# Information and behavioural instruction along the health-care pathway: the perspective of people undergoing hernia repair surgery and the role of formal and informal information sources

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#### **Abstract**

**Background** Provision of information and behavioural instruction has been demonstrated to improve recovery after surgery. However, patients draw on a range of information sources and it is important to establish which sources patients use and how this influences perceptions and behaviour as they progress along the surgical pathway. In this qualitative, exploratory and longitudinal study, the use of information and instruction were explored from the perspective of people undergoing inguinal hernia repair surgery.

**Methods** Seven participants undergoing inguinal hernia repair surgery were interviewed using semi-structured interviews 2 weeks before surgery and 2 weeks and 4 months post-surgery. Nineteen interviews were conducted in total. Topic guides included sources of knowledge, reasons for help-seeking and opting for surgery and factors influencing return to activity. Data were analysed thematically according to Interpretative Phenomenological Analysis.

Findings and conclusions Participants sought information from a range of sources, focusing on informal information sources before surgery and using information and instruction from health-care professionals post-surgery. This information influenced behaviours including deciding to undergo surgery, use of pain medication and returning to usual activity. Anxiety and help-seeking resulted when unexpected post-surgical events occurred such as extensive bruising. Findings were consistent with psychological and sociological theories. Overall, participants were positive about the information and instruction they received but expressed a desire for more timely information on post-operative adverse events.

## Introduction

There is good evidence that preparation for surgery, using information and behavioural instruction, improves post-operative outcomes including pain, medication use and behavioural recovery. Information can be sensory (e.g. explaining what a procedure feels like) or procedural (detailing what, when and how procedures occur). Behavioural instruction involves

telling patients what behaviours they should perform and how they should perform them to aid recovery.<sup>2</sup>

Reducing pre-operative anxiety is an important goal of preparation; anxiety may affect recovery through various mechanisms. Preoperative anxiety has been consistently found to predict post-operative pain,<sup>3</sup> anxiety or stress can affect the wound healing process<sup>4</sup> and pain may seem less severe to relaxed than to anxious people.<sup>5</sup> Anxiety may also influence recovery by affecting behaviours. For example, if someone does not perform activities that would assist recovery because of worry about pain or injury, then the recovery process may be prolonged (as per theories of fear avoidance<sup>6</sup>). Sensory information may decrease distress by reducing the discrepancy between expected and actual sensation; <sup>7</sup> Johnston<sup>8</sup> found that people whose pain was less than expected had lower distress than those whose pain was greater than expected. Procedural information may prevent people from worrying about unexpected processes which are normal aspects of care.<sup>9</sup>

Behavioural instruction is expected to influence recovery by encouraging beneficial behaviours. Instructions can include advice/training on activities to be carried out post-surgery; breathing training has been demonstrated to improve outcome after coronary artery bypass graft surgery. 10 The mechanism by which behavioural instruction might aid recovery seems straightforward, assuming that such instructions are appropriate. If someone follows instructions regarding when to rest and when to recommence activity, it would be expected that they would recover quicker than someone who either does damage by doing too much or who overly delays return to activity. However, a patient is also a person in the 'real world', exposed to information and advice from a range of sources, including friends and colleagues, and also has commitments to fulfil. When undergoing surgery, an individual must make multiple behavioural decisions such as seeking help, opting for surgery, taking medication and regaining activity. How do people value and make use of information and instruction from different sources and which advice is followed when conflicts arise? There are a number of psychological and sociological models [e.g. The Common Sense Self Regulation Model (CS-SRM<sup>11</sup>) and the Network-Episode Model<sup>12,13</sup>] that provide frameworks for analysing such behaviour. However, little is known about patients' direct experiences of the surgical journey and few studies have followed patients from before their operations until recovery, with a focus on how information is accessed and used. In particular, most empirical studies on the effectiveness of information or instruction interventions have focused on information provision by health-care professionals (HCPs) or looked at information seeking at a single time point. Patients draw on a range of information sources, including friends, books and the internet.<sup>14</sup> Little research has explored information usage at different stages along the surgical pathway.

