together with the patients' willingness to be involved and the high level of involvement in the care of their headaches, as
indicated by this study, demands that migraine and CDH should not be ignored in this new approach to the management of chronic disease.

Migraine and CDH affect a large number of the general population and lead to high costs to health services and to society in general (Chapter 2). The management of migraine and CDH is not optimal, as shown by the high levels of disability and greatly reduced quality of life suffered by these patients (Chapter 2). Thus migraine and CDH management needs to be improved. Initiatives to improve migraine and CDH management have been taken, but they have predominantly focused on facilitating the health care professionals' role, such as guidelines for health professionals on the treatment of migraine, disability assessment tools and different approaches to clinical management (Chapter 2). But despite these initiatives, migraine and CDH patients continue to experience great morbidity. To date, migraine and CDH patients have largely been ignored as a resource to effective management, despite the involvement of the patient being advocated within headache literature (Silberstein et al., 2000). Thus, rather than only aiming to facilitate headache management for health care professionals, research and clinical practice should aim towards developing the patients' expertise and involvement in their headache care. One US study, testing a disease management programme for headache patients, has recently shown that educating patients is beneficial to patients in terms of reduced headache frequency and to health care in terms of reduced direct cost (Maizels et al., 2003).

The information from this study can be used to inform and help develop education programmes for headache patients. These programmes can be used to educate and empower patients towards taking responsibility for the management of their migraine and CDH, thus putting more emphasis on patient self-management and helping make
self-management more effective. In terms of headache practice and health care generally, the results from this study can be used to inform health professionals and headache clinicians, and to improve the communication between and the collaboration of the health care professionals and headache patients. This may help to improve, facilitate and maximise headache management towards finding more appropriate (preferred) and effective management earlier in the course of the disease.

The aim of this study was to gain insight into the patients’ perspective, thus the final word is given to one of the respondents of the survey, who added this comment to the questionnaire. This view both illustrates the pro-active and highly involved attitude of this patient, as well as the challenge of finding effective management.

“...I never stop trying to find a cure, even though it is like trying to find a needle in a haystack...”
10.5. References


Appendices:
### Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linet et al., 1991</td>
<td>USA</td>
<td>9380 individuals aged 12-29 who reported headache within previous year</td>
<td>Telephone interview using standardized questionnaire</td>
<td>1. Physician consultation 2. Factors influencing consultations</td>
<td>1. Majority of subject with at least one headache in the last 12 months had not consulted a physician. 5.6% of men and 13.9% of women had consulted within the last 12 months: 8.0% of men and 12.8% of women had ever consulted for migraine. 2. Women were more likely to consult than men. Headache patients with higher levels of disability were more likely to consult. Those who consult were more likely to have more severe, longer lasting (women only) and more likely to have migraine characteristics than those who did not consult with recent headaches.</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Edmeads et al., 1993 | Canada | Population-based multi-stage design  
- Prevalence survey n=24159 households of IHS headaches  
- Telephone survey migraines (n=138) and tension-type headache (n=83)  
Diary study migraines (n=95) and tension-type headache (n=55) | Prevalence of migraine- ever, within last year and within last month  
Diary study over 3 months | Telephone interviews  
Diary study | 1. Effect of headaches on relationships and lifestyle  
2. Physician consultation  
3. Medication use | 1. Headaches affected relationships with family, friends and colleagues in high proportion of headache sufferers. Limitations on regular activities in 78% of migraines and 38% of TTH sufferers. Migraine impinged more frequently on lifestyle than TTH.  
2. 64% of migraines and 45% of TTH reported physician consultations at some time. 41% of migraines and 32% of TTH reported specialist referrals. Of 76% of headache patients who had ever consulted, only 32% returned for follow up  
3. OTC (91%) used more frequently that prescription (44%) drugs by both migraines and TTH. 62% of those who consulted were prescribed medication. |
| Stewart and Lipton, 1993 | USA | 15000 households contacted  
63.4% response rate  
IHS migraine n=2479 | Mailed self-administered questionnaire | 1. Medication use | 1. Over 95% of migraine suffers took some form of medication. OTC medications were used most commonly. Among patients who have 3 or more severe attacks per month, 43% of men and 34% of women do not take prescription medication. Among patients with moderate or severe headache-related disability, 61% of men and 47% of women do not take prescription medication. |
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kryst and Scherl, 1994</td>
<td>USA (Kentucky)</td>
<td>647 persons, serious headache (including migraine)</td>
<td>12 months</td>
<td>Telephone survey</td>
<td>1. Medication use</td>
<td>94.3% of all serious headache patients used medication. 50% took non-prescription medication, 42.7% used prescription medication, 7.3% used both prescription and OTC medication.</td>
</tr>
<tr>
<td>Scharff et al., 1995</td>
<td>USA</td>
<td>149 women and 23 men, 69 IHS migraine, 52 IHS TTH and 53 combined headaches (M-TTH)</td>
<td>Rating on 7-point Likert scale</td>
<td>1. Likelihood of engaging in behavioural responses to headache</td>
<td>1. Percent of patients reporting to use coping behaviours at least sometimes: 'take time off' 75% (78.3% M, 73.1% TTH and 69.3% M-TTH), 'avoid physical activity' 91.2% (94.2% M, 88.2% TTH and 90.0% M-TTH), 'avoid/reduce light' 87.9% (94.2% M, 76.9% TTH and 90.4% M-TTH), 'avoid/reduce noise' 92.5% (95.7% M, 88.5% TTH and 92.3% M-TTH), 'reduce social contacts' 86.7% (95.7% M, 78.9% TTH and 82.7% M-TTH), 'lie down' 90.8% (94.2% M, 82.7% TTH and 94.2% M-TTH), 'go on with activities' 81.7% (71.6%M, 71.6% TTH and 88.2% M-TTH), 'take medication' 93.0% (92.7% M, 92.7% TTH and 94.2% M-TTH) and 'sleep' 75.6% (83.6% M, 83.6% TTH and 76.9% M-TTH)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>To and Wu, 1995</td>
<td>Canada</td>
<td>61239 individuals 135062 migraineurs 60364 controls</td>
<td>Physician consultation and Emergency room use in last 12 months Medication use in last 4 weeks</td>
<td>Personal interview and mailed questionnaire Part of Ontario Health Survey examining chronic conditions</td>
<td>2. Physician consultation 3. Emergency room use 4. Medication use</td>
<td>2. Majority of migraineurs and controls had visited physician in last 12 months. Migraineurs had significantly (p&lt;0.0001) more physicians visits than controls. Significantly larger proportion of migraineurs visited specialist (p&lt;0.0000). 3. Almost 1/3 migraineurs had visited ER vs. 1.5 controls (p&lt;0.001) 4. Migraineurs heavier users of all medication (e.g. analgesics, vitamins, stomach remedies/ laxatives) than controls apart for hypertension medications. Migraineurs significantly higher use of pain relievers (p&lt;0.0001)</td>
</tr>
<tr>
<td>Clarke et al., 1996</td>
<td>UK</td>
<td>4200 employees of Trust hospital 45% response rate 158 IHS migraine sufferers</td>
<td>Previous 3 months</td>
<td>Postal questionnaire</td>
<td>1. Physician consultation 2. Medication use 3. Alternative therapies</td>
<td>1. 32% had consulted their GP, 6% a hospital doctor and 5% the occupational health service. 60% had not consulted anyone. 2. 28% of patients took prescription medication and 78% took OTC medications 3. 13% of patients used alternative therapies such as homeopathy, yoga and acupuncture</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michel et al., 1996</td>
<td>France</td>
<td>6000 households 563 IHS migraine sufferers 525 controls response rate 87% for migraineurs and 82% for controls</td>
<td>3 months history of migraine 6 months consultation history 6 months history of well-being</td>
<td>2 stage mailed questionnaire, 1st stage on general health and 2nd stage headache specific. Diagnostic algorithm for IHS migraine Own questions, and questions from Composite International Diagnostic International (CIDI) for psychological well-being</td>
<td>1. Prevalence 2. Health care consumption 3. Social support 4. Medication use 5. Psychological well-being</td>
<td>1. 49% headache, 13% migraine (18% women and 8% men) 2. Migraineurs consulted their GP significantly (p=0.01) more often 3. Majority of migraineurs reported to have 'often' or 'sometimes' spoken to their doctor/ friends or family about migraine (57, 48 and 69%) 4. 72% of migraineurs generally treated their attacks with medication, high frequency migraineurs least likely to use medication, 50% of medication were OTC 5. Significantly more migraineurs than controls reported reduced well-being</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ferrari et al., 1997</td>
<td>Italy</td>
<td>280 headache patients newly admitted to headache centre Episodic headache (EH): 183 IHS migraine patients, 14 IHS TTH sufferers Chronic headache (CH): 39 IHS CTHH and 45 migraine with interparoxysmal headache according to (Manzoni et al., 1995)</td>
<td>Questionnaire administered at the patients visit to the clinic</td>
<td>1. Type of analgesic used 2. Medication use on working days and days off</td>
<td>1. Majority of patients (54%) thought it was better to treat with OTC medications, 40% preferred a prescription analgesic and 6% preferred not to take medication. 49% of patients actually used OTCs, 43% used prescription medication and 8% reported not to use any medication. 2. On working days, only 13.3% EH and 13.1% CH patients reported to break off work. 47.9% EH and 60.7% CH sufferers continued to work after taking medication, 38.8% EH and 26.2% CH patients continued to work without taking medication. On days off, 48.5% EH and 32.1% CH patients discontinued their activities; 35.2% EH and 4.52% CH patients took an analgesic and continued their activity and 16.3% EH and 22.6% CH patients carried on regardless. Medication use was significantly different on work days and days off (p&lt;0.0001) and between EH and CH patients on their days off (p&lt;0.05)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sakai and Igarashi, 1997</td>
<td>Japan</td>
<td>4029 subjects, 242 IHS migraine sufferers</td>
<td>12 months</td>
<td>Telephone interview, Mailed questionnaire to headache sufferers (including migraine)</td>
<td>1. Physicians consultation, 2. Medication use, 3. Use of other strategies</td>
<td>1. 2.7% of patients had visited a physician regularly in the last year, 12.2% occasionally (once or twice) and 15.6% had visited a physician at least once for headaches in their life, but not in the past year. As many as 69.9% had never consulted a physician for headache. 2. 56.8% of patients were taking OTCs only, 5.4% were taking prescription medication only, 18.6% were taking both OTCs and prescription medication and 19.2% were not taking any medication. 3. 40% of patients used sleep, 21% used shoulder and neck massage, 12% used compressions of the head and 9% used cooling of the head to relieve migraine.</td>
</tr>
<tr>
<td>Antonov and Isacson, 1998</td>
<td>Sweden</td>
<td>16741 persons within the Survey of Living Conditions, Headache patients n=11957</td>
<td>2 weeks</td>
<td>Interview survey, Recurrent headache or migraine self-reported</td>
<td>1. Medication use in headache sufferers</td>
<td>1. Analgesics were used more frequently among women with headache (73.9%) than men (64.1%). Among women with headache, 47.9% used nonprescription analgesics, 14.4% used prescription analgesics, 11.4% used both. Among men, 42.9% used nonprescription analgesics, 13.7% used prescription analgesics and 7.4% used both.</td>
</tr>
</tbody>
</table>
### Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lipton et al., 1998</td>
<td>USA</td>
<td>15000 US households contacted 2479 patients with IHS migraine 69.4% response rate in second phase</td>
<td>Mailed questionnaire for diagnosis Second mailed questionnaire to migraine sufferers</td>
<td>1. Physician consultations 2. Type of physician consulted</td>
<td>1. 68% of women and 57% of men had ever consulted. 2. The majority consulted in primary care setting. Initial consultations were with the general/family practitioner (46.4% of women and 48.1% of men), neurologist (13.6% of women and 10.4% of men), internist/ paediatrician (11.5% of women and 14.1% of men), obstetrician/ gynaecologist (4.2% of women), ophthalmologist (3.6% of women and 1.9% of men), emergency physician (3.4% of women and 1.9% of men), pain/headache specialist (1.6% of women and 4.7% of men) and other (15.7% of women and 18.0% of men). Most frequent consultations were with the general/family practitioner (43.8% of women and 38.5% of men), neurologist (12.3% of women and 10.3% of men), internist/ paediatrician (14.9% of women and 15.4% of men), obstetrician/ gynaecologist (2.6% of women), emergency physician (0.4% of women), ophthalmologist (0.9% of women), pain/headache specialist (1.3% of women and other (23.8% of women and 23.8% of men).</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dowson and Jagger, 1999</td>
<td>UK</td>
<td>50000 questionnaires 40% return 9770 analysed Male to female ratio 1:3</td>
<td>Mailed questionnaire</td>
<td>1. Diagnosis and consultation 2. Therapies 3. Satisfaction with migraine therapy</td>
<td>1. 69% reported physician diagnosis of migraine, 25% had not consulted a physician 2. 94% were taking some medication, over 50% reported using simple analgesics 3. Overall satisfaction rated at 6 out of 10</td>
<td></td>
</tr>
<tr>
<td>Lipton and Stewart, 1999</td>
<td>USA</td>
<td>5094 persons 688 IHS migraine sufferers</td>
<td>Telephone survey</td>
<td>1. Physician consultation</td>
<td>1. 46.7% of patients had consulted in the last 12 months, 20.6% had lapsed from consultation and 32.3% had never consulted a physician</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Siniatchkin et al., 1999</td>
<td>Russia</td>
<td>90 headache sufferers with either migraine without aura, CDH evolved from migraine without aura, TTH or CTTH in accordance with IHS criteria 26 migraine, 19 CDH evolved from migraine, 21 TTH and 24 CTTH patients.</td>
<td>Diaries for 2 months</td>
<td>Structured interview Validated headache diaries for headache characteristics Psychological tests: Beck Depression Inventory, State-Trait Anxiety Inventory Pain coping strategies: Kiel Pain Inventory</td>
<td>1. Psychological data 2. Pain-coping strategies</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Migraine (nontransformed and chronic) differed significantly from TTH. State-anxiety impairment of well-being/quality of life significantly more pronounced in TTH, reflecting more distinct psychological disabilities of these patients during headache-free period. Transformed forms of headache are characterised by elevated scores of anxiety, depression and more pronounced impairment of well-being and quality of life compared with nontransformed ones.</td>
</tr>
<tr>
<td>2. Migraineurs characterised by more marked disabilities in coping with pain. Some positive coping strategies more frequently used in migraine. Patients with nontransformed headaches more frequently use negative emotional and cognitive coping strategies and behave more passively in pain situations demonstrating more avoidance behaviour (TTH) and seeking for social support (migraine). Active positive strategies are rarely used by patients with transformed headaches.</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Adelman et al., 2000 | USA | 801 IHS migraine sufferers in a sample of 1317 severe headache sufferers | Consultations within last year and at some time | Telephone interview using screening questionnaire | 1. Physician consultation  
2. Consultation practices  
3. Current treatment practices  
4. Sources of information | 1. 45% current consulters, 32 lapsed consulters and 23% non-consulters. Consulters (79% current and 80% lapsed) were more likely to identify their severe headaches as migraine than never consulters (60%).  
2. Consulters reported having seen an average of 3 physicians about migraine. GP responsible for migraine care (56% of current consulters and 48% of lapsed consulters). Most consulters saw their physician more than once about migraine. 86% of non-consulters reported that they would consider to see a physician for their migraine.  
3. Prescription medications were the most common treatment for consulters who were diagnosis. 64% of those who were prescribed medication, took the medication regularly to relieve migraine.  
4. 42% of current, 60% of lapsed and 65% of non-consulters felt that they did not have the most current information on migraine. |
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pavão Martins and Parreira, 2001a</td>
<td>Portugal</td>
<td>55 IHS migraine patients in 2 outpatient headache clinics</td>
<td>Face to face interview including open and closed questions</td>
<td>1. Manoeuvres and behaviours during migraine attacks</td>
<td>1. Patients spontaneously reported using an average of 2.9 manoeuvres and 6.4 after completion of the questionnaire. The percentage of patients using specific manoeuvres were: 100% for 'changing position'; 98.2% for 'taking drugs'; 94.4% for 'isolation'; 88.9% for 'immobility'; 78.2% for 'local pressure'; 58.2% for 'sleeping'; 50.9% for 'application of cold'; 23.6% for 'eating specific food'; 61.8% for 'not eating'; 16.4% for 'inducing vomiting' and 67.3% for 'spontaneous vomiting'.</td>
<td></td>
</tr>
<tr>
<td>Wang et al., 2001</td>
<td>Taiwan</td>
<td>3377 subjects, 328 (9.7%) with IHS migraine and 1754 (52%) with non-migraine headache</td>
<td>Headache history for past year Consultation frequency per year</td>
<td>Face to face interview 3 part questionnaire: demographics, clinically validated headache questionnaire and Chinese Health Questionnaire</td>
<td>1. Physician consultation rate</td>
<td>1. 54% of migraineurs and 31% of non-migraine headache patients reported consultations with a physician (p&lt;0.0001). Average consultation frequency for subjects with headaches was 1.23, with consultations significantly higher in migraineurs than in non-migraine headache patients. Patients mainly consulted family physician (migraine vs. non-migraine headache 29% vs. 14%), internists (17% vs. 10%), ENT doctors (14 % vs. 7%), neurologists (12% vs. 5%). In migraine, 12% of the migraine patients and 6% of non-migraine patients accounted for 50% of total consultations.</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lavados and Tenhamm, 2001</td>
<td>Chile</td>
<td>1540 subjects, 101 migraine and 373 TTH according to IHS</td>
<td>Consultation at some time</td>
<td>Face to face, 2-step questionnaire</td>
<td>1. Use of health service</td>
<td>1. The odds of ever consulting were significantly higher in migraineurs. 31% of men and 68% of women with migraine ever consulted. 32% of men and 42% of women with TTH ever consulted.</td>
</tr>
<tr>
<td>Lu et al., 2001</td>
<td>Taipei, Taiwan</td>
<td>3377 participants 108 with CDH (according to (Silberstein et al., 1994))</td>
<td>One year prevalence Baseline and 2 year follow up</td>
<td>Face to face interview (stage 1) and telephone interview (stage 2 and follow-up) Questionnaire screening (Chinese Health Questionnaire, General Health Screening Questionnaire)</td>
<td>1. Prevalence 2. Subtypes 3. Medication overuse 4. Physician consultation</td>
<td>1. 3.2% CDH 2. TM most common subtype with 55% of all CDH and 1.7% of all participants. 44% of all CDH and 1.4% of all participants met CTTH criteria. 3. 34% of all participants met criteria for medication overuse. Of them 65% had overused medication for &gt;6 months in the previous year. OTC was the most common medication overused (73%), followed by prescription (22%) and both (5%). 4. 57% CDH patients had consulted physicians for their headaches during the previous year. 19% had consulted &gt;10 times. Patients mostly consulted family physicians (41%) and neurologists (28%).</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Pavão Martins and Parreira, 2001b | Portugal | Migraine (n=72) or TTH patients (n=28) according to IHS criteria | 1. Overall number of manoeuvres to relieve pain was 2.4 (range 0-6) when reported spontaneously and 5.3 (1-10) when prompted. Migraine patients reported significantly more tricks and behaviours than patients with TTH (p<0.00). Total number of manoeuvres was positively correlated to higher education, more severe attacks, less frequent attacks, overall duration of illness and negatively correlated with age at headache onset.
2. Most common behaviours: drug intake (91.8% of patients), isolation from light, sound and people (90.8%), changing posture (87.7%), trying to keep still (77.6%), alimentary changes (70.4%), avoiding foods (53.1%), pressing pain site (57.1%), trying to sleep (50%), using local cold (39.8%), other measures (27.6%) and inducing vomiting (15%). Migraineurs took medication, induced vomiting, modified posture, remained immobile, applied local cold, tried to sleep or avoided light, noise and people more frequently than TTH patients.
3. Efficacy of behaviours relieving pain was 92.5% for pressing site of pain, 90.8% for taking medication, 84.2% for using local cold, 80.2% for isolation, 73.1% for other measures, 64.4% for immobility, 62.1% for vomiting, 60% for sleep. Not all manoeuvres were used for pain relief, but to avoid aggravation of attack. |
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Methods</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lipton et al., 2001</td>
<td>USA</td>
<td>Population-based survey 20000 households 3577 individuals with severe headache meeting IHS criteria for migraine</td>
<td>Mailed questionnaire</td>
<td>1. Medication use</td>
<td>1. 41% of IHS migraineurs used prescription medication. 57% of IHS migraineurs only used OTCs.</td>
<td></td>
</tr>
<tr>
<td>Lanteri-Minet et al., 2003</td>
<td>France</td>
<td>10,858 persons 3087 people with headaches 151 CDH patients (CDH diagnosed if headache frequency &gt;15days per month)</td>
<td>Face to face interview 'Qualité de vie et migraine' questionnaire; MIDAS questionnaire</td>
<td>1. Physician consultation 2. Alternative health practitioner consultations 3. Medication use</td>
<td>1. Average of 5.36 physician consultations per 6 months, 1.98 visits/subject/6months with GPs (46% of subjects), 2.6 visits/subject/6months with specialists 2. 0.87 visits/subject/6months with alternative practitioners 3. 84.4% of patients took medication, but only 6.6% used prophylaxis. Analgesics (55%) and NSAIDs (24.5%) were used most widely. Triptans were used by 5.3% of patients.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

