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Alcohol-related liver disease patients' beliefs about their illness and factors that influence their self-management.

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Alcohol-related liver disease patient survey

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TITLE: Alcohol-related liver disease patients' beliefs about their illness and factors that influence their self-management.

ABSTRACT

AIM

To determine the association between illness belief and self-efficacy to provide the evidence-base to develop a personalised framework to support self-management in patients with alcohol-related liver disease.

BACKGROUND

Research in a variety of long term illnesses suggests patients' illness beliefs are a more influential factor for patient recovery than the severity of the illness. However, research into illness belief and self-efficacy of patients with alcohol-related liver disease is sparse.

DESIGN

A cross-sectional survey.

METHODS

A cohort of 159 alcohol-related liver disease patients who attended the Liver Outpatient Clinics at a London Hospital (October 2012 to November 2013) completed a set of validated instruments measuring illness beliefs, self-efficacy, emotional states and quality of life.

FINDINGS

The mean age of enrolled patients was 52 years, 67% male, 26% live on their own, 61% had no previous history of other chronic illness and average Model for End-Stage Liver Disease

and The AUDIT Alcohol Consumption Questions scores were 11.0 and 3.5 respectively. After adjusting for demographic and illness characteristic components, multiple regression analysis shows that the 3 illness belief components 'Symptoms', 'Understanding' and 'Concerns' made a significant contribution to their confidence to self-manage their liver condition and the 'Symptoms' component makes a signification contribution across to all outcome measures: Anxiety, Depression, Quality of Life, and Self-Efficacy.

CONCLUSION

Interventions designed to improve alcohol-related liver disease patients understanding of their illness and strategies to manage their symptoms are likely to improve their self-management, quality of life and reduce anxiety and depression.

KEY WORDS: alcohol-related liver disease, illness belief, self-efficacy, self-management, nursing.

SUMMARY STATEMENT

Why is this research or review needed?

- Alcohol-related liver disease has significantly contributed to the rise in hospital admissions and mortality rate, yet there is a lack of research about alcohol-related liver disease patients' experience.

- To provide an effective and evidence-based approach to promote self-management of alcohol-related liver disease it is important to have a clearer understanding of what influences these patients' confidence to self-manage.

- This study is the first study of alcohol-related liver disease patients to examine the relationship between illness belief and their confidence to self-manage their condition.

What are the key findings?

- The alcohol-related liver disease patients identify the most commonly experienced symptoms as 'sleep difficulties' and 'fatigue'.

- 'Understanding of their liver condition', 'experience of the number of symptoms' and 'concern about their illness' are significantly associated with confidence to self-manage in alcohol-related liver disease patients.

- 'Experience of the number of symptoms' is significantly associated by alcohol-related liver disease patients with anxiety, depression, quality of life and the confidence to self-manage their chronic liver condition.

How should the findings be used to influence policy/practice/research/education?

- Healthcare practitioners should address patients' illness beliefs to create individualised responses to meet patients' needs and better support self-management of their condition.

- Strategies to address symptoms identified by alcohol-related liver disease patients are likely to improve their quality of life and confidence to self-manage, and reduce anxiety and depression.

- Information obtained from patient illness beliefs and expectation assessment could be used systematically to formulate a personalised patient education plan to support health behaviour changes.

INTRODUCTION

Liver disease is the 5th largest cause of death in the United Kingdom. The average age of death from liver disease is 59 years, compared to 82-84 years for heart & lung disease or stroke (British Association for the Study of the Liver (BASL) & British Society of Gastroenterology (BSG), 2009). Hospital admissions and the mortality rate in England are increasing for patients with chronic liver disease. The underlying reasons for this increase are complex, but alcohol-related liver disease (ALD) makes a major contribution to this rise in admissions and the mortality rate (Thomson et al., 2008). The rapid review of the evidence relating to liver disease epidemiology, treatment and service provision, identified the key modifiable risk factors that are relevant to a large proportion of patients with liver disease as: excessive drinking, infection with hepatitis B or C and obesity (Department of Health 2007). One of the key evidence gaps noted by the review was the need for research that includes patients' perspectives and experience of treatment and care delivery (Kaner et al., 2007). The National Plan for Liver Service U.K. (BASL & BSG, 2009) has also reported the lack of research about chronic liver disease patients' experience and the poor organisation of secondary care of liver disease.