If information from HCPs is to be effectively targeted, it is important to know when and how people use different information sources and which take priority at which stage. The present study explored these issues in people undergoing inguinal hernia surgery. Inguinal hernia is a common condition with an incidence of 6-12% in adult males. 15 The condition presents as a lump, due to a protrusion of intestine through a weakness in the abdominal wall in the groin, which can limit daily activities and the ability to work. 16 Treatment is usually surgical repair; 8023 such operations were performed in Scotland in 2007. The Surgery repairs the defect, reduces symptoms and prevents serious bowel complications. Although a common operation, this procedure may cause nerve or tissue damage, resulting in long-term pain and numbness for some patients.<sup>16</sup> In a review of 40 studies published between 1987 and 2000, the frequency of chronic post-surgical pain after hernia surgery ranged from 0% to 54%. 18

The aim of this study was to gain an understanding of the utility of information and instruction from patients' perspectives throughout the surgical pathway. Participants were interviewed at three time points, using in-depth, qualitative interviews. We sought to identify the different sources of information used, how and when information affected perceptions and behaviour, and how participants valued and used potentially competing information in the context of other life demands.

#### Methods

This study was approved by Grampian Research Ethics Committee and NHS Grampian Research and Development.

# Design

A longitudinal design was employed with semistructured in-depth interviews at three time points: 2 weeks before surgery (time 1, T1) and 2 weeks (time 2, T2) and 4 months post-surgery (time 3, T3). These were chosen as key times in the surgical process: first, when surgery is imminent and an appointment has been confirmed, second, shortly after surgery, in the immediate recovery period and at 4 months after surgery, when any residual chronic impairments or activity limitations are apparent.

# **Participants**

Participants were seven adult male, Englishspeaking patients scheduled for elective inguinal hernia repair surgery at Aberdeen Royal Infirmary between 5 May and 5 September 2006. Male gender was not an inclusion criterion but the sample reflects the condition's gender distribution. 15 For this exploratory and longitudinal study, in-depth insights were gathered over time with a small number of cases. This design is consistent with Interpretative Phenomenological Analysis (IPA) where use of small, homogeneous samples is advised because the purpose is to examine, in detail, people's perspectives. 19 We aimed to recruit a sample of between 5 and 10 participants to be interviewed at three time points. Following standard hospital procedure, medical secretaries informed people of their surgery date by post approximately 2 weeks preoperatively. On sending this letter, secretaries of five surgeons also sent a study invitation pack that included an information sheet and a reply slip for indicating interest in the study. From 5 May to 11 August, 28 invitation packs were sent. Seven people responded positively and constitute the present sample. Interviews were conducted between May 2006 and January 2007.

## Data collection

Interview schedules began in a deliberately open-ended way by inviting participants to describe 'everything that happened' either since they first suspected a problem (pre-surgery interview) or since they had undergone surgery (post-surgery interviews). A topic guide was developed and included open-ended questions addressing issues including sources of knowledge, reasons for help-seeking and opting for surgery, expectations of recovery (pre-surgery) and factors influencing return to usual activity (post-surgery). Topics covered at all interviews included pain, other symptoms and activity limitations. General biographical data were also collected including age, occupation, type of surgery and length of hospital stay.

Individuals were contacted by telephone to arrange an interview time. Participants were interviewed at the University of Aberdeen when possible; other interviews took place in the participant's home, work place or (one interview) Aberdeen Royal Infirmary. Informed consent was given by participants before the interview commenced. Interviews were taperecorded and sessions lasted up to 1 h.

## **Analysis**

Transcribed interviews were analysed thematically and the participant's perception of events was taken as central. Analysis was also interpretative, recognizing the interaction between the researcher and the data. This approach is consistent with IPA.<sup>20</sup> It was therefore highly appropriate for this study where the experiences and perspectives of people undergoing surgery were of primary interest but where the lead author's research experience in health

psychology is such that interpretation of data could not occur independently of an understanding of health psychology theory and psychological preparation for surgery.