<table>
<thead>
<tr>
<th>Authors, Year</th>
<th>Country</th>
<th>Sample</th>
<th>Time scale</th>
<th>Design</th>
<th>Items studied</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacGregor et al., 2003 (randes, 2002)</td>
<td>USA, UK, Germany, France, Italy</td>
<td>5333 adult IHS migraine</td>
<td>12 months</td>
<td>Adapted Kiel headache questionnaire, MIDAS Semi-structured interviews</td>
<td>1. Physician consultation 2. Medication prescribed 3. Therapies to supplement prescription medication</td>
<td>1. 48% had consulted a physician (63% in France, 58% in Germany, 53% in Italy, 46 in the UK and 41% in the USA) 2. 3-19% were prescribed triptans, 22-54% were prescribed analgesics 3. 62% of patients supplemented their prescription medication with bed rest, 33% with avoidance of triggers, 20% with stress management, 19% with relaxation therapy, 18% with regular exercise, 14% with herbal remedies and 7% with homeopathic remedies</td>
</tr>
</tbody>
</table>
Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches

References


Appendix 1: Surveys on migraine and chronic daily headache patients management of their headaches


Appendix 2. Ethical approval for Phase 1 (qualitative)
Dear Ms Peters

**Migraine management in General Practice (ACE/2000/60/EIHMS)**

I am writing to inform you that the Advisory Committee on Ethics has considered the above protocol and the subsequent information supplied and has approved it on the understanding that the Ethics Guidelines are observed.

The letter of approval relates only to the study specified in your research protocol (ACE/2000/60/EIHMS). The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected (with reasons). I enclose a copy of the Ethics Guidelines for your information.

Date of approval by the Advisory Committee on Ethics: 05 October 2000
Date of expiry of Advisory Committee on Ethics approval: 04 October 2005

Please inform me when the research has been completed.

Yours sincerely

A C Watson
Senior Assistant Registrar

cc: Professor L J King, Chairman, ACE
Dr M Murphy, Principal Investigator, EIHMS
Dr A Dawson, Co-Investigator, Royal Surrey Hospital
Do you suffer from migraine?
If yes, are you willing to take part in a study on migraine management?

The study will involve interviews during which you will be asked to talk about your migraine experience, your treatments and the medical support you seek and receive.

If you have any questions about this study or would like to obtain an information sheet or would like to take part, please contact

Ms. Michele Peters
European Institute of Health and Medical Sciences
University of Surrey
Tel: (01483) 879000 ext. 4537
Email: M.Peters@surrey.ac.uk
Appendix 4: Cover letter (Phase 1)

(sent to 20 members of the Migraine Action Association)

Dear Madam, Sir,

I would like to invite you to take part in a study about Migraine Management in General Practice, which I am carrying out as part of my Ph.D. Please find enclosed an information sheet about the study, which is carried out under the supervision of Professor H. Abu-Saad, Dr M. Murphy (University of Surrey) and Dr A. Dowson, (Royal Surrey Hospital). Although the study mainly focused on consulting your General Practitioner (GP), you do not need to have consulted or to be currently consulting your GP. This study will allow you to voice your opinion, beliefs and experiences about both positive and negative aspects of care in general practice to help improve migraine management.