Evidence has shown that a motivational enhanced interviewing approach might help to modify health behaviour by challenging ALD patients' illness perspective and experience (Weinrieb et al., 2011; Wilk et al., 1997). Physicians treating patients with ALD recommend a complex treatment plan involving health education to address modifiable risk factors and rigorous self-management practice to achieve optimal care. However, intervention to promote self-management in patients with a long term health condition is itself complex (Lau-Walker & Thompson 2009). To develop an effective evidence-based complex intervention (Medical Research Council, 2008) to promote ALD patients' self-management it is vital to establish

what are the 'active components' that influence self-management. In order to support doctors and nurses to provide an effective and evidence-based approach to promote self-management for patients living in the community, it is important to have a clearer understanding of what influences patients' confidence to self-manage their condition following discharge from hospital.

BACKGROUND

A personalised care approach is likely to optimise self-care management in patients with a long-term condition (Department of Health 2006) and evidence from a range of long term conditions including coronary disease (Ekman et al., 2012), asthma (Effing et al., 2009) and diabetes mellitus (Warsi et al , 2004) has suggested that a personalised care approach might improve healthcare outcomes. The two psychological theories - illness representation (Leventhal et al., 1984; Leventhal et al., 2001) and self-efficacy (Bandura, 1997) - feature prominently in research in the development of a personalised care approach. An Interactive Care Model (Lau-Walker, 2006) was conceptualised combining the therapeutic use of these two psychological theories which aims to promote a personalised care approach by addressing patients' illness perceptions (illness representation) and their confidence in self-management (self-efficacy). Research findings based on the Interactive Care Model (Lau-Walker, 2006) in patients with a long term cardiac condition suggest that the two key components of illness beliefs (identity and control/cure) are significantly associated with patient self-management and quality of life in the long term (Lau-walker, 2007; Lau-Walker et al., 2009). Research of ALD patients' illness perception and self-management is sparse. To our knowledge, the current study which will apply the Interactive Care Model (Lau-Walker, 2006) to patients with ALD is the first study to examine ALD patient's illness beliefs, their confidence in self-management and quality of life. We hypothesise that ALD patients'

perception of their illness symptoms (identity) is associated with their self-management confidence, anxiety and depression and quality of life.

THE STUDY

Aims

Aim of the study was to determine the association between illness perception and confidence in self-management; and to provide the evidence-base for the development of a personalised framework to support self-management in patients with alcohol-related liver disease.

Primary question

Are chronic liver disease patients' perceptions of their illness symptoms associated with their confidence to self-manage and their quality of life?

Study objectives

1. To explore and describe ALD patients' illness perception.
2. To assess the association between ALD patients' illness perception and their confidence to self-manage, anxiety and depression and quality of life.
3. To explore the association between ALD patients' characteristics (including self-reported alcohol intake - The AUDIT Alcohol Consumption Questions (Audit C) scores and severity of alcoholic-related liver disease - Model for End-Stage Liver Disease (MELD) scores) and their confidence in self-management, anxiety and depression and quality of life.

Design

A cross sectional survey was carried out with ALD patients who attended the Liver Outpatient Clinic at a London Hospital (KCH) over a period of 12 months (October 2012 to November 2013) were invited to participate in the study and to complete a set of validated instruments measuring illness beliefs, self-efficacy, emotional states and quality of life.

Participants

Inclusion Criteria

-Patients with a confirmed primary diagnosis of alcohol-related liver disease as determined by the hepatologist caring for the patients and who were attending the liver outpatient clinics at a London Hospital were eligible for the study.

Exclusion criteria

-Patients below 18 years of age

-Patients unable to understand and read English unaided which would affect their ability to participate in the study

-Patients with severe cognitive impairment which would affect their participation in the study

Sample size

To detect a relationship between the Self-efficacy measures and the Illness Perception Questionnaire components described by a regression line with slope of 0.45 based on previous studies (Lau-Walker, 2004; Lau-Walker, 2007), assuming an SD of the Self-efficacy of 1.0 and an SD of 0.5 for the Brief Illness Perception Questionnaire components (Broadbent et al., 2009), a sample size of 150 was sufficient to test the effect specified with 80% power and a 5% level of significance.

Data collection

Patients who attended the ALD Liver Outpatient Clinic at a London Hospital (KCH) were screened by an ALD Nurse Specialist and the patients who met the inclusion criteria were invited to participate in the study. After gaining informed consent the participants completed a set of validated questionnaires to assess their illness perception, self-efficacy, quality of life and emotional state. Additionally an assessment of patient alcohol intake and severity of the liver condition was undertaken using the Audit-C tool and the MELD score respectively.