In accordance with guidelines.<sup>21</sup> transcripts were read and re-read, and thoughts, comments and emerging themes were noted on the manuscript. A list of superordinate and subthemes was drawn up. Using this list, manuscripts were coded so that charts indexing extracts belonging to each theme for each participant could be produced. This document enabled the results to be structured according to theme with supporting evidence given verbatim. Detailed records of the analysis process were kept by the first author, allowing a co-author (JB) to review the analysis, including the themes identified and interpretations made of the data. No disagreements arose. With the small number of cases, it was possible to both build insights into particular patients' unique surgery journeys and information-seeking behaviours as well as to compare cases.

## Results

## Descriptive data

Participants were aged between 34 and 77 years. They underwent different procedures: laparoscopic surgery as inpatients (P1 and P3), open surgery as a day-case patient (P2), bilateral laparoscopic and bilateral open surgery as inpatients (P4 and P5 respectively) and open surgery for recurrent hernias (P6 and P7). The group had a range of occupations: engineer (desk work), crane-operator (some manual work), buildings inspector (desk work/walking), shipping engineer (some manual work), teacher (desk work/walking), part-time security work (desk work/walking) and one participant was retired.

P3's response to the study invitation was only received after he had undergone surgery; this participant was therefore first interviewed after surgery but questions about pre-surgical experiences were asked retrospectively in the 2-week post-surgery interview. P6 was too ill with

another condition to take part in the 4-month interview. A total of 19 interviews were conducted.

T1 interviews took place between 1 and 15 days before surgery (median: 13.5 days), T2 interview dates ranged from 7 to 16 days post-surgery (median: 14 days); T3 interviews ranged from 18 weeks to 23 weeks after surgery (median: 19 weeks).

## Sources of information

Pre-operatively, participants used a wide range of sources for information about their hernia(s) and the forthcoming surgery. Informal social networks were used: P3 drew on the experience of male relatives with hernias and P2 identified his symptoms as indicating a hernia because his colleagues had hernias. The internet was a popular information source (P1, P2, P4 and P5, T1) and P7(T1) used 'some old literature': an old medical dictionary.

Past experience appeared to be an important information source for those who had undergone previous hernia surgery (P6 and P7, T1), with both citing previous experience as their means of correctly identifying their condition. However, they used this experience differently when forming expectations about surgery. P7 thought it would be 'just like the first one...I would have to deal with it just like I dealt with it the first time'. In contrast, P6's brother had recently undergone a hernia repair with modern mesh techniques and P6 recognized that this was different to his own experience some years ago: 'It is different now to what it was for the, I had my first one done'.

Information from HCPs was referred to by participants in the pre-operative interview but seemed to be the key source of information after surgery. Participants seemed pleased to receive additional information: 'she [the surgical registrar] told me things that I didn't find out on the internet...which was quite interesting' (P4, T1). Patients may go into consultations with a good level of knowledge 'He [the consultant] told me stuff that I'd already researched online' (P5, T1).

Influence of information and behavioural instruction on perceptions and behaviour

## Seeking help

Participants cited various reasons for initially seeking medical advice, including consulting the GP for other reasons and mentioning the hernia at the same time (P1, P6, T1) and having the hernia detected whilst under investigation for another condition (P4, T1). The information sources discussed above were critical in the help-seeking of P7 (T1) who from past experience suspected he had a second hernia and P5 (T1) who investigated his symptoms on the internet: 'once I saw what they could lead to...I thought "oh, I don't fancy that much" so I went to see the doctor'. Behavioural instruction from family was a motivator for P3 (T2) to seek support: 'I was sort of nagged'.

## Deciding to have surgery

Reasons given for deciding to have surgery were, for some participants, directly related to information. Advice from medical staff was important for some; P1 received advice about the possible consequences of not having surgery: 'over time it gets worse and worse so...surgeons said it's best to get it done and over with' (P1, T1). P6's decision-making seemed to be based on his earlier experience of having hernia surgery when he asked for medical advice as to whether or not to have surgery:

He [the 'doctor'] said 'Well there's three things you can do'...he says 'you can ignore it', he says 'you can wear a truss or you could have the operation'. So I just said 'Well, say you had this hernia, what would you do?' He said 'I would have the operation'. I says 'right, I'll have the operation'.