If you would like to take part or if you have any questions with regard to this study, please contact me by telephone or email (the details can be found on the information sheet).

Thank you for your interest.

Yours sincerely,

Michele Peters
Appendix 5: Information sheet

(Phase 1)

Information Sheet

Migraine is a common condition among adults. The severe pain, nausea and/or vomiting, dislike of noise and/or light and aggravation by physical activity is often a major burden to migraine sufferers. The sufferers' ability to carry out paid work and housework or to fully enjoy family and social life can be greatly reduced. Treatments, providing significant relief of migraine and its burden, are available, but few migraineurs use these treatments. We need to gain insight into the reasons for migraine sufferers not relying on these treatments. These reasons will provide the key to improve migraine care, to reduce the burden of migraine and to improve the sufferers' quality of life.

You can take part in this study if you:
1. Suffer from migraine
2. Are aged between 18 and 65
3. Are willing to talk about your migraines, consultation practices and treatments.

You will be asked for an individual meeting with Michele Peters, the interviewer, to ask questions, to sign the consent form, for an interview. You may be invited for further individual and group interviews. All interviews will be tape-recorded. The tapes will be destroyed when the study has been completed.

Personal information gathered during this study will remain confidential. The research may be published in the scientific literature, but you will not be identified by name. All records will be kept in a locked cupboard and will not be accessible to anyone other than the investigators.

After reading this information sheet, you must ask about anything that is unclear before you sign the consent form. Your participation in this study is voluntary and you have the option not to participate or to withdraw at any time without giving any reasons. If you volunteer to participate in this study you should notify your GP and give him/her a copy of this information sheet.

If you would like any further information or have any questions, please contact Michele Peters at the below address/telephone number or email.

Ms M Peters, Prof. H Huyer Abu-Saad and Dr M. Murphy
European Institute of Health and Medical Sciences
Dr A Dowson
Kings Headache Service and Neurology Research Unit, Royal Surrey Hospital, Guildford, Surrey
Contact Michele Peters Tel. No.: 01483 87 9000 ext. 4537 Email: M.Peters@surrey.ac.uk
Appendix 6: Interview guide

(Initial interview guide)

Migraine
- Describe your migraine.
- When did you start suffering from migraine?
- How long have you suffered from migraine?
- How severe are your migraines?
- Which symptom do you find the most difficult to deal with?
- How often do you get migraine?
- How long do your migraines last for?

Migraine impact
- How do your migraines affect your everyday life?
- What activities do you miss out on because of your migraine?
- How do your migraines affect your work?
- How do your migraines affect your family/social life?

Treatment
- How do you treat your migraine?
  - Which medication/drugs do you use when you have a migraine?
  - Are there any other medications that you use/have used in the past?
  - Which medication do you use/have you used every day to prevent your migraine?
  - Which prescription medication do you use?
  - Which Over the Counter medication do you use?
  - Which other medication do you use?
  - Which alternative therapies do you use?
  - What else do you use to help relieve your migraines?
  - How does your treatment differ between different attacks?
  - How do you decide which treatment to have?
- What are the reasons for using this treatment?
- Who has chosen this treatment for you?
- How did you choose this treatment?
- How helpful/good is the treatment that you are using?
- What were the reasons for changing your treatment?

- How satisfied/happy are you with your treatment?
  - How good do you think your treatment is?
  - What do/don’t you like about your current treatment?
  - What are the good points about your treatment?
  - What are the bad points about your treatment?
  - What could be improved about your treatment?
  - What would you like to be different with your current treatment?
  - What are the differences in response to your treatment for different attacks?
  - What are the side effects of your treatment?
  - How acceptable do you find those side effects?

- What do you expect from migraine treatment?
  - What would be the ideal treatment for migraine?
  - How quickly would you like your treatment to relieve your migraine?
  - What is the longest time you would find acceptable to get relief from your migraine?
  - What is the main aim of your treatment?
  - What other aims are there?
  - How important is it that your treatment will take away symptoms other than the pain/headache?
  - Which part/symptom of the migraine is the most important to treat?
  - How acceptable do you find it if your treatment doesn’t completely relieve the headache/your other symptoms?

- What do you hope migraine treatment to do?

- How would you go about getting different treatment?
  - Who would you ask for help to find a different treatment?
  - What are your intentions on changing your treatment?
Consultation/ advice

- Who gives you advice about your migraines/ who do you consult?
  - How often/ when (how regularly) do you talk to somebody about your migraines?
  - Why do you talk to somebody about your migraine?
  - Who else would you like to talk to/ find it useful to talk to?
  - Who else do you think might be able to help you?
  - Do you talk with your friends and family about your migraines?
  - Which health professionals do you consult/ have you consulted?
  - Who diagnosed your migraine/ headache?
  - How much have you read about migraine?
  - How happy are you with the advice you are/ have been given?
  - How useful do you find the advice you are/ have been given?

- Tell me more about talking to your GP about your migraine / your visit to a migraine clinic?
  - What were the reasons for consulting your GP / going to a migraine clinic?
  - When did you first talk to your GP about your migraine?
  - How often do you talk to your GP specifically about migraine?
  - How often do you talk to your GP about your migraine when you see him/ her for another reason?
  - When did you have a follow up appointment?
  - When did you last talk to your GP about your migraine?

- What were you expecting from your GP when you first spoke to him/her about your migraine?
  - What did you expect from your follow up appointment(s)?

- What do you discuss with your GP about your migraine?
  - What else would you like to discuss with him/ her?

- How satisfied (happy) are you with your migraine consultations?
  - How helpful do you find consulting your GP?
  - Which aspects of the consultation did you find helpful?
  - What problems did you have when talking to your GP?
- What do you hope your GP will be able to do to treat your migraines?
  - What would you like your GP to do to help treat your migraine?
- What are the reasons for consulting/not consulting your GP?
  - What are your intentions to see your GP (again)?
  - Which initiatives have you taken to talk to your GP about your migraines?
  - What would make you go to see your GP about your migraines?
  - Has anybody ever suggested that you talk to your GP?
  - How much or how often do you think about seeing your GP about your migraine?
  - What are your reasons for not seeing your GP (anymore)?
  - If you went to see your GP, what would you like to discuss with him/her?
- Who/what else do you think may be able to help?
  - What else do you think your GP could do to help you?
Appendix 7: Interview guide

(Interview guide comprising issues raised in previous interviews)

Migraine Diagnosis
- When, how old were you
- Who made the diagnosis
- Symptoms
- Other headaches
- How do you make the difference between different types of headache

Treatment/Management strategies
- Taken, current and previous
- Satisfaction, how well do they work
- Choice, how and who by, why did you change
- Why is that treatment (management strategy) better/worse
- Expectations, what were you expecting of the treatment (management strategy)
- Improvements, what could be better
- Availability, how easy is it to get the treatment (management strategy)
- Readiness/happiness to take drugs (other management)
- Treatment preferences/ideal treatment (management)
- Cost of treatment

Consultation
- Whom have you spoken to
- Why do you prefer/choose to speak to
- When, why not immediately
- Reasons/cues to action
- What happened/what was discussed/were you diagnosed/discussed all headache types
- What might happen (perceived action)
- Priorities, how many illnesses were discussed, did you use term migraine
- Expectations/hopes, what did you want to achieve through the consultation
- Criteria of a good consultation
• Satisfaction, did he have enough time, did he help, did he understand/
discuss the “right” issues
• Improvements
• Intentions/readiness/ follow-ups
• Barriers to consultation, accepting migraine (living with it), don’t want to
take drugs, nothing to offer, tried it didn’t work, seen parent/ close person cope
with it, other people’s experience

GP
• How many different GPs
• How helpful
• How sympathetic
• Satisfaction/ expectations, could he/ she do any more, understanding,
knowledge, time
• Ease to book appointment
• Confidence in GP
Appendix 8. Consent Form

Migraine Management

I will only participate in this study if all responses to the statements below are positive:
1. I have read the information sheet and I understand the purpose and nature of this study
2. I have had the opportunity to ask questions and I have received satisfactory answers to all my questions
3. I confirm that I am aged between 18 and 65 years
4. I understand that I am free to withdraw from the study at any time without giving any reasons
5. I have had sufficient time to come to my decision and agree to comply with the instructions of the study
6. I voluntarily agree to take part in the study on migraine management in general practice

I understand that by signing this form I have not waived any legal rights, which I would have as a patient in a research study

Name of Volunteer (Block Capitals) .................................................................
Signed ............................................. Date ...........................
Name of Witness (Block Capitals) .................................................................
Signed ............................................. Date ...........................
Signature of Investigator .................................................................

Ms M Peters, Prof. H Huyer Abu-Saad and Dr M. Murphy
European Institute of Health and Medical Sciences
Dr A Dowson
Kings Headache Service and Neurology Research Unit, Royal Surrey Hospital, Guildford, Surrey
Contact Michele Peters  Tel. No.: 01483 87 9000 ext. 4537 Email: M.Peters@surrey.ac.uk
Appendix 9. Interview example.

Interview with 36 year-old female migraine patient (Pt6).

I: I usually start with the diagnosis of the migraine. So if you could just go through describing.

Pt 6: my symptoms?

I: your symptoms.

Pt 6: [clears throat], ok, ehm I’ve had them; I can’t really remember when they started, but I think it was sort of late teens, early twenties.

I: mm.

Pt 6: and ehm, I get symptoms of like severe pain in my head. I don’t get any sort of visual flashing or any of that, although my mother and my grandmother suffer from those sorts of migraines, although I suffer from the pain type. And the, the area of the pain does vary. So, sometimes it’s right behind my eye, sometimes it’s one-sided, either side, sometimes it goes down my neck, sometimes, it’s right on top of my head. So I have pain that, it is, can be all over my head. It’s not always in one specific area. And I always feel sick. And I always have got problems with it, and sometimes diarrhoea.

I: mm.

Pt 6: I always feel as though I want to be sick, but I haven’t actually yet been sick through them. And eh, mainly you know, I have to sleep. And I do; although I don’t get the visual flashings, I do sometimes get sort of slanted vision, slight slanted vision. So it does affect my vision, but not in the classical way with the flashing lights. What else?

I: maybe if you can think about the pain a little bit more, how intense is the pain?

Pt 6: ehm [pause] again it depends. Sometimes they’re; they can be relieved by painkillers, sometimes they can’t. And they; I just need to sleep through them. So sometimes I do get severe pain.

I: mm. And how long do they normally last for?

Pt 6: ehm [pause] anything probably from half a day to three days.

I: and how often do you get them at the moment?

Pt 6: at the moment, they’re about sort of three times a month, I would say.

I: so that’s quite a lot.

Pt 6: yeah.
I: and ehm, describe the pain a little bit more. You say it can be quite severe, but is it a throbbing sort of pain, or constant?

Pt 6: ehm, it can; it can be throbbing and I feel as I can almost touch it, especially if it is in my temples. If I press it, it seems to relieve it a bit. So I feel as though I can almost touch it. And also when it’s behind my eyes, I feel as though if I press it, it would go away. So it is; it is sort of a thumping ache. Eh, but a lot of it, is sort of like inside, you feel as though you can’t get to it, it’s all inside your head.

I: mm, ok. Do you get symptoms, eh light, any sensitivity to light?

Pt 6: I think I am, yeah I do get sensitivity to light and that increases the pain. And I don’t like light, although I don’t usually put myself in a darkened room. I mean it might improve it if I do, but eh I am quite sensitive to bright light while I’m having one.

I: noise, are you sensitive to that?

Pt 6: ehm [pause], I suppose I am yeah. I become very ratty, definitely. And I suppose I am, I haven’t really noticed that I am sensitive to noise, but you know I probably go very short-tempered and perhaps it is the noise that affects me, such as the children [laughter].

I: [laughter] and when you’ve actually got the headache, does it get worse when you’re physically active, when you walk up the stairs?

Pt 6: ehm, not really. I don’t really notice. Previously, you know, like ten, fifteen years ago, when I used to have them, I used to find sometimes, if I did something like aerobics, it used to go, whereas other times it used to make it worse. So there doesn’t seem to be a constant pattern with physical activity. And, so I mean it; it’s something that sometimes relieves it and sometimes it doesn’t, yeah.