Ethical considerations

Ethical approval was obtained from the National Research Ethic Service Committee-Fulham (REC reference 11/LO/0472) and the study was registered with the Research and Development at a London Hospital (REC Ref: KCH11-085).

Measures

The instruments used in this study have proven validity and reliability. Wherever possible the short forms of these measures were selected to reduce barriers to participation in line with the research team's previous experience of chronic liver disease patients' behaviour with survey returns. As a result the following measures were chosen and used:

Independent variable

Illness beliefs: The Brief Illness Perception Questionnaire (BIPQ) (Broadbent et al., 2009) was developed to provide a quantitative assessment of the illness perception components described in Leventhal's Self-regulatory Model (Leventhal et al., 2001). The BIPQ has been validated as a short form measure developed from the original Illness Perception

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Questionnaire (IPQ) (Weinman et al., 1996) and the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002). Broadbent et al (2009) reports the psychometric properties of the BIPQ including the test-retest reliability, concurrent validity, predictive validity and discriminant validity of the BIPQ with IPQ, IPQ-R and other relevant measures and, in summary, the evidence shows the BIPQ to be a valid and reliable measure of the illness perception with a variety of illness groups. The 8 BIPQ components: 'Consequence' (illness effect on their life), 'Timeline' (length of illness), 'Personal control' (feel in control), 'Treatment control' (treatment can help illness), 'Identity' (experience of symptoms), 'Concern' (concern of illness), 'Understanding' (understanding of illness) and 'Emotions' (affected emotionally) were used to assess patient's perception of their illness. Apart from the 8 BIPQ components, the original IPQ identity dimension scale 'Symptoms' was also used in this study to provide a more detailed analysis of the patient's identity beliefs (Broadbent et al., 2009). For each component a low score was good and a high score was bad e.g. consequence 'How much does your illness affect your life' 0 = 'No affect at all' and 10 = 'severely affects my life'. The 'Symptoms' –identity dimension scale reflect the individual's perception what the problem was and requires participants to rate how often (never, occasionally, frequently and all the time) they experienced a list of ALD illness related symptoms (n=15) and they were added together to produce a summary score (Weinman et al., 1996). A collinearity analysis of the eight BIPQ components and original IPQ did not indicate that this was a problem (the condition index was 22.1 below the threshold of 30 suggested for potential removal of variables from the model (Belsey & Kuh 1980, Belsey 1991).

Outcomes measures

1. Confidence in self-management (SE): The Self-Efficacy for Managing Chronic Illness Scale consists of eleven statements rated on a 10 point scale to produce two summary scores

on Self-Efficacy Chronic (SE Chronic) and Self-Efficacy Liver (SE Liver). These scales were developed from Lorig et al's (2001) work on several self-efficacy scales for Chronic Disease Self-Management studies.

- The 'SE Chronic' scale consists of six statements to measure patient confidence in their ability to manage their illness in relation to fatigue, pain, emotional and symptom distress and performing daily tasks. Lorig et al (2001) reports the test for Internal Consistency and Reliability of the SE Chronic scale on 605 subjects (mean 5.17 SD ±2.22) with chronic illness was 0.91.

-The 'SE Liver' scale consists of five statements to measure patients' confidence in the management of the modifiable risk factors such as diet, exercise, smoking, alcohol intake and adherence to medicine. The scale was tested for internal consistency and Cronbach alpha reliability coefficient was 0.83.

For both scales a statement score of 0 equated to feeling 'not at all confident' and a score of 10 to feeling 'totally confident'.

2. Emotional state: The Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983) is a self-assessment scale and was found to be a reliable instrument to detect states of 'Depression ' and 'Anxiety' in the setting of an hospital medical outpatient clinic (Zigmond & Snaith, 1983). It has been widely used in healthcare settings to measure psychological well-being. It consists of 14 questions measured on a four-point scale from 1 = low to 4 = high. For example if a person said they were tense or wound up 'most of the time' they received a score of 1, and 4 if 'not at all'.

3. Quality of life: The EuroQoL Health Questionnaire (EQ-5D) (EuroQoL Group, 1990) was used. It is a standardised non-disease-specific instrument for describing and valuing health-

related quality of life. The EuroQoL Group (1990) summarised the development and reported the instrument consistency testing (the multiple regression results showed that the value of R^2 in all three cases is very close to 1) in the three extensive studies conducted in the United Kingdom, Netherlands and Sweden. The 'EQ-5D' instrument has been validated for use in economic evaluation and was originally designed to be used in combination with other quality of life measures and more recently it has been used independently to produce summary scores for quality of life. Participants were asked to describe 'Your own health state today' on a 10-point scale from 0-10 'Worst imaginable' to 91-100 'Best imaginable health'.