P3 (T2) explicitly linked an informal information source (his father) and his reasons for taking action:

my father had one before and his strangulated eventually and that's nae very pleasant at all 'cause his bowel damaged and leaked into his system...so I thought I'd better get something done before it got to that stage.

As a result of his father's experience, P3 had a vivid perception of the potential consequences of not having surgery.

## *Use of post-operative analgesics*

All participants reported taking analgesic medication after surgery. This may seem an obvious response but was an interesting finding because, at the pre-surgical interview, four participants (P2, P5, P6 and P7) expressed a general reluctance to take pain medication - 'I don't take painkillers' (P5, T1). Surgery is, perhaps, an exceptional situation even for the most stalwart but medical advice appeared to be an important influence for some participants: P2 took them because they had been prescribed, and P5 and P6 were advised to take them – 'I try not to take too many painkillers and that but the doctor said "No, take them", so I did' (P5, T3).

# Concerns and actions regarding post-operative symptoms

Symptoms experienced after surgery included pain, bruising, swelling and numbness. The extent to which symptoms caused concern depended on the extent to which they were expected. Some participants reported bruising after surgery. This bruising could be striking [a broad band of black extending round the abdomen (P6, T2)] or feature 'in places where you didn't expect it' (P5, T2) (extending down to the scrotum). P5 saw his GP the day after surgery for reassurance - 'It wasn't so much the pain...it was the bruising I was worried about because the pain you'd expect' (T2). In contrast, P6's friend had experienced similar bruising to him so P6 was able to dismiss it as 'normal' - 'if I hadn't been speaking to this other lad and he said he was all black. I mean, I just couldn't believe it...but then this lad saying that I says "Oh well, it's normal"...you just accept it' (T2). Similarly, P1 and P3 (T2) sought medical advice because of unexpected swelling and/or bruising whereas P2 was unconcerned about expected sensations of numbness - 'I'm sure the surgeon told me there'd be numbness...so it's not worrying me' (T3).

## Returning to activity

Advice and behavioural instruction from HCPs were taken very seriously when deciding when to return to work and in limiting physical activities – 'I'm nae allowed to lift...if they say to me...you cannae bowl for six weeks, I dinna bowl' (P6, T2). Such instruction even had a strong influence when participants felt well and able, mainly because following medical advice was seen as a way to limit potential damage to the hernia site:

I dinnae feel that I couldnae do it...but I know it wouldnae do the whole thing any good to go and do physical exercise and the doctors have said don't do it

and, later in the same interview: 'You have to do what you're told because you know if I'm going to do something silly I'm back where I started' (P3, T2).

In addition, a comment by P6 (T2) suggests that, for some, the doctor knows best and so if you have expert advice it is sensible to follow it: 'There's no point in the doctor saying...don't do this and don't do that and you go and do it...stupid you see'. Rather than evaluate what ignoring medical instruction might do in terms of damage to the wound, P6 just accepted the doctor's advice.

## How information is used and valued

# Amount of information desired

Information-seeking was not uniform in quantity across participants: it ranged from intense internet searching 'I went on the internet and got a lot of information' (P2, T1) to relatively passive methods of information gathering – relying on the experience of the self and others in the immediate social circle (e.g. P6, T1). Where the internet was used, some participants seemed eager to learn all they could about their condition whereas others were more restrained – 'I just had a quick look at the internet and stuff then I freaked myself out and stopped looking at it, just left it [laughs], I didn't want to know what it was' (P1, T1). Wariness of the quality of available information also affected the extent of

internet searching – 'I just go on the National Health, I don't go any further...they tell you absolutely crazy things. Crazy people' (T2).