I: Do you get any other headaches apart from these?

Pt 6: ehm, I s; I suppose I do get sort of mild forms. As I say some of my migraines I can relieve with painkillers and you know I call those headaches, although sometimes I know that if I’m not careful about what I do, then they can develop into migraines. So…..

I: so what’s the difference between what you call a headache and what you call a migraine?

Pt 6: oh dear, ehm; I can always tell when it’s going to be a migraine, when it’s going to develop further. I don’t know, the pain is [pause] slightly different. Eh, it’s; it’s a little bit more intense, I suppose at the start, and I always feel sick and quite tired, I think when it’s going to be a migraine. When it’s just a headache, if I; like dehydration headache, you know I haven’t drunk enough, then it; it’s not the same sort of pain. It’s a bit difficult to explain exactly why it’s different, but I know a migraine sort of is, feels like a big weight on my head. And I do always feel sick. Whereas with the other headaches, it’s not quite as severe pain at the beginning. Is that ok?
I: yeah, that's fine. Ehm, how often do you get those headaches?

Pt 6: ehm, I; I haven't really noted the frequency to tell you the truth. I mean sometimes I sort of wake up with a slight headache, which often goes after I'm; I mean it could just be caffeine withdrawal almost. You know, after I've had my cup of tea and had something to drink, ehm, [pause].

I: do you notice them more often than the migraines or less often?

Pt 6: [pause], ehm, probably, mild headache, which doesn't really affect what I do, probably more often than the migraines. But then I; it wouldn't disable me in any way, I wouldn't stop what I was doing or anything with the headaches.

I: that's why you don't pay so much attention to them?

Pt 6: yeah, that's right, yeah.

I: ok, that's fine, that's that bit sorted out. And now I've got a little bit of something for you to do.

Pt 6: all right.

I: this is a MIDAS questionnaire, which is meant to measure disability from headache and it covers the period of the last three months. So if you can just go through the questions and answer in days for the last three months.

Pt 6: right.

I: and talk about them while you're thinking.

Pt 6: ok [pause]. With; about missing work; I don't, although I should perhaps, I don't stop work because of them. Although ehm, my efficiency at work is probably very much reduced. So I don't actually, usually come home [phone rings].

I: do you want to get that?

Pt 6: no, my husband can get it. Ehm, so; so I haven't actually had any days off work.

I: ok, so if you just put zero days.

Pt 6: zero.

I: and the next one actually relates to your efficiency.

Pt 6: ok [pause]. Is this specifically about my work place work? 'cause rather, I do; I do sometimes do work at home. I suppose I wouldn't have done if I had a migraine.

I: but is that work, for your work?

Pt 6: yes.

I: you're not talking about household work?
Pt 6: no. So we’re just talking about.

I: so I think, even if you’re working at home, that’s still your paid work.

Pt 6: so you’re talking about paid work yeah [pause]. Three days [pause].

I: and you’re working part-time?

Pt 6: yeah, I work part-time, three out of five days, but I work school hours. So I drop my children off at school, go to work and come back and pick them up from school, yeah [pause]. When you count, I mean I know that I; I know that sort of almost, ehm, the days that I’m going to have a headache, in that it ties in with my cycle. So I know I sort of have one like a week before I’m due, probably the day I start and the middle of the month, ovulation. So I can almost sort of count back to that, but I can’t remember exactly whether that was right for every month. I mean do you want me to just estimate it in that way, when it says how many days in the last three months did you have a headache?

I: yeah.

Pt 6: it’s just an estimate.

I: yeah, if that is all you can give me.

Pt 6: all that I can give.

I: I know that it might be slightly different.

Pt 6: then I’ll put nine [pause]. Ok [passes back MIDAS].

I: ok, thanks. If you like I can explain that a little bit later, but I don’t want to have all of that on the tape.

Pt 6: ok, sure [laughter].

I: I don’t want to have to type all that [laughter].

Pt 6: it will save you a bit of time.

I: well I don’t like listening to myself. Well, the first thing I really want to talk about is your treatment. What do you do at the moment for your treatment?

Pt 6: I usually just take painkillers and I have Ibufen, which I find is quite good. I usually take; I was; I was advised and I think it’s better for me to take, as soon as I know that I am going to get it, even when the pain’s not severe, ehm, I should take tablets and regularly while I still get the pain. And I’ve been; it often does alleviate it. However, I’m often not as good as that, and I often just “oh, it’s gonna go away” and leave it until it gets to a state where it is so painful that the painkillers don’t touch it. So if I’m good then I take them at the beginning and if I’m not then I take when it’s probably too late. And then I; then I have to really just rest and sleep to; to alleviate it.
I: so who advised you to take it?
Pt 6: ehm, the doctor.

I: so you have seen your GP about it?
Pt 6: yes, I have yeah.

I: eh, so how helpful do you find them when you first take them? When you say at the beginning, how quickly do they work?
Pt 6: eh, probably about an hour, I'd say. They do; I mean it depends, sometimes, you know it can clear it up all together with just one dose. Sometimes if it's gonna be worse for whatever reason, you know I need two doses, or sometimes it doesn't alleviate it at all. But generally if I; if I take them as soon as I think I'm going to get one, then usually one or two doses is enough.

I: mm.
Pt 6: to prevent the really severe pain and having to go to bed really.

I: and how acceptable do you find that that is? I mean obviously never knowing really if it's going to work or not.
Pt 6: yes, I mean it would be better if there was obviously guarantee that it's going to help; that is going to work. It's that the sort of; is that what you mean [laughter]?

I: yeah [laughter]. Well, it's; lots of people are taking things that either take a long time to work or that; are not always that good at later stages.
Pt 6: mm.

I: during the migraine, so you either have to take it really early.
Pt 6: mm. Yeah, I mean if I have got my full; you know; if it's got the pain and the sickness and if I take a tablet then, I might as well not bother, because also I think I get problems with ehm, you know, my gastro-intestinal tract. And I don't think I absorb it, quite honestly, which is another thing. The doctor did actually give me some other tablets, which are called Motilin, which are meant to be anti-nausea medication, which are meant to help me absorb the painkillers, which he suggested taking one of those every time you have a dose of painkillers. Which, ehm I have taken, but I have now run out and I haven't bothered to go back to the doctors to get some more. And they did actually help, they did help the nausea and possibly the absorption of them. So they were; they were quite good as well.

I: mm. So that made a difference when you took them to the effect of the painkillers?
Pt 6: yeah, it did yes. And because also, the nausea and everything was also relieved. I think the whole group of symptoms was just must easier to tolerate it.

I: so normally with the painkillers the nausea is not relieved?
Pt 6: no it’s not relieved at all, no.

I: right.

Pt 6: just the pain, the head.

I: but even when you take it early, it just affects the pain or the nausea?

Pt 6: ehm [pause] eh [short laughter].

I: [laughter].

Pt 6: I haven’t really thought about it. I suppose it does in a way relieve the nausea, but more the pain. Often I am left with the nauseous side of things and I don’t have severe, as severe pain.

I: mm and is that ok then?

Pt 6: I can; I can suffer the nausea much better than I can suffer the pain, definitely. It’s the pain that really, ehm, it’s much worse for me. I can’t do things when I’ve got that really severe pain, whereas I can; I can still carry on almost as normal with the sickness.

I: mm, ok. So you just get your painkillers over the counter, you don’t get a prescription?

Pt 6: yeah, no.

I: and you get the anti-emetics as a prescription?

Pt 6: I had those; yeah I had those as a prescription, yeah.

I: I am assuming you can’t buy those over the counter.

Pt 6: I don’t know, I haven’t, I mean my doctor prescribed these particular ones and he said there was other ones that we can try, but they seemed to work. Ehm, I haven’t tried buying them over the counter to tell you the truth.

I: yeah, I’m just.

Pt 6: I don’t know.

I: I don’t know if you can buy them over the counter. Ehm, so what would you say are the main reasons for using this treatment?

Pt 6: ehm [pause] probably because they; the thing that really affects ehm [pause] my working efficiency and just generally affects me, is the pain. And so obviously I want to relieve the pain, so therefore I’m taking painkillers. That; the; the anti-nausea medication was, as I say the nausea is; or is not; is not good, but I can stand that better. But I; the anti-nausea drug, did help me absorb the other ones, I think. So, that’s why I take I suppose [laughter].

I: have you ever taken anything else, apart from that?
Pt 6: yeah, I have taken the; I have taken other painkillers yeah. Paracetamol don’t work, or dispirin or aspirin don’t seem to have the same effect as Nurofen. But I usually just get the just the general Boots’ own Ibufen ones. So I need a sort of fairly strong one, and I always have to take at least two tablets. Ehm, I did try other treatment. Do you want me to talk about that? I have tried other treatment before this.

I: yeah.

Pt 6: yeah, and that was Migraleve, where you have the pink and the yellow tablets. Do you know this?

I: everybody talks about the pink and yellow tablets [laughter].

Pt 6: yeah [laughter]. I know it was such a long time ago, I can’t remember which one you take first. One when it’s just started and then you take the other ones all the way through it. It had no effect on my. It didn’t really do me any good. It didn’t seem to work with me. Ehm, so that’s the only other treatment I’ve taken.

I: so you’ve tried different things?

Pt 6: yes.

I: and just went onto something else when it didn’t work?

Pt 6: yes, that’s right. I mean especially painkillers, you know. I think; I find Ibufen is better. I have had some; I had an operation in hospital and they gave me some, ehm codeine and paracetamol, which were very strong. And I have used those, just because I didn’t use them for the pain I had from the operation and they seemed, I suppose it’s good, but they don’t seem any better. They didn’t seem to relieve it any better than the Ibufen, so I; I just get that.

I: ok. Obviously you’ve mentioned your doctor and what he prescribed a little bit already. And of the main things I really wanted to talk about, was about advice that you get.

Pt 6: right.

I: generally from people, but then more specifically from the GP.

Pt 6: right.

I: where, generally speaking, do you get advice from?

Pt 6: ehm, mainly from the GP. I mean my Mum’s quite concerned about my headaches, and she probably is more active than I am. And she wrote to the; the Migraine Society. So I’ve got their leaflet on it, which I’ve read. It’s quite general, but I haven’t taken it any further than that. Ehm [pause] so main; most of the advice is either taken from friends, who tell you about their experiences or from the GP, from my doctor. And I have been to, I mean I’ve had these headaches for a while, and I went to, when I was an undergraduate student at S, I went to the doctor there, who gave me the Migraleve. But my doctor here, he, you know; he’s very good, but he’s only, as I said, only suggested these anti-nausea drugs with the painkillers.
I: right, ok, maybe if I can you trough all the different consultations that you had with the doctor.

Pt 6: right.

I: when did you first go to see somebody?

Pt 6: eh.

I: you said as an undergraduate?

Pt 6: yes [pause] eh, was it, so that was probably about; say it was about; perhaps it was about '88, all those many years ago [laughter].

I: do you remember what the reason was that you went to see somebody at that time?

Pt 6: ehm [pause].

I: it sounds like it took you a little bit of time before you went to see somebody.

Pt 6: yes, well I just used to sort of just suffer the pain really. And I think it was just getting, probably my Mum again saying “you should go and see someone about it, they might be able to help you”. I mean I was just thinking it’s just like a headache, and you just have to take painkillers and that’s the only; the only relief that you can get. But I thought I’d go to the doctor and try and get other treatment to see; ‘cause pain relief wasn’t really working that well.

I: mm.

Pt 6: and eh, then I got Migraleve and it didn’t really work, so I just went back to painkillers. And then when I was; when I was; had eh, when I was here, after my; I didn’t have migraine during my first pregnancy at all, but during my second pregnancy I had, I did have a number of very severe migraines, which is quite unusual I think during pregnancy they are often alleviated. So after that I went to my doctor. It must have been about, ehm, a couple of years ago, ’99.

I: can I bring you back to your first consultation.

Pt 6: right.

I: you went a little bit fast.

Pt 6: sorry [laughter].

I: oh no, that’s all right [laughter]. Ehm, what actually happened when you went to see the GP? Can you remember a lot about it?

Pt 6: no really [laughter].

I: or just tell me the things that you do remember.

Pt 6: ehm.
I: how helpful do you think it was or what suggestions did they come up with?