Other measures used to assess patient characteristics

Audit C score: is a brief screening test consist of 3 alcohol consumption questions extracted from the Alcohol Use Disorders Identification Test (AUDIT) tool and is used for the assessment of heavy drinking and/or mental and behavioural disorders due to use of alcohol. Bush et al (1998) evaluate the validity and reliability of the Audit C tool as a brief screening test for heavy drinking and/or active alcohol abuse or dependence and found that the AUDIT C is a practical and validated tool. The AUDIT C has been widely adopted into primary care settings and a score of 5 or above is considered to be hazardous drinking (Bradley et al., 2007).

MELD score: MELD score is calculated from serum creatinine, prothrombin time (INR) and serum bilirubin to produce a summary score that reflects the severity of patients' liver condition (Dooley et al., 2011). MELD score is a scoring system to measure severity of chronic liver disease and subsequently it has been used successfully to predict mortality in

patients awaiting transplant and on average, patients with a MELD of 20 are considered for transplantation (Dooley et al., 2011).

People were classified as having comorbidity if they listed one or more (e.g. severe kidney disease, cardiovascular disease, cancer, diabetes, high blood pressure etc.).

For the regression analysis demographic and profile variables used in the model were dichotomised into whether the following characteristics were present or absent: male, has a partner, lived alone, racial background was white, employed, been awarded a degree, were a smoker and had one or more comorbidities. Obesity was categorised into three groups (BMI $\geq$ 30, BMI <30, BMI unknown).

Data analysis

Multiple regression analysis was used to examine the association between illness belief components and the five outcome measures 'Anxiety', 'Depression', 'EQ-5D, 'SE Chronic' and 'SE Liver'. The primary aim of the study was to assess the association between patient illness beliefs and their confidence in the self-management of their chronic liver condition. In the multiple regression analysis, each of the independent variables was evaluated in terms of its independent predictive power, over and above all the other independent variables in the model. All regression (partial R^2) results are reported as beta coefficients along with 95% confidence intervals. Normality probability plots and residual scatter plots were used to test the normality assumptions for the multiple regression models. All analyses were performed using IBM SPSS Version 22.

RESULTS

Demographic and illness characteristics data

Between October 2012 and November 2013, 159 ALD patients completed the questionnaire pack. Patients ages ranged from 27 to 80 (mean 52.3) and two thirds were male. Many were married or with a partner (54%); 19% were single. Eighty one percent were white and the level of qualifications ranged from none (18%) to university degree (25%). While 26% of patients reported that they were in employment or on sick leave, 26% were unemployed and 19% were retired. On their BMI index 34% of patients were unsure about their score while of those who were sure 25% (BMI ≥30) were obese and 75% (BMI<30) were not; and 29% of patients reported they were current smokers. Patients' mean MELD and AUDIT C scores were 11.0 (range 6-28) and 3.46 (range 0-12) respectively and 38% (n=61) of all patients did not have any other chronic condition/comorbidity (see Table 1).

Table 1

Illness Belief, emotional state, confidence in self-management and quality of life data

The illness belief that produced the highest score was 'Timeline', followed by 'Concerns'. The lowest scoring illness beliefs were 'Treatment control' followed by 'Personal control' and 'Understanding'. Overall, patients recognised that their ALD was a long term condition and displayed concern about their illness. Patients appeared to suffer greater levels of 'Anxiety' than 'Depression' based on HADs (Mean 2.76 vs. 3.14) and were more confident about management of modifiable lifestyle factors such as diet, physical exercise, smoking, adherence to medication and abstaining from or modifying alcohol intake (SE Liver Mean=7.42) than they were with managing the long term physical and emotional aspects of the disease and managing daily tasks (SE Chronic Mean=5.79) (Table 2).

Table 2

ALD patients' perception of their illness symptoms are described in Table 3 when patients were asked to score how often they experienced each of the listed symptoms. The result indicated that more that 50% of the patients in this survey experienced 'sleep difficulties' and 'fatigue' frequently or all the time. The next of the most commonly experienced symptoms were 'sore joints' and 'concern about illness complications' and more than 40% of the patients experienced these symptoms frequently or all the time. The least commonly experienced symptoms were 'jaundice' and 'pain in the right upper abdomen'.