When referring to the time surrounding the surgery and after the operation, participants spoke positively about all information received – 'Everybody explained ... I was well informed at every stage, they told you what was happening' (P2, T3) and P4 (T3) referred to a follow-up visit as 'the most interesting part' – he discussed his operation with the consultant surgeon and clearly enjoyed the meeting - 'I asked him different questions and that so then he showed me the photographs and I thought that was, that was quite interesting'. The only negative comments were heard when participants felt they needed more information - 'They should have given me a bit more advice about what to expect afterwards. Something sore and a bit black in places, that's a bit worrying until you know' (P1, T3). This is consistent with the finding that those with unexpected symptoms sought further medical advice. P1 (T2) was also critical of the timing of advice-giving: 'all the surgeons were brilliant...but they gave me any advice...when I was all drugged up on the Saturday night and I couldn't remember who my wife was'. Perhaps this participant was given all the information he needed from the perspective of medical staff but had been unable to effectively process the information.

As discussed earlier, participants relied heavily on behavioural instruction for managing returning to activity. This was another domain where the desire for more information was expressed – 'I would want to ask medical advice about when I can start digging again...I want to know when I can move stones around' (P6, T2).

Information and conflicting life demands: the case of occupation

Participants were influenced by medical instructions but a second factor influencing return to activity/work was occupation type. Two participants worked freelance: if they did not work, they received no income. This prompted P5 (T2) to drive earlier than he

believed he should have: 'Yesterday I went out in the car to see, it was the first time, I know I'm not meant to go but I've got to go to work next week and I'm worried about that because I don't get paid if I'm not going out'. P1 (T2), the second freelance worker, was 'back to work within the week'.

In contrast, for others, return to work could be not only influenced but actively controlled by the medical profession because of the need for medical clearance - 'I was held up for a week because I couldn't get back to work until I had a medical from the company doctor. I was ready to go back after eight weeks...they sent me for a medical first so that put me back another week' (P2, T3).

One participant reported receiving conflicting advice from the surgeon and his GP - 'I wasn't able to return to work as soon as expected - it was about five, six weeks before I got back to work rather than the two to three...The doctor [GP] wouldn't let me back, the surgeon said I could go back and do anything I wanted but the doctor wasn't as keen as what the surgeon was' (P3, T3). Such conflicting advice also affected P3's return to other activities, with the GP being more cautious than the surgeon: 'the surgeon [at a follow-up visit] here had said just go away and play a round of golf if you want to but the GP was much more cautious about the whole thing' (T3). Probing revealed that it was the GP's advice that P3 followed. This fits with observathat participants followed medical instruction to limit activity even when they felt able in order to avoid causing damage. From this damage limitation perspective, it is logical to be cautious rather than risk over-activity.

## Importance of information sources

Participants highly valued information and instruction from HCPs after surgery. However, informal information sources seemed to be crucial for enabling participants to appraise their condition as requiring medical attention in the early, pre-operative stages, as well as for increasing understanding and enhancing communication with HCPs. For example, P4 talked about the internet as a tool to gain baseline

knowledge that permitted access to further information: he believed that the consultant told him more about his operation because he demonstrated a high level of knowledge - 'he explained that to me more because I know, I'd found it out' (T3).

#### Discussion

Participants undergoing hernia surgery drew on a range of sources for information: friends, family, books and the internet were reported as sources. In addition, participants with recurrent hernias also used their own experience and the influence of HCPs was evident throughout the health-care process. These findings are similar to those of Proude et al.;14 in a survey of 1571 people scheduled for elective surgery, 20% reported accessing information from friends or relatives, 15% from books or magazines, 11% from television or radio and 10% from the internet. Fourteen percent accessed information from allied health practitioners.

Participants used information when making decisions about a number of behaviours: initial help-seeking, deciding to have surgery, using analgesics, taking action with respect to postoperative symptoms and returning to activity. Whilst informal information sources apparently influenced decisions to seek help and to have surgery, decisions made after surgery, during the recovery process, seemed more reliant on information from HCPs. Avoiding damage to the repaired site was highly important and participants looked to professionals for advice on minimizing this risk; when conflicting advice was received, the most cautious advice seemed to be favoured. On experiencing unexpected postoperative complications, participants sought further medical advice.