Pt 6: I mean I think, eh the main thing he said was [pause] was; you know; I can’t remember. You know he suggested this Migraleve in that, you know to take the, this medication as soon as I had the migraine. He was probably the person; the first person to say that rather than I used to just let it carry on, thinking “oh it’s gonna go” and it hardly ever did. And so, he told me to take the medication, this Migraleve medication as soon as I had the headache, whether it was a pink or a yellow I can’t remember [laughter]. So and then you’re meant to take then and then obviously the subsequent, the other one, the pink or the yellow, through the migraine. And that’s all I can really remember.

I: right. Do you remember him going through the diagnosis, discussing your symptoms with you?

Pt 6: not really. I think I just, I can’t really remember, ‘cause I know, I know there is sort of certain types of migraines, and I said I had just the pain and not the flashing lights. And he did accept that that was a migraine. But I don’t think, I don’t remember him going through the; the diagnosis of it, no.

I: so you, ehm, did you actually go in and say to him straight away “I suffer from my migraine”, rather than saying “I suffer from headaches” and then he had to.

Pt 6: no, I think I said to him “these are my symptoms and I think it’s a migraine”. I think he probably said “yes”. So I mean I thought it was a migraine, before I went to him. It wasn’t him who told me that.

I: so it’s through your Mum?

Pt 6: probably, yeah, yes, yes.

I: did he come up with any suggestions about what you can do apart from medication?

Pt 6: ehm, you know I can’t really remember. But I mean I know from somewhere that things can affect migraines, like alcohol and chocolate and things like that. so, he may have suggested that to me, the fact that they could be triggers for it. Ehm, and I think with mine, I found that; it’s not; I don’t find that any food is in particular a trigger, but I find that if I’ve got a headache, I don’t really; I can’t drink alcohol at all. And ehh, tea and coffee I don’t really want. So I don’t know if it’s related or not. It doesn’t seem to bring them on, but while I’m having them, it’s not a; I don’t really...

I: that might probably be more related to the nausea.

Pt 6: yeah.

I: you go off certain things.

Pt 6: yes, yeah.
I: right and then after you'd seen him and the Migraleve didn't really work, why didn't then go back and see him again to get something else. Why did you just go back to painkillers?

Pt 6: ehm [pause] I don't know really, I just; he didn't really say that there was much, many other treatments. So, I just; I don't know, I just suffered it, I suppose [laughter]. Eh [pause].

I: I am trying to understand the reasons, why people don't go back. It's actually quite a lot of them, they tell me I just don't know why.

Pt 6: yeah. I mean although it is very disabling really to have a migraine [pause] somehow, you know you just think, you should; it's just a headache and nothing is going to help it really. If painkillers don't work, then there is probably nothing else that is going to work. Once I've tried that, Migraleve, I thought that was it, obviously the treatment he suggested to me and then it didn't work.

I: mm. What do you think now then? Are there any other treatments apart from painkillers?

Pt 6: [pause].

I: do you know of any?

Pt 6: ehm [pause] not; not really, not specifically, unless they are things like relaxation or trying to determine when certain triggers. But then I don't know of any specific ones, no [laughter].

I: that's ok, that's fine [laughter].

Pt 6: good [laughter].

I: as I say, I am not testing your knowledge. So, eh after that first consultation, was it until that last; or that consultation you were talking about now, a couple of years ago.

Pt 6: yeah.

I: was it that long in between when you didn't see anybody?

Pt 6: yes, it was really, yes. I mean think every time I re-registered with a doctor, you know when you go through your medical history. You know they say “do you suffer from anything” and I said “yeah, migraines”. And I remember another doctor saying “what do you do” and I said “painkillers”. And he said “is that; is that enough for you” and I said “well, it doesn't always shift the pain”. But he didn't seem to be that interested in it, that's the trouble [daughter comes to interrupt and is taken away by Dad].

I: why didn't you take him up; maybe talking about it again to see if whether there is something else.
Pt 6: ehm, 'cause I mean; I thought, although it was; although it is; it is [pause] it is debilitating for me, I just felt as though, I suppose, I could cope with it. I didn't sort of want to make a fuss or go through any more [pause], I don't know, any more consultations about it, suppose [laughter]. Very difficult questions [laughter].

I: [laughter], yeah, well, it's just interesting that people don't really know why they didn't go back.

Pt 6: yes.

I: but then after a while, obviously you went back again. What was the reason that made you go back at that time?

Pt 6: ehm, it was getting to a stage where I was getting quite severe, you know; severe migraine, quite frequently. They; I mean they come in cycles, I think around about my pregnancies I think they relieved them a little bit, being pregnant and during lactation and things. Although then they started coming back more frequently and more severely and it was affecting me a lot more. And the doctor I've got is very good, so I thought, and he's very understanding and he does listen and discuss things with you. So I thought it would be interesting to have his opinion on them, to see if there is anything that he could suggest.

I: mm. And do you remember a lot about that consultation?

Pt 6: yeah, I mean, our doctor, I mean he's very I mean; he's very interested in what you say and he got me to list everything, all my symptoms. And he said that, you know he explained the different types of migraines to me and he said "yeah, that is a migraine" and the possible treatments. I mean because mines are, he thinks; because mine's a cyclical one that is obviously associated with my hormones or my cycles, he said, you know, he said that it may be that that is actually the trigger for it. Ehm, and he suggested, because I suffer from nausea, he suggested the anti-nausea and the painkillers, and he said he could give me other stronger painkillers, if I didn't find any that suited me.

I: right.

Pt 6: and also for a while actually, it might have been around the time they started. I started on the pill, and I think that, it was during that time, I was having it for quite a long time, I think that probably didn't help. And then I came off the pill for the reason of the headaches, which was about; which was quite a long time ago. And eh, and he said "perhaps start on a different pill", you know, oral contraceptive to see if that had any beneficial or detrimental effects on it. And eh, it didn't really make that much difference, it didn't relieve them. I went on the progesterone only pill. It didn't relieve them, but it didn't seem to make them worse. They don't seem to have any effect on them.

I: mm. So you got the ehm pain, you have the painkillers and you got the anti-emetic and you said that that is working quite well.

Pt 6: yes.

I: but now you said you've run out of them.
Pt 6: I’ve run out of the, yes [laughter].

I: [laughter], you know what I am going to ask. Why didn’t you go back?

Pt 6: probably just, because I’ve been busy. And eh, although it is, it is; it does make it easier, having those, eh, recently I suppose; I mean I haven’t really thought about it, but recently they’ve been slightly less severe than I have had in the past. So it hasn’t been such a problem, because it’s the pain that always really affects me. So if I, if I can relieve the pain with the painkillers, as I say, I can sort of suffer the nausea. So I haven’t been back and I should. And it’s just because I’ve been, I suppose, not that you can ever be too busy, but I feel as though I’m too busy. Or other things to do with laziness, perhaps [laughter].

I: priorities [laughter].

Pt 6: yeah, priorities, that’s what it is, that’s better [laughter].

I: ehm, but don’t you think if you’re going to have the; even if they are not as bad at the moment; if you are going to have the anti-emetic to go with the painkillers, that’s going to relieve the pain quicker because you get, it gets absorbed quicker?

Pt 6: yes, yes, it would [laughter] so I should really go [laughter], I’ll book an appointment now [laughter].

I: [laughter] I’ll stop the tape if you like.

Pt 6: yeah [laughter].

I: ehm, did your GP when you were seeing him come up or suggest anything apart from painkillers and anti-emetics? Did he talk to you about migraine specific medication?

Pt 6: no, not really, not that particular type, because he said “try these and if you find that they’re beneficial or if they’re not then come back and we can talk about it again”. So I mean I did find that they were better and again if I’m good and I take them bef; just as my headache starts then I think it definitely improves the outcome of the treatment, rather than leaving it.

I: how do you actually decide when you’re going to take the medication?

Pt 6: [pause].

I: because you don’t seem to be very consistent.

Pt 6: no, not really. Well, I don’t; I don’t like taking medication for starts, so really if I can get away with not taking medication then I prefer not to. And I think this is why I always leave it too late, because I think “oh well, it’s going to go” and it never; very rarely; well it never does. But every time I kind of think “well, I just leave it, this one might go”. But nowadays, I think recently ehm, I am more likely to take it when it’s just coming on. Ehm, which is; gives me better relief really.

I: so you have learnt from past experience [laughter].
Pt 6: oh, yes it’s taken me a long time [laughter]. So and also if I’ve got; you know, if I’m going out or something and I’m starting a headache then I take it earlier. Whereas if I’m just staying in the evening, it doesn’t really make any difference, it’s not going to affect what I am going to do. Then I’m more likely to leave it.

I: so what worries you about taking the drugs?

Pt 6: I mean, nothing really [short laughter], I just feel as though it’s better if I don’t have to take medication.

I: ok, fine. If you think maybe about, again, seeing the GP and obviously you’ve had some help, but is there anything else you’d think you’d like to discuss with the GP or maybe another health professional about the migraine that might help you?

Pt 6: chm [pause].

I: to prevent getting so many or being so severe.

Pt 6: yes I mean, if; if I thought that there was a treatment out there that would relieve them completely then I would make the effort to go. But I just; I have; speaking to other people, and probably because they are the same as me and don’t go back to the doctor, they say there is nothing really that has ever helped them completely. And they just alleviate the symptoms, rather than actually getting at the reason why they are having them.

I: mm.

Pt 6: so if I could be confident in a treatment, then I would probably seek more help.

I: right, so if anybody told you now.

Pt 6: [laughter].

I: there is actually something, that also work at later stages of the migraine.

Pt 6: right.

I: that you could take. It takes, I mean in a lot of people, it doesn’t work for everybody, but it takes away the nausea as well.

Pt 6: yes.

I: and lots of the symptoms.

Pt 6: yes, I would.

I: then I think you should go back.

Pt 6: [laughter] is there a treatment?

I: yeah, there are some things, I can tell you a little more about.

Pt 6: ok.
I: I have got some reading for you as well.

Pt 6: ok.

I: so, is there anything else, apart from medication that you could, any other advice that you’d like, or more information about certain aspects of it?

Pt 6: ehm, I mean I have ehm, I mean I know of work that’s been done on looking at the dietary triggers for it and if you’ve got perhaps an underlying food allergy, then I know that that can affect your migraine. And you need a trigger food. And I did some work on food allergy. But knowing how awful it is to go on an exclusion diet, I have never pursued that side of things, the dietary side of things. And being a nutritionist I possibly should have done [laughter] searching into allergies as I did.

I: I don’t agree with that [laughter].

Pt 6: no [laughter], it’s awful, it’s, we never do the right thing as us nutritionists. But I haven’t, because I know how horrendous exclusion diets are. Ehm, and they are not always conclusive anyway. So, ehm another thing that I; I; that does affect it, my migraines, is stress, either a relaxation or a stress. If I do for any reason get ehm, you know, an acute stress, for whatever reason, I got a deadline that’s like tomorrow and I have only just heard about it, then I can feel the migraine coming on. And often I used to have migraines on a Friday, especially when I was a student. Ehm, and especially when I went home and I think that is often a relaxation thing. So perhaps to control, you know, this stress and relaxation may help.

I: have you heard about anybody that you can go and see about relaxation?

Pt 6: not really.

I: are there other treatments that you might have?

Pt 6: no, I haven’t had, not specifically for migraines, no.

I: and have you ever read anything, I mean you know about the food triggers, where do you know about those? Just from being a nutritionist?

Pt 6: yeah, I did; I did some research into food allergies, so I learned just from doing literature surveys.

I: but you haven’t read in magazines or?

Pt 6: ehm, I don’t; I don’t really get magazines, but I mean I have; I have seen them in a few magazines, when they talk about migraines. And obviously if there is a magazine there and I am waiting in the doctor’s surgery or the dentist’s, I would read the one that is about migraine. It’s just because it’s, you know, of particular interest, but I don’t read an awful lot of magazines. Although I know that they are written in there a lot about conditions like migraines.

I: mm. A lot of people say that and I never see anything.

Pt 6: oh really [laughter].
I: [laughter] in fact there was something on TV the other day as well, and I missed that.

Pt 6: [laughter], I didn’t see that.

I: ehm, if you could maybe think about an ideal treatment for migraine. What would that be? What would that do?

Pt 6: it would completely take away, well it would prevent me having them, I think, rather than treating them. Just taking take away having them completely. Is that what you mean?