Table 3

Association between Illness Beliefs and emotional states

Regression analysis showed that Anxiety (Table 4a) and Depression (Table 4b) were associated with several factors. 'Symptoms' (β = -0.77 95% CI =-1.00 to -0.54, p<0.001, partial R^2 = 0.31) and 'Emotions' (β = -0.07 95% CI =-0.11 to -0.03, p=0.002, partial R^2 = 0.10) were significantly associated with 'Anxiety' (Table 4a) and 'Symptoms' (β = -0.38 95% CI =-0.56 to -0.19, p<0.001, partial R^2 = 0.15), 'Emotions' (β = -0.04 95% CI =-0.07 to 0.00, p=0.030, partial R^2 = 0.05), 'Personal control'(β = -0.04 95% CI =-0.07 to -0.01, p=0.009, partial R^2 = 0.07), 'Consequences' (β = -0.04 95% CI =-0.07 to -0.01, p=0.022, partial R^2 = 0.05) and 'Current smoker' (β = -0.23 95% CI =-0.40 to -0.07, p=0.007, partial R^2 = 0.07) were significantly associated with 'Depression' (Table 4b).

Overall, patients' who experience a high number and frequency of illness related symptoms and who perceive their illness has a high emotional impact on them are more anxious. Patients who experience a high number and frequency of illness related symptoms, perceive their illness to have a high emotional impact on them, feel less in control personally, and perceive their illness has a high consequence on their life and who are current smokers are more depressed.

Table 4

Association between Illness Beliefs and quality of life

'Symptoms' (β = -0.92 95% CI =-1.80 to -0.03, p=0.043, partial R2 = 0.04) was the only independent variable significantly associated with EQ-5D (Table 5). Patients who experience a high number and frequency of illness related symptoms have a poorer quality of life.

Table 5

Association between Illness Beliefs and confidence in self-management

'Symptoms' (β = -1.84 95% CI =-2.72 to -0.96, p<0.001, partial R2 = 0.15), 'Personal control' (β = -0.22 95% CI =-0.36 to -0.09, p=0.002, partial R2 = 0.10) and 'Treatment control' (β = -0.16 95% CI =-0.31 to -0.01, p=0.035, partial R2 = 0.04) were significantly associated with SE Chronic (Table 6a) and 'Symptoms' (β = -1.39 95% CI =-2.17 to -0.60, p=0.001, partial R2 = 0.11), 'Concerns' (β = 0.19 95% CI =0.06 to 0.32, p=0.006, partial R2 = 0.08), 'Understanding' (β = -0.20 95% CI =-0.33 to -0.07, p=0.004, partial R2 = 0.08), Audit C (β = -0.15 95% CI =-0.24 to -0.07, p<0.001, partial R2 = 0.12), Male (β = -0.98 95% CI =-1.70 to -0.25, p=0.009, partial R2 = 0.07) and 'Current smoker' (β = -0.84 95% CI =-

1.56 to -0.12, p=0.023, partial R^2 = 0.05) were all significantly associated with SE Liver (Table 6b).

Patients who experience a high number and frequency of illness related symptoms, who perceive their treatment is less likely to help their illness and who feel less in control personally are less confident in the management of their chronic condition.

Patients who experience a high number and frequency of illness related symptoms, who have a poorer understanding of their liver condition, who are more concerned about their illness, who reported that they had a higher alcohol intake, are male and who are currently a smoker have less confidence in the management of their alcohol-related liver condition.

Table 6

In the multiple regression models (Tables 4,5 & 6), a number of the demographic and illness characteristic variables were found to be significantly associated with the outcome measures, smoking was significantly associated with 'Depression'; alcohol intake, smoking and gender were significantly associated with 'SE Liver'; while having other chronic illnesses was significantly associated with 'EQ-5D'. Finally, it is also interesting to note that the MELD score which represents the severity of the liver condition made no significant contribution to any of the outcome measures such as self-efficacy, anxiety and depression and quality of life.

DISCUSSION

The design of the current study aimed to assess patients' 'illness beliefs' and their 'self-efficacy' to provide evidence for the development of effective personalised patient education/care. Assessment of patient's illness beliefs can be used to understand their

personal illness perspectives, while the assessment of patients confidence to manage their condition - Bandura's *self-efficacy*, which he identifies as 'a powerful determinant of behavioural change'(Bandura 1997) - can be used to inform strategies to promote self-management. By understanding the associations between patients' individual illness belief components and self-efficacy, healthcare professionals gain valuable information to better help their patients make sense of their illness beliefs and to make connections between these beliefs and any available relevant educational material, and, consequently, to improve the exploration of the individual's self-management strategies for the relevant modifiable health behaviour changes.