At the key decision points, information was used to assist participants' understanding and interpretation of their condition. Initially: was there something wrong? If so, what? Was a visit to the GP merited? After diagnosis: does having a hernia matter? Would surgery help? After surgery: is severe bruising normal or does it indicate something is dangerously wrong

requiring medical assistance? It is valuable to consider some theories that may prove helpful in assessing what processes occur in the face of medical or health threats. A model developed to understand how people assess a health threat and select coping actions is the CS-SRM.<sup>11</sup> This proposes that, when faced with a health threat (e.g. a hernia or post-operative symptoms), we form illness representations: we appraise the threat in terms of its *identity* (the symptoms and label attached to the threat), timeline (the expected duration), cause, consequences ('expected outcomes' e.g. severity of the health threat) and control (e.g. whether the threat can be effectively treated or cured). Appropriate coping procedures are selected according to the illness representations held by the individual. The effects of the coping actions are appraised; this appraisal influences how the threat is then perceived in terms of illness representations. A parallel emotional appraisal process occurs: we appraise how we feel as a result of the threat and form a strategy to cope with this emotional response.

If we consider our findings in relation to the CS-SRM,11 people did appear to seek and use information in line with the model. Participants initially looked for information to determine whether their symptoms (identity) merited a visit to the GP. In making the decision to have surgery, advice about consequences of not having the surgery was crucial, as was the understanding that the operation could *control* the hernia. After surgery, information was sought to facilitate the understanding of unexpected postoperative symptoms (*identity*). Where bruising, swelling or numbness was construed as part of the normal healing process or an expected outcome likely to resolve with time, the condition was not appraised as threatening and no action was taken. However, where the cause and consequences of the symptoms were mysterious or worrying to participants, they became anxious and sought further information. Information gained allowed them to reappraise symptoms as harmless. The action (seeking medical advice) was an effective strategy for re-appraising the symptoms in terms of identity, timeline, consequences, cure and control, and also acted as an effective emotional coping strategy: reassurance was gained on contacting HCPs.

The level of information sought at the preoperative stage varied. However, information relating to surgery and recovery was welcomed; negative comments were only received when information was perceived to be insufficient. Behavioural instruction from medical professionals was taken extremely seriously and seemed to be strictly adhered to by many participants. Nevertheless, it was not followed blindly: when advice clashed with the need to earn a living, compromises were made.

Information relating to post-operative complications and return to usual activity seemed to be of particular importance. This is consistent with Jacobs' study of perceived information needs in 45 patients discharged after surgical procedures (including hernia repair).<sup>22</sup> Items related to which activities could be safely performed and how complications could be identified were both rated highly. Also, while 84% of the participants reported being given advice about activities, only 57% reported receiving information regarding how to recognize a complication, and 56% reported receiving advice on when to seek urgent assistance for a complication. These data, and those from the present study, are insufficient to explain why patients report not receiving sufinformation about post-operative symptoms. It could be that information is presented at a time when some patients are not fully alert, or that they do not fully understand what is implied. For example, when they are warned of 'bruising', they may not appreciate the extent to which bruising is considered 'normal' in this context. Perhaps, from the perspective of medical personnel, these procedures are minor. Something that is nothing to worry about from a medical perspective may still cause concern to a lay person and lead to further help-seeking. It may also be that hospital staff are less aware of patients' anxiety levels and the need for reassurance post-surgery than pre-surgery because they see less of it: people are now discharged very soon after

surgery. However, it has been demonstrated that anxiety levels can remain high for at least 5 days after surgery.<sup>23</sup>

Once participants had entered into the health-care system, advice from professionals seemed to take priority over other information sources but informal sources were crucial in making that initial decision to enter the system. The internet was one such source but wariness about the quality and accuracy of information was seen. This finding has been found in other health contexts: Ziebland et al.24 found cancer patients also made use of the internet before seeing a doctor, and some participants expressed wariness of information available online. Such scepticism seems merited: Rose et al.25 asked participants to provide search terms they used to describe their knee injuries and the authors searched the internet using these terms. Only 7% of the web pages retrieved provided relevant information. Murphy and Joyce<sup>26</sup> searched the internet for three surgical conditions, including inguinal hernia surgery. They found that websites did generally contain 'comprehensive' information regarding aetiology and clinical aspects but information provided on treatments, including comparisons between treatments and likely outcomes, was less consistent. Krones et al.27 also carried out an imitation of a lay search, using the term 'inguinal hernia'. The majority of pages did not rate highly on their standardized rating system. A common finding was the failure of sites to objectively discuss treatment alternatives; 80% of sites presented a single treatment option.