I: well, I am just trying to work out what would be the ideal thing for you.

Pt 6: yes.

I: and obviously it’s different for different people.

Pt 6: you know, when I think really never to have a migraine, would be great, if there was anything that could be taken. Again if they said “if you take this drug every day, this medication and you’ll never get a migraine”, I would again think twice about that. Because although migraines are bad, again I don’t know if I’d want to take medication every day and there might be side effects. A friend of mine had, you know, severe migraines and they put her beta-blockers, you know, for a long period of time, which controlled her migraines. And now she just takes one when she’s getting a migraine. But again, I know about beta-blockers, I wouldn’t like to be on them long-term.

I: mm.

Pt 6: so, it depends, you know, on what you have to actually do to get no migraines, I’d have to consider, if it’s not medication, possible side effects.

I: ehm, probably thinking about the GP again, a little bit more. They; so they haven’t really told you about any more specific medications for migraine?

Pt 6: no, only the Migraleve.

I: or mainly painkillers?

Pt 6: yes, yeah.

I: how encouraging were they to come back, if what they prescribed or if what they suggested to you wasn’t working?

Pt 6: ehm, I mean, my recent GP, he always says “do come back and talk about it again, if it’s not relieving your symptoms”. As I say, I haven’t really been, I mean I did go back and say that they were working and I got a repeat prescription of those. And he did say, you know, “is that, is the treatment ok for you”? [daughter comes in, Dad takes her away]. We’ve got a busy house [laughter].

I: don’t worry [laughter].
Pt 6: sorry about that. So, he has been; he has been very understanding, and he would probably discuss it more with me and be happy to do that. It’s just me, that I haven’t gone back to him and said “look, it’s not working, I want more treatment”.

I: mm, when you actually go in and see him about it, or the times that you have been, do you only go in to specifically discuss the migraines? Or did you also discuss something else?

Pt 6: something else as well, yeah. So, I; it’s; yeah; I mean I’m probably when I went the first time with the migraine, I didn’t; I waited until there was a few other things I had to tell him about, before; I didn’t go in specifically for the migraine. There was at least another reason why I went in to see him.

I: but they were still quite happy to discuss things, because there is a lot of people who mention the migraine with something else and then it gets sort of pushed in the background.

Pt 6: yes.

I: and he deals with one problem, but not with the other.

Pt 6: but not with the other, yes. Ehm [pause], yeah, I mean he did; yeah; he probably dealt with the first problem, which seemed more immediate then he did with the migraine. And he did give me treatment for it, as I said, but ehm, I suppose it wasn’t, he didn’t seem that much more concerned about the migraine as he did about the other thing.

I: yeah, ok. But it seems though, I mean you say that you need to have something first to go and see him.

Pt 6: [laughter] yeah.

I: it just doesn’t seem very high priority to get it sorted out.

Pt 6: no. I know, I really don’t know why it is. In my mind I don’t put my priority, because it’s probably the thing that causes the most effect on my work, out of everything is the fact that I’ve got a migraine. And it is weird that people don’t go back and I don’t go to seek more help. And I really; I just don’t know why. And your research would be interesting [laughter].

I: [laughter].

Pt 6: to determine why we don’t go back [laughter].

I: well, they just say they don’t know why they don’t go back [laughter].

Pt 6: I know [laughter], that’s no good, is it for you? Have you done men as well? I mean are men different to women? Perhaps it’s just that us women think that this is what we get every month, especially when it’s with the menstrual cycle and this is what we’ve got to suffer.
I: no, it's the same thing. I think women go and see the GP more often, but I think that's generally speaking and for headache that's true as well.

Pt 6: yes.

I: but women suffer more frequently than men.

Pt 6: yes.

I: but I do get the same responses.

Pt 6: yes.

I: I mean not even thinking about the GP helping, why haven't you taken more initiatives to find out more like going to the Migraine Association?

Pt 6: [clears throat], well the thing is when you haven't got a migraine, you kind of think, you sort of hope that you are not going to get another one for a while. Although as I say, I; I; it was only recently, again talking to my friend who was; was prescribed these beta-blockers, she said that it was very cyclical hers. And I thought mine was, but I hadn't really written down exactly when I had them, and I hadn't really taken any mental note. And it was when she was talking about it that I decided that I'd try and see if there is any pattern to mine. I found there seemed to be a pattern. Ehm, so [pause] I; I sort; when you haven't got one, as I said, you don't feel as though you're going to get one, or you just hope that it's not going to come again. And because it's a thing that I feel as though, you know, can't be treated, except with painkillers, or that's the impression you get from other people, unless you going to go onto something like beta-blockers or something like that. You feel as if it's almost not worth going to the doctor's.

I: mm, because you can just buy them over the counter?

Pt 6: yes, that's right, yes.

I: well, that does make sense. I mean if you don't think that the GP can do anything to help you any further, then you are not going to go.

Pt 6: mm.

I: that's why I'd really like to know what other things people think that the GP might be able to do for them.

Pt 6: mm.

I: have you ever thought about seeing a headache specialist? Do you think there is such a thing as a headache specialist or somebody else apart from a GP?

Pt 6: no, I didn't know there was necessarily a headache specialist, but after I have got the; the Migraine Society's leaflet, so obviously I could go to them and they would possibly put me in touch with other sort of treatments. Again, I haven't done that [laughter] as yet. Yeah, I mean I didn't know there was any specific headache specialist.
I: does that sound like a good idea to have somebody more specific, I mean even a
GP with a special interest, who'd really know a little bit more. There are other
treatments apart from just painkillers, whether it is that GPs don't want to prescribe
them.

Pt 6: yeah or don't know, yes.

I: it is difficult knowing exactly what's going on.

Pt 6: yes, I mean; I think with a lot of GPs, I mean they have such a broad range of
conditions that they need to know about. I mean, you can't often blame them for not
knowing the up to date treatment for everything, but as you say you can around that
with possibly having people that are interested in a certain conditions. And you
know, it would help; help the patient.

I: ehm, maybe just mentioning the treatment again. We've have spoken a little bit
about the aims of your treatment, but what it is that you expect from the treatment?

Pt 6: ehm, what I'd like is, you know, if I'm obviously going to get migraines, is that
as soon as I get a migraine, then to have the pain relieved immediately. That would
be great. And not to feel sick.

I: what is immediately. What's the acceptable length of time?

Pt 6: ehm [pause], eh, half an hour or something [short laughter], half an hour after
taking the medication, if that's what you're doing.

I: how important is it that, obviously taking the pain away, but how important is it
that it treats the other symptoms?

Pt 6: ehm [pause], it is, I mean it is important. It is important, I don't like going
around feeling sick or having diarrhoea or anything like that. But the pain is the most
thing, without a doubt. And if it could relieve everything that would be great. I mean,
ideally, yes to relieve everything, pain and nausea and everything. Ehm, but to
relieve the pain is almost sort of good enough, because that's so awful.

I: mm. What would you not find acceptable?

Pt 6: ehm, if it doesn't relieve the pain I suppose. Is that what you mean, yeah?

I: well, some people say that they wouldn't like something that they'd have to take
every day.

Pt 6: oh I see what you mean, oh. Yeah, I wouldn't like; I wouldn't like to have to
take something every day. You know, especially because I don't particularly like
taking medic; I mean I'm not completely adverse, of course I take things if they are
prescribed to me and I; they; I need them. But ehm, I would prefer not to take
medication, if I can help it.

I: so have you tried any other forms of relief when you've actually got a migraine,
apart from taking medication. And what do you do at the times that you are not
taking any medication?
Pt 6: ehm, I do sometimes, I mean if you, you can almost; sometimes when I’m not taking the medication, if I concentrate and try and sort of shift the pain myself almost, I can do that for a bit. You have to; you know; concentrate and you; we learned some things when I; when we went to the National Childbirth Trust for labour pains. You can concentrate on the pain and try and shift it and move it up your body and things like that. And it does work for a bit, but quite honestly it takes so much effort, that it doesn’t work all the time. And you’re going to keep that up for a while, I mean things like not looking at bright lights and, you know, and if I sleep than that helps. And to drink, you know to drink fluids, water, does relieve; it doesn’t relieve it, but you know, I think it’s better to drink water than not. Because you don’t want to be dehydrated, those sort of things.

I: when you actually sleep, because you’re saying that you can get them for up to three days, so you can go to sleep.

Pt 6: and still wake up with them, yeah. I mean that is quite unusual, three days. It is unusual, but I mean they do sometimes. I mean sometimes I sleep and you still got it the next day. And as the day progresses it sort of gets worse and then, you have to, you know, you sleep. Sleep usually does relieve it, but not always.

I: right, so when you wake up with it the next morning, is it actually, do you feel a little bit better or does it?

Pt 6: sometimes it does. As soon as you wake up, it does feel better, and you Icnow if you get up and as you go through the day, then it gets worse again.

I: what do you do then.

Pt 6: the trouble is, I always try and carry on and not, you know, not sort of put myself in a dark room, and perhaps that might help. So I mean I try and carry on a bit, but sometimes I just lay on the sofa all day, just sort of sleeping. I don’t usually sort of go to bed. But eh, you know; I usually try and rest, I would say.

9.1. I: ok, where [end of tape]

Pt 6: besides the GP you mean?

I: well if you just think about it, or go through the procedure, the process that would have to happen for you to go and see somebody, who would you ask then. I mean, if it suddenly got worse would you talk to your Mum?

Pt 6: oh I see yes.

I: or go to the GP.

Pt 6: I mean you always discuss things with your friends. I mean I would probably go to the GP or even write or phone up the Migraine Society, those, yeah those two roads.
9.2. I: what do you think the Migraine Society could do for you?

Pt 6: [clears throat]. They might have new treatments that have been successful with other sufferers, because obviously they are in touch with a number; a lot; a much larger number of people than probably the GP is. So they might have more of different treatments that can be used and possibly support for the sufferer.

I: mm, so yeah think about it, they might have more of different treatments that might work better.

Pt 6: yes.

9.3. I: does that make you want to write to them or get in touch with them?

Pt 6: [short laughter], yes.

I: [laughter] I know I'm always going back to the same thing.

Pt 6: why are you so lazy? That's what you're trying to say. Yeah, I suppose so. The thing is while I can sort of stand the; you know; the pain even after, when using the painkillers, when it's to a sufferable level than I sort of live with that. Although as you say, ideally I'd prefer it to go away completely. So yes, perhaps I should go there, be pro-active in looking for treatment.

I: how do you deal with other problems, because a lot of people put dealing with things off, unless it's really acute.

Pt 6: mm.

I: more or less an emergency, then they do something about it, but how pro-active are you?

Pt 6: chm, other problems you mean?

I: I am just wondering generally, some people are very get up and go and get this sorted out, and others haven't got time, maybe it will go away.

Pt 6: yeah, I do a bit, a little bit of maybe it will go away. So I do leave things, I mean other sort of medical conditions you mean or possibly just life.

I: yeah.

Pt 6: well, I mean I do often, you know, if I have a medical; a symptom or something, I often leave it a little bit. I don't run immediately down to the doctor's until it gets to a stage where I think "well it's not going to go away and I probably need help". Then I do go to the doctor's.

9.4. I: so you still think your migraine is going to go away?

Pt 6: well people do say that you grow out of them. I mean this is, I'm always hoping that I will eventually grow out of them.

I: yeah, but that might not be for twenty years.
Pt 6: no, I know [laughter], I'm hoping.

I: is that enough? It may take years.

Pt 6: yes, ever hopeful me [laughter]. Yes, perhaps I ought to go and get some more help.

I: what are your intentions at the moment to get some help. I mean, don't let me influence you in thinking you should go, if you don't think you want to go at the moment.

Pt 6: I mean before; you know before this interview then I probably wouldn't have done. I would have probably gone to the doctor's when I could be bothered to get some more Motilin. Ehm, but then I mean possibly I should go and get more help. And I'd like some ideas for me to go [laughter], which I'm sure you can tell me.

I: well I can tell you a few things or you can read about them. Ok, well, has it actually only been two times that you have spoken to your GP about the migraine?

Pt 6: I've spoken to my GP at the moment at least twice about it.

I: oh yeah, you did say that.