Research evidence has shown that to provide generic health education information does not necessarily help patients to adopt the suggested health behaviour changes. To be effective patient education needs to be personalised (Mullen et al., 1992). For example, only educating patients about harmful effects of smoking, lack of exercise, and diet on their health condition often does not enable patients to make or sustain their health behaviour changes. Patients are, however, more likely to act on the educational material that they can understand and find relevant and meaningful to their individual needs or circumstance (Bandura, 1997).

To develop an effective personalised patient education intervention to support self-management the information provided to patients needs to be specific and situation related (Lau-Walker & Thompson, 2009). This study sought to examine ALD patients' illness experience and to establish the evidence for the development of personalised patient education to support self-management in ALD patients. Hence, the current study sought to assess in detail patients' views and experience of their associated illness symptoms using the

IPQ identity dimension 'Symptom', to understand how often patients experience their illness symptoms (Table 3).

As shown in Table 3, individual beliefs and experiences are more likely to shape the effectiveness of the patient's care than the severity of the patient's condition. Research has shown that patients' illness beliefs and expectations are more influential than the severity of patients' illness condition to their health behaviour changes (Petrie & Weinman, 1997). Indeed, the study findings indicate that the MELD score, which represents the severity of the liver condition, made no significant contribution to any of the outcome measures of self-management, anxiety and depression, or quality of life.

Confidence to self-manage

The study's data show that patients' experience of number and frequency of their illness symptoms ('Symptoms'), their sense of personal control ('Personal control') and believe that treatment can help ('Treatment control') are the key factors that influence their confidence in their ability to manage their chronic condition. 'Symptoms' is also significantly associated with anxiety, depression and quality of life. These results are consistent with other research findings in the self-management of other chronic illness conditions such as chronic heart failure, chronic obstructive pulmonary disease and diabetes (Ekman et al., 2012; Effing et al., 2009; Warsi et al., 2004). The IPQ 'Symptoms' identity dimension scale has consistently emerged in studies of chronic illness self-management as an important variable that is significantly associated with health outcomes or health behaviour changes (Petrie & Weinman, 1997).

The current study has shown that when patients respond to self-efficacy questions specifically related to the self-management of their liver condition (SE Liver), as well as 'Symptoms', two other illness belief components 'Understanding' and 'Concerns' were identified to be significantly associated with patients' confidence in self-management (SE Liver). Therefore, to promote self-management in ALD patients, it is also important to ensure patients understand their liver disease, that measures are taken to help patients to address the illness concerns they themselves identify, and that they are able to recognise and manage their illness symptoms effectively. One noteworthy result shows a different direction of association that patients who are more concerned about their illness have more confidence in the ability to manage their alcohol-related liver condition which is not expected; the findings suggests that it is important to raise patient awareness and concern of the consequence of their alcohol-related liver condition to encourage patients to develop their confidence in managing their alcohol-related condition.

Personalised patient education and care

A review of Liver Services in the UK has identified the urgent need to ensure that healthcare practitioners who care for patients with liver illness should have adequate and specific knowledge and skills (DH, 2011; BASL & BSG, 2009) and a set of national liver care competences has been developed as guidelines to ensure good practice (RCN, 2013). In addition, to provide an effective liver service there is a need to develop effective personalised patient education based on the illness beliefs of the patients being supported. The IPQ 'Symptom', 'Personal control', 'Treatment control', 'Concerns' and 'Understanding' are the five IPQ components that have been found to be related to patients' confidence to self-manage. These findings provide us with an insight into patients' personal perspectives of their illness and, together with the associations between patients' illness perspectives and

their confidence in their own self-care provides useful information to develop individual strategies to promote ALD patient self-management. The management of realistic expectations and a clear understanding of the illness condition informed by relevant and individualised information are vital for the successful support of self-management.

Development of personalised self-management strategies

Previous research has suggested that there is a marked divergence of focus between patients and doctors on what is important to identify priorities to address their condition (Wenger et al., 1984; Calkins et al., 1991; Lau-Walker et al., 2009). Doctors tend to focus on the symptoms generated by the severity of the condition or its prognosis, and undervalue the symptoms patients report. Rather than the severity of their condition, patients placed more focus on the limitations their illness imposes on their daily activities which impact on their quality of life.