Nevertheless, participants did report benefits to using the internet, including one participant who found himself in a better position to ask questions and understand information given by the consultant; he felt that the consultant explained more because he demonstrated existing knowledge. This is a welcome finding in view of recent research in the mental health context: participants reported finding information to be empowering but felt that HCPs responded negatively, regarding this self-education as a 'challenge'. 28 Our findings also

correlate with studies of medicine-related information. In a systematic review of the role of written information for medicines, Grime et al.<sup>29</sup> found that people reported using written medical information similarly to how our participant used internet information: to facilitate consultations with medical professionals. This information suggested suitable questions to ask, and allowed people to feel that it was legitimate to discuss medication in consultations.

Thus far, the discussion of the effects of information and instruction on decisions and behaviour has focused on the participant as a rational individual who collects information, appraises the health threat and available options, and decides on the appropriate action in a linear process. However, as highlighted by Dingwall<sup>30</sup> and Pescosolido<sup>12,13</sup> (Network-Episode Model), people are part of social networks and illnesses are understood, and decisions reached, not only by individually processing events but also by processes of social interaction. Pescosolido examines the importance of social influence on the key time points in the 'illness career' such as on whether and how people enter a formal health-care system. 12,13,31 We found that, pre-operatively, participants drew on a range of informal information sources, including social networks and experiences of others with similar conditions. Social networks did not merely provide information – they could lead to further help-seeking – 'I was sort of nagged' (P3, T2). As recognized by Pescosolido, a social network can also function to regulate, facilitate or coerce its members' behaviour. 12,13,31

Once participants had entered the formal health-care system, our data suggest that HCPs, particularly doctors, had a strong influence on participants' decisions. Behaviours performed after surgery (particularly analgesic use and the return to activity) were largely governed by this highly respected social group because its members are perceived to be knowledgeable and expert about what would contribute to a good recovery. This deference to expert knowledge and the power of professional knowledge has been acknowledged by other research.<sup>32</sup>

## Limitations

A standard requirement of research ethics committees is that the first contact with participants is made by a member of the care team. In our study, this was achieved using a cover letter signed by a consultant surgeon. Even though the study information sheet and the interviewer attempted to clarify that the research was independent of their care and that data were treated confidentially and anonymously, some participants apparently did not fully appreciate this. For example, one participant kindly commented on his interview experience in a card sent to his surgeon. Seeing the interviewer as associated with the clinical team has the potential to influence responses about information received and the extent to which behavioural instruction was followed: people may want to be seen to be following doctors' instructions.

The purpose of the methodology used in this study was to gain rich insights into individual perspectives and to deepen understandings rather than to form conclusions that will generalize to the wider population. 19,33 This method proved highly valuable for identifying important conceptual issues and has enabled a deeper investigation of those issues than would be possible with a design employing a larger, statistical sample. In addition, the longitudinal design provided very informative and rich data on the pathway of care and recovery. This study would merit development with larger patient populations where different patient cohorts and surgical conditions could be assessed. Questions arise about gender effects, nature of the disease and activity limitations. However, the implications are suggestive that HCPs still hold a pivotal role in advising, informing and guiding patients, despite the information technology revolution, the proliferation of information sources and complex social situations. Timing of information and sensitivity to different patient needs at different stages would appear to be important.

# **Conclusions**

Participants undergoing hernia repair surgery sought information from multiple sources, making use of informal sources when initially deciding whether to seek help and using information and instruction from HCPs in the post-operative period. Participants spoke positively about medical information received but expressed a desire for more information about post-operative symptoms. Unexpected post-operative events led to concern and further help-seeking. Findings illustrated the need for future research in this area to be sensitive to timing: participants used different information sources and had different information needs according to the stage of the health-care pathway.

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