Pt 6: yes. And yeah, and this, the first one I think, I might have mentioned it when I went on the pill, but he wasn't very good, the doctor at the health centre at the university wasn't particularly good from what I remember. And I mentioned it to him and he wasn't interested. And then it got to a state where I thought I want to do something about again, and he mentioned this Migraleve. And then I didn't go back to him after that. It didn't work, but I lost interest.

I: so there were times where you actually mentioned it where you didn't really get the response you wanted.

Pt 6: yes, from the medical; from the health centre, one when I was a student.

9.5. I: and was that only that once, or did you try and mention it to somebody else?

Pt 6: no, just I think, just that once from what I can remember, just him.

I: ok. Right, well I think that's about all I wanted to talk about, unless there is anything that you wanted to add about consultations, or treatment.

Pt 6: no, I don't think so. I mean as I say I haven't gone to anything more specific than the medication that I said.

I: ok, thank you very much.

Pt 6: that's ok.

[tape off, duration 54.43 mins]
Appendix 10: Coding Instructions

General hints

- Codes are labels for assigning units of meaning to units of text of various sizes
- Codes have to
  - fit into a structure (need to relate to or be distinct from other codes in meaningful, study-important ways)
  - be defined to enable other analysts to understand the definitions and identify, quickly and easily, a segment fitting the definition
  - be neither too specific nor too broad
  - remain flexible (they are likely to change and develop during the coding procedure) and to be reviewed continuously
- Sub-sections and coded units of text can overlap, hence one sub-section may be labelled by one or more master codes and units of text may be labelled by one or more codes
- Not all units of text need to be coded

Developing a code list by coding one interview

- Read through the whole interview to familiarise yourself with the information contained in the interview
- Re-read interview and write down key issues to give list of master codes
- Give broad explanation/definition of each master code (use no more than 10 master codes)
- Re-read interview and give sub-headings to different sections using master codes, thus creating sub-sections
- Read each sub-section and identify descriptive (sub)code(s) for each unit of text (using one or multiple sentence units)
- Code the unit of text (clearly identify the unit of text and write code into left hand margin of the transcript)
• Write code (label) with explanation/ definition down on a separate sheet of paper

• Continue coding the document by using identified codes or by creating new codes

• For example: master code MIGRAINE DIAGNOSIS

  • (Sub)codes: pain (including location, intensity, quality, any pain increasing/ reducing strategies such as walking up stairs or lying down), nausea and vomiting (presence), phobias (presence), other symptoms, frequency (how often do the migraine occur, both previous and current experience) and duration (how long do the migraines last from, previous and current experiences)

Reviewing codes

• After coding the an interview, review the (master and sub) codes by comparing codes and their descriptions

• Codes may have to be re-grouped into broader codes or split into more specific codes

• Codes may also have to be deleted or newly created

Coding further interviews

• Write this start list (without explanations) onto single sheet of paper for reference during further coding

• Code further interviews by reading interview, giving sub-headings according to master codes, labelling units of text in the sub-sections according to list of codes, identifying and defining new codes and reviewing codes
Appendix 11: Copy of the questionnaire for the postal survey
HEADACHE MANAGEMENT
QUESTIONNAIRE

Contact:
Ms Michele Peters
Tel. No.: 01483 68 45 37
Email: M.Peters@surrey.ac.uk

In collaboration with:
AstraZeneca Pharmaceuticals and the Migraine Action Association
Introduction

This questionnaire aims to find out about how you manage your headaches to draw a comparison between the management of headache in people who suffer from different types of headache. The questions will focus on what you have done in the last 12 months for treating and preventing your headaches.

In this questionnaire, the term 'headache' is used as an overall term for the different types of headache. The types of headache include migraine (with and without aura) and chronic daily headache.

Throughout the questionnaire, you will be asked questions about your headaches, and their impact, the things that you do to relieve your headaches, and the things you do to reduce the amount of headaches that you have. You will also be asked about your sources of support and information about headache and what you think about headaches.

Instructions

The questionnaire is divided into 8 sections and you will need to reply to all the sections. To fill in the questionnaire you will need to tick the appropriate boxes as indicated: ☑

Any further instructions will be given where appropriate.

Section 1: Headache information

In section 1, we would like to find out about your headaches. This will allow us to divide you into groups of people who suffer from the same type of headache. We would also like to find out about the severity and frequency of your headaches and how your headaches affect your life.

1. How old were you when you first started suffering from headache?
   ______ years

2. In a typical month, on how many days do you have a headache?
   ______ days

3. How long do your headaches typically last when you do not take medication?
   ☐ Up to 4 hours
   ☐ 4-12 hours
   ☐ 12-24 hours
   ☐ 2 days
   ☐ 3 days
   ☐ More than 3 days
4. How long do your headaches typically last when you take medication?
   - [ ] Up to 4 hours
   - [ ] 4-12 hours
   - [ ] 12-24 hours
   - [ ] 2 days
   - [ ] 3 days
   - [ ] More than 3 days

5. How painful are your typical headaches? (Put a cross on the line to indicate your level of pain)
   
<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>(no pain)</td>
<td>(worst pain ever)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. Are your headaches most commonly on... (please tick one)
   - [ ] One side of the head?
   - [ ] Two sides of the head?

7. Is the pain of your headaches most commonly... (please tick one)
   - [ ] Pulsating or throbbing?
   - [ ] A steady ache?
   - [ ] Like a tight band around your head?

8. Do your headaches get worse when you are physically active (such as walking up the stairs)?
   - [ ] Yes
   - [ ] No

9. What other features, if any, are typically associated with your headaches?
   **Symptom**
   - [ ] Dislike of light
   - [ ] Dislike of noise
   - [ ] Nausea and/ or vomiting
   - [ ] Visual disturbances (such as flashing lights, blind spots)
   - [ ] Speech disturbances
   - [ ] Pins and needles
   - [ ] Numbness
   - [ ] Dizziness
   - [ ] Other, please specify
     ____________________

App-56
10. In the last 12 months, which aspects of your life have been affected by your headaches? (tick all that apply)

- Paid work
- Housework
- Leisure activities
- Family life
- Social life
- Career opportunities
- Education
- Other. Please specify __________________________

11. In the last 12 months, how much have your headaches affected your life? (Put a cross on the line to indicate the level)

<table>
<thead>
<tr>
<th>0</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>10</th>
</tr>
</thead>
</table>

(not at all)  (a lot)

Section 2: Consultations

In section 2, we would like to know if and how often that you have consulted health professionals (including for example doctor, nurse or osteopath) about your headaches.

12. In the last 12 months, have you spoken to any of these health professionals about your headaches? (tick all that apply)

   Health professional
   - Acupuncturist  □ Yes  □ If yes, how often? _____times
   - No  □ Don't remember
   - Chiropractor  □ Yes  □ If yes, how often? _____times
   - No  □ Don't remember
   - Doctor specialising in headache  □ Yes  □ If yes, how often? _____times
   - No  □ Don't remember
   - General practitioner  □ Yes  □ If yes, how often? _____times
   - No  □ Don't remember
   - Homeopath  □ Yes  □ If yes, how often? _____times
   - No  □ Don't remember
Section 3: Medication use

Part 1: Medication for the treatment of headache

Section 3 part 1 refers to medication that you use to treat your headaches, i.e. the medication that you take when you have got a headache.

13. In the last 12 months, have you taken any medication that you bought Over the Counter (without a prescription) to treat your headaches?

☐ Yes  if ‘yes’, please specify ______________________
☐ No
☐ Don’t remember  Go to question 15

14. On average in the last 12 months, how often have you taken Over the Counter medication to treat your headaches?

☐ 5-7 times a week
☐ 2-4 times a week
☐ Once a week
☐ Every 2-3 weeks
☐ Once a month
☐ Less than once a month
15. In the last 12 months, have you taken any medication that was prescribed by a doctor (your GP or neurologist) to treat your headaches?

- Yes if 'yes', please specify __________________________
- No
- Don't remember

16. On average in the last 12 months, how often have you taken prescription medication to treat your headaches?

- 5-7 times a week
- 2-4 times a week
- Once a week
- Every 2-3 weeks
- Once a month
- Less than once a month

17. In the last 12 months, have you taken any homeopathic/herbal remedies to treat your headaches?

- Yes if 'yes', please specify __________________________
- No
- Don't remember

18. On average in the last 12 months, how often have you taken homeopathic/herbal remedies to treat your headaches?

- 5-7 times a week
- 2-4 times a week
- Once a week
- Every 2-3 weeks
- Once a month
- Less than once a month

Part 2: Medication to prevent your headaches

Section 3 Part 2 refers to medication that you have taken within the last 12 months to prevent headaches (medication that you take every day).

19. In the last 12 months, have you taken medication that has not been prescribed by your doctor to prevent your headaches?

- Yes if 'yes', please specify __________________________
- No
- Don't remember
20. **In the last 12 months**, have you used any medication that has been prescribed by your doctor to prevent your headaches?
- Yes if ‘yes’, please specify ________________________
- No
- Don’t remember

21. **In the last 12 months**, have you taken any herbal/homeopathic medication to prevent your headaches?
- Yes if ‘yes’, please specify ________________________
- No
- Don’t remember

22. **In the last 12 months**, have you taken any vitamins or minerals to prevent your headaches?
- Yes if yes, please specify ________________________
- No
- Don’t remember

### Section 4: General management strategies

In section 4, you will be asked about general strategies (such as avoiding triggers or relaxation) that you may use to treat and prevent your headaches.

23. **In the last 12 months**, how often have you used any of these techniques to treat your headaches? (this refers to when you have a headache)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid bright light</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid certain foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid head movement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid housework</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid noise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoid tea/coffee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

App-60
<table>
<thead>
<tr>
<th>Technique</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leave social events</td>
<td>Never</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td>Often</td>
</tr>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td>Leave work</td>
<td>Never</td>
</tr>
<tr>
<td>Lie down</td>
<td>Never</td>
</tr>
<tr>
<td>Slow down</td>
<td>Never</td>
</tr>
<tr>
<td>Use biofeedback</td>
<td>Never</td>
</tr>
<tr>
<td>Use cold treatment</td>
<td>Never</td>
</tr>
<tr>
<td>Use heat treatment</td>
<td>Never</td>
</tr>
<tr>
<td>Use massage</td>
<td>Never</td>
</tr>
<tr>
<td>Use relaxation</td>
<td>Never</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>Never</td>
</tr>
</tbody>
</table>

24. In the last 12 months, how often have you used these techniques to prevent headaches?

<table>
<thead>
<tr>
<th>Technique</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid bright light</td>
<td>Never</td>
</tr>
<tr>
<td>Avoid exercise</td>
<td>Never</td>
</tr>
<tr>
<td>Avoid noise</td>
<td>Never</td>
</tr>
<tr>
<td>Avoid stress</td>
<td>Never</td>
</tr>
<tr>
<td>Avoid food triggers</td>
<td>Never</td>
</tr>
<tr>
<td>Avoid other triggers</td>
<td>Never</td>
</tr>
<tr>
<td>Eat regularly</td>
<td>Never</td>
</tr>
<tr>
<td>Sleep regularly</td>
<td>Never</td>
</tr>
<tr>
<td>Exercise</td>
<td>Never</td>
</tr>
<tr>
<td>Use relaxation</td>
<td>Never</td>
</tr>
<tr>
<td>Other, please specify</td>
<td>Never</td>
</tr>
</tbody>
</table>
**Section 5: Sources of information**

Section 5 refers to where you seek and/or obtain your information about headache from. This relates to sources of information other than health professionals.

**25. In the last 12 months, how often have you sought or received information about treating and preventing headaches from these people or organisations?**

<table>
<thead>
<tr>
<th>Source of help</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>Charity publications</td>
<td>□</td>
</tr>
<tr>
<td>Charity telephone/email help-line</td>
<td>□</td>
</tr>
<tr>
<td>Family</td>
<td>□</td>
</tr>
<tr>
<td>Friends</td>
<td>□</td>
</tr>
<tr>
<td>Internet</td>
<td>□</td>
</tr>
<tr>
<td>Magazine articles</td>
<td>□</td>
</tr>
<tr>
<td>Newspaper articles</td>
<td>□</td>
</tr>
<tr>
<td>Other headache sufferers</td>
<td>□</td>
</tr>
<tr>
<td>Patient support groups</td>
<td>□</td>
</tr>
</tbody>
</table>

- **Scientific articles**
- **Television**
- **Work colleagues**
- **Other, please specify**

App-62
**Section 6: Effectiveness of management strategies**

In this section, we would like you to tell us your opinion on how effective you find the different management strategies to treat or prevent your headaches.