In the current study we examined patient views of their illness associated symptoms using the IPQ identity dimension scale and found that the two most common symptoms experienced by ALD patient are 'fatigue' and 'sleeping difficulties'. Observations have shown that physicians treating ALD patients are more likely to prioritise the assessment and treatment on patients' physical symptoms such as 'jaundice' and 'upper abdomen pain'- which, of the symptoms listed in this study, are the two which patients give least priority (Table 3- 'Symptoms'). Physicians are less concerned with the treatment or advice to patients on the management of 'fatigue' or 'sleeping difficulties', which patients place at the top of their list of symptoms they are concerned about (Table3- 'Symptoms').

This lack of a shared focus between patients and their health carers is likely to lead to a sub-optimal improvement of the patients' quality of life and self-management of their illness. The study findings would suggest that in providing patient-centred care, it is important that we address patients' key concerns and prioritise the treatment and care of symptoms such as 'fatigue' and 'sleeping difficulties' in these patients.

Implications for practice

To establish patient's individual perspectives of their illness, and thus to create the basis for an individualised programme of education and care, patients' illness beliefs and expectations of self-efficacy should be routinely and systematically assessed. We recommend that information obtained from the illness beliefs and expectation assessment can be used to formulate a personalised patient education plan/protocol to help patient to understand their individual illness condition and to make sense of the recommended modifiable health behaviour changes.

In line with previous research identifying effective personalised patient education to support self-management in chronic long term health conditions, this study also indicates that to effectively support self-management in ALD patients, appropriate patient education and guidance needs to:

- help patients to assess the severity of their symptoms step by step, including to recognise whether the symptoms are related to their ALD condition;
- interpret the severity and impact of the symptoms;
- identify the appropriate response and action; and
- establish how to monitor and evaluate progress.

Limitations

Multiple regression analysis was used to identify the strength and pattern of association between the variables examined; however with the cross-sectional design it is not possible to establish the direction of the relationship. Data collection from ALD patients is known to be challenging and the project team did not have sufficient resources to carry out a longitudinal study.

CONCLUSION

The National Plan for Liver Service U.K. (BASL & BSG, 2009) calls for more research to better understand chronic liver disease patients' experience to improve care. The current study provides valuable information about key components of ALD patients' illness beliefs and their associations with confidence to self-manage their chronic condition (SEChronic) and their confidence to manage modifiable lifestyle changes (SELiver). Interventions designed to improve ALD patients' understanding of their illness and the strategies to manage their symptoms are likely to improve their quality of life and reduce anxiety and depression and improve their confidence in self-management. It is feasible to elicit patient illness beliefs using standardised questions and educate clinicians to utilise the information gained to provide effective personalised patient education to improve self-management.

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TABLES

Table 1: Demographic & illness characteristics

Table 2: Illness belief, emotional state, self-management and quality of life – summary statistics

Table 3: 'Symptoms'(IPQ identity dimension scale): Patients' experience of each of the following symptoms.

Table 4: Regression analysis for illness perception and patient characteristics on emotional states

Table 5: Regression analysis for illness perception and patient characteristics on Quality of life EQ-5D

Table 6: Regression analysis for illness perception and patient characteristics on Self-management

Table 1: Demographic & illness characteristics (n=159)			
Demographic			
Age	Mean 52.3 SD±10.9 Range 27-80		
		No.	**%**
Gender	Female	48	30
	Male	107	67
	Unknown	4	3
Marital status	Single	30	19
	Partner	18	11
	Married	68	43
	Divorced/separated/widowed	31	19
	Unknown	12	8
Do you live….	Alone	42	26
	With somebody else	84	53
	Other	15	9
	Unknown	18	11
Ethnicity	White	128	81
	BME/Mixed	25	16
	Unknown	6	4
Educational qualification	None	29	18
	GCSEs/ O levels	29	18
	A Levels	15	9
	University degree	39	25
	Vocational /other qualification	16	10
	Other	10	6
	Unknown	21	13
Employment status	Employed	30	19
	On sick leave	11	7
	Home maker	11	7
	Retired	30	19
	Not employed	42	26
	Other	19	12
	Unknown	16	10
Illness characteristics			
Comorbidities	None	97	61
	One or more	62	39
Body Mass Index	< 30	79	50
	≥30	26	16
	Unknown	54	34
Current smoker	Yes	46	29
	No	98	62
	Unknown	15	9
MELD score	Mean 11.0 SD± 4.4 Range 6-28		
AUDIT C score	Mean 3.46 SD±4.47 Range 0-12		