26. State your level of agreement with the following:

<table>
<thead>
<tr>
<th>Medication is effective to manage my headaches</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-help (such as avoiding triggers) are effective to manage my headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative therapies (such as osteopathy) are effective to manage my headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving advice from friends and family is helpful to manage my headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reading about headache is helpful to manage headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with my headache management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Talking to the doctor about my headaches is helpful

<table>
<thead>
<tr>
<th>Talking to health professionals other than the doctor about my headaches is helpful</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know how to manage my headaches effectively</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would like better management for my headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 7: Your opinion about headache

Section 7 looks at your opinion about headaches and headache management.

27. Would you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headaches can be treated successfully</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Headaches are curable</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Headache treatment has improved in the last ten years</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Headaches make life difficult</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Headaches are a misunderstood condition</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Taking medication always leads to side effects</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Everybody gets headaches like I do</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Headaches are a serious health problem</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Section 8: About yourself

Finally, we would like to ask a few questions about yourself. This will help us to compare your answers to other headache patients, without telling us who you are.

28. What is your gender?
   - ☐ Male
   - ☐ Female

29. What is your date of birth? Day____ Month____ Year____

30. What is your marital status?
   - ☐ Single (never married)
   - ☐ Married
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed

31. Do you live...
   - ☐ On your own?
   - ☐ With partner/ husband?
   - ☐ With family?
   - ☐ Other? Please specify ______________________
32. What is your ethnic group?
   □ White
   □ Mixed
   □ Asian/ Asian British
   □ Black/ Black British
   □ Chinese
   □ Other, please specify __________________________

33. Which one of these qualifications do you have? (Please tick all that apply)
   □ 1+ O levels/ GSEs/ GSCEs (any grades)
   □ 5+ O levels/ 5+ CSEs (grade 1)/ 5+ GCSEs (grades A-C)/ School Certificate
   □ 1+ A levels/ AS levels
   □ 2+ A levels, 4+ AS levels, Higher School Certificate
   □ First degree (e.g. B.A., B.Sc.)
   □ Higher degree (e.g. MA, PhD, PGCE)
   □ NVQ Level 1, Foundation GNVQ
   □ NVQ Level 2, Intermediate GNVQ
   □ NVQ Level 3, Advanced GNVQ
   □ NVQ Level 4-5, HNC, HDN
   □ Other qualifications (e.g. City and Guilds, RSA/OCR, Edexcel)
   □ No qualifications
   □ Other. Please specify __________________________

If you do paid work, please answer questions 35 and 36.

34. What is your current work status? (Please tick all that apply)
   □ Employed
   □ Self-employed
   □ Casual work
   □ Retired
   □ Look after home/ family
   □ Unemployed
   □ Student
   □ Other. Please specify __________________________

35. Do you work
   □ Full-time?
   □ Part-time? (if so how many hours _____)
   □ Shifts?

36. What is your current job title?
   __________________________

App-65
Thank you for taking the time to fill in this questionnaire.

Please return the questionnaire to the University of Surrey in the stamped and addressed envelope.

If you have any questions, please contact Ms Michele Peters, European Institute of Health and Medical Sciences, University of Surrey, Guildford, Surrey, GU2 7TE. Tel. no. 01483 68 45 37, email: M.Peters@surrey.ac.uk
Appendix 12: Cover letter for survey

November 2002

Dear Member

Michele Peters, a PhD student at the University of Surrey is writing her thesis on the management of migraine and chronic daily headache and would appreciate it if you could help by completing the enclosed questionnaire. Evaluation of the questionnaires will provide information on the strategies patients use to treat and prevent attacks and will give us valuable information for initiatives to manage the condition.

The study is carried out under the auspices of the European Institute of Health and Medical Sciences (University of Surrey) and has been approved by the University of Surrey Ethics Committee.

Enclosed you will find an information sheet, that will tell you more about the study and what is expected of you, the questionnaire and a stamped and self-addressed envelope in which to return the questionnaire.

If you have any more questions or any difficulties filling in the questionnaire, please contact Michele by telephone on (01483) 684537 or by email:
M.Peters@surrey.ac.uk

Thank you in anticipation for taking the time and trouble to participate in this study.

Yours sincerely

Ann Turner (Mrs)
Director
Appendix 13: Information sheet

Headaches, particularly migraine and chronic daily headache, can be a great burden to a sufferer. Many different forms of treatments are available to the patients, but little remains known about the strategies that patients employ to treat and to prevent their headaches. This study will look into the management strategies that migraine and chronic daily headache sufferers have used within the last 12 months. The findings of this study will help to assess the needs and the preferred methods of treatment of headache patients. It will also inform us whether there is a difference between the management used by patients with different types of headache.

To take part in this study you will need to be an adult (aged 18-65) headache sufferer who is a resident in the UK. You will not be able to take part if you are pregnant. The study involves filling in a questionnaire. At the end of the questionnaire you will find a blank page, which you can use to give any other information that you may feel is relevant.

When you have completed the questionnaire, you will need to return it to the researcher in the provided stamped and self-addressed envelope. We would be grateful if you could return the questionnaire within two weeks. Your participation in this study is voluntary and you have the option not to participate or to withdraw at any time without giving any reasons.

The research may be published in the scientific literature, but you will not be identified by name and personal information gathered during this study will remain confidential to the researchers.

After reading this information sheet, please contact Michele Peters (contact details below) if you have any questions or would like any further information.

Ms M Peters, Prof. H Huyer Abu-Saad, Dr V Vydelingum and Dr M. Murphy
European Institute of Health and Medical Sciences
Dr A Dowson
Kings Headache Service and Neurology Research Unit, Royal Surrey Hospital, Guildford, Surrey

Contact Michele Peters Tel. No.: 01483 684537 E-mail: M.Peters@surrey.ac.uk

App-68
Appendix 14. Ethical approval for Phase 2 (survey)
25 June 2002

Ms Michele Peters
EIHMS
Level 5
University of Surrey

Dear Ms Peters

Management of migraine and chronic daily headache: a questionnaire study
(ACE/2002/36/EIHMS)

I am writing to inform you that the Advisory Committee on Ethics has considered the above protocol (and the subsequent information supplied) and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed and the following condition is met:-

1. That in the Instructions Sheet for the questionnaire the sample box is marked accordingly, as this has been omitted.

2. That the Section 4: Medication Use is amended to make it clearer whether you are asking about doses for a single episode or treatment for separate episodes.

For your information, and future reference, the Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (ACE/2002/36/EIHMS). The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons.

Contd ....
I should be grateful if you would confirm in writing your acceptance of the condition above, forwarding the amended documents for the Committee's records.

Date of approval by the Advisory Committee on Ethics: 25 June 2002
Date of expiry of approval by the Advisory Committee on Ethics: 24 June 2007

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Advisory Committee on Ethics

cc: Chairman, ACE
    Dr M Murphy, Supervisor, EIHMS
    Prof H Huyer Abu-Saad, Principal Investigator, EIHMS
    Dr V Vydelingum, Co-Investigator EIHMS
    Dr A Dowson, Co-Investigator, RSH Guildford
Appendix 15. Headache Management Questionnaire Evaluation Form

Please read the cover letter and information sheet and then fill in the sections below. Circle your response and add any comments in the space provided or on the cover letter and/or information sheet.

Cover letter

Does the cover letter contain all the necessary information? Yes No

If no, please comment:

Is the cover letter clear? Yes No

If no, please comment:

Information sheet

Does the information sheet contain all the necessary information? Yes No

If no, please comment:

Is the information clear? Yes No

If no, please comment:

Is there any additional information that you would like? Yes No

If yes, please specify:

App-70
Once you have read and commented on the cover letter and information sheet, proceed to fill in the questionnaire. When you have completed the questionnaire, please complete the section below. If you have any specific comments while completing the questionnaire, please write the comments onto the questionnaire.

**Questionnaire**

Were you given enough instructions on how to fill in the questionnaire?  Yes  No

If no, please comment:

Is the questionnaire presented nicely (layout, font size)?  Yes  No

If no, please comment:

Did you understand all the questions?  Yes  No

If no, please give the number of the questions you found unclear and comment:

Did you find the questions relevant to the management of headache?  Yes  No

If no, please comment:
Are there any additional questions that you would like to be included? Yes No

If yes, please specify:

Did you like the order of the questions? Yes No

If no, how would you prefer the order of the questions:

Was the questionnaire too long? Yes No

If yes, please comment:

Do you have any other comments?

Thank you for taking the time to fill in the questionnaire and this assessment form.

If you have any questions, or further comments, please contact Michele Peters, M.Peters@surrey.ac.uk, Tel: 01483 68 45 37.
Appendix 16: Cover letter for testing of diagnostic tool within the questionnaire

Dear Madam/ Sir

I am writing to you with regards to a questionnaire study on headache management, which is currently being carried out at the European Institute of Health and Medical Sciences, of the University of Surrey. The questionnaire will inform us on the strategies that headache patients use to treat and prevent their headaches and will give us valuable information on their initiatives to manage their condition.

An important aspect of this study is to diagnose the volunteers correctly. I would be grateful if you could help with the evaluation of this part of the questionnaire. Enclosed, you will find section 1 of the questionnaire, which aims to collect information about the headaches of the study volunteers. Could you please complete this section (questions 1 to 9) and return the form in the provided stamped and self-addressed envelope within the next two weeks.

If you have any questions, please do not hesitate to contact me via email: M.Peters@surrey.ac.uk or telephone: 01483 68 45 37.

Thank you in advance for your help.

Yours sincerely,

Michele Peters
## Appendix 17: Diagnosis validity

<table>
<thead>
<tr>
<th>Patient number</th>
<th>Diagnosis (questionnaire)</th>
<th>Diagnosis (clinician)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>3</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>4</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>5</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>6</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>7</td>
<td>CDH</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>8</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>9</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>10</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>11</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>12</td>
<td>Migraine ?aura</td>
<td>Migraine, inconsistent aura</td>
</tr>
<tr>
<td>13</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>14</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>16</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>17</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>18</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>19</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>20</td>
<td>Migraine with aura</td>
<td>Migraine with aura</td>
</tr>
<tr>
<td>22</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>23</td>
<td>Migraine with aura (? Non-migraine headaches?)</td>
<td>CDH</td>
</tr>
<tr>
<td>24</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>25</td>
<td>Migraine without aura</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>26</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>28</td>
<td>CDH</td>
<td>CDH</td>
</tr>
<tr>
<td>29</td>
<td>Migrainous headache</td>
<td>Migraine without aura</td>
</tr>
<tr>
<td>30</td>
<td>CDH</td>
<td>Migraine without aura</td>
</tr>
</tbody>
</table>

26 patients- 22 valid diagnosis- 84% validity
Appendix 18: Advert for recruitment

(For Migraine Action Association web-site and newsletter)

The Management of Migraine and Chronic Daily Headaches

Researchers at the European Institute of Health and Medical Sciences from the University of Surrey are looking for Migraine and Chronic Daily Headache patients who would be willing to fill in a questionnaire on the management of their headaches. The questionnaire collects information on strategies that patients employ to treat and to prevent their headaches, including aspects of care such as medical consultations, use of medication and alternative therapies, support from friends and family and self-help measures.

To participate in the study you will need to be aged between 18 and 65 years and you will need to be a UK resident. You cannot take part in the study if you are pregnant.

If you have any questions about the study or would like any further information, please contact Ms Michele Peters.

If you are interested to take part in the study, please email, fax or telephone your postal address to Ms Michele Peters by 1st November 2002 and copy of the questionnaire and information sheet will be sent to you.

Contact: Ms Michele Peters
Email: M.Peters@surrey.ac.uk
Address: EIHMS, University of Surrey, Guildford, Surrey, GU2 7TE
Fax Number: 01483 68 25 41
Telephone number: 01483 68 45 37

Ms M Peters, Prof. H Huyer Abu-Saad, Dr V Vydelingum and Dr M. Murphy
European Institute of Health and Medical Sciences
Dr A Dowson
Kings Headache Service and Neurology Research Unit, Royal Surrey Hospital, Guildford, Surrey

Contact Michele Peters  Tel. No.: 01483 684537  Email: M.Peters@surrey.ac.uk