Table 2:
Illness belief, emotional state, self-management and quality of life – summary statistics

Illness belief:

	n	Mean	SD	Range
Consequences	159	5.77	3.03	0-10
Timeline	152	7.74	2.80	0-10
Personal control	158	3.99	2.90	0-10
Treatment control	151	2.21	2.33	0-10
Identity	158	5.32	3.04	0-10
Concerns	157	7.42	2.92	0-10
Understanding	157	2.15	2.41	0-10
Emotions	157	5.50	3.32	0-10
Symptoms (IPQ 'identity' scale)	157	2.19	0.61	1.07-3.73

Emotional states:

	n	Mean	SD	Range
Anxiety	158	2.76	0.71	1.29-4.00
Depression	158	3.14	0.61	1.57-4.00

Self-management:

	n	Mean	SD	Range
SE Chronic	154	5.79	2.53	0-10
SE Liver	152	7.42	2.16	0.80-10.00

Quality of life:

	n	Mean	SD	Range
EQ5D	155	6.33	1.95	1-10

Table 3 'Symptoms'(IPQ identity dimension scale):			
Patients' experience of each of the following symptoms in percentage (%), n=159.			
Symptoms: **(How often you experience each of the following symptoms?)**		**Never / Occasionally**	**Frequently / All the time**
	n	**%**	**%**
Sleep difficulties	152	42.1	57.9
Fatigue	150	44.7	55.4
Sore joints	157	59.2	40.8
Concern about illness complications	155	59.4	40.7
Discomfort	154	62.3	37.7
Decreased appetite	154	63.0	37.0
Depression	155	63.2	36.8
Irritability	153	65.4	34.6
Worry about family situation	155	56.1	33.9
Difficulty in concentrating	156	67.3	33.7
Itch	155	71.0	29.0
Swollen abdomen (ascites)	154	72.1	27.9
Confusion or drowsiness (encephalopathy)	153	74.5	25.5
Pain in the right upper abdomen	155	81.9	23.4
Jaundice	153	91.5	8.5

Table 4:   Regression analysis for illness and patient characteristics on emotional states

   a) Anxiety

	β	(95% CI)	p-value	Partial R^2
Consequence	0.022	(-0.021 to 0.064)	0.31	0.011
Timeline	-0.021	(-0.059 to 0.017)	0.28	0.012
Personal control	-0.001	(-0.036 to 0.035)	0.97	0.000
Treatment control	0.000	(-0.039 to 0.038)	0.99	0.000
Identity	0.034	(-0.011 to 0.078)	0.14	0.023
Concerns	-0.009	(-0.047 to 0.029)	0.64	0.002
Understanding	-0.007	(-0.047 to 0.032)	0.71	0.001
Emotions	-0.070	(-0.113 to -0.027)	0.002	0.097
Symptoms	-0.768	(-0.997 to -0.538)	<0.001	0.312
MELD	0.006	(-0.016 to 0.027)	0.61	0.003
Audit C	-0.011	(-0.035 to 0.014)	0.38	0.008
Age	0.003	(-0.005 to 0.012)	0.46	0.006
Male	0.071	(-0.140 to 0.282)	0.51	0.005
Married/partner	0.083	(-0.134 to 0.299)	0.45	0.006
Living alone	0.106	(-0.143 to 0.355)	0.40	0.007
Ethnicity- white	-0.099	(-0.358 to 0.161)	0.45	0.006
Education- degree	0.014	(-0.198 to 0.226)	0.90	0.000
Comorbidities	0.006	(-0.169 to 0.181)	0.95	0.000
BMI ≥ 30	-0.095	(-0.339 to 0.150)	0.45	0.006
BMI unknown	-0.181	(-0.402 to 0.040)	0.11	0.026
Current smoker	-0.127	(-0.337 to 0.084)	0.24	0.014
Employment	0.002	(-0.257 to 0.261)	0.99	0.000

Overall Model: F(22,97) = 10.34, p<0.001, Adjusted R^2 = 0.63
Continued

Table 4: **Regression analysis for illness and patient characteristics on emotional states, continued**

b) Depression

	β	(95% CI)	p-value	Partial R^2
Consequence	-0.039	(-0.072 to -0.006)	0.022	0.053
Timeline	-0.002	(-0.032 to 0.028)	0.89	0.000
Personal control	-0.037	(-0.065 to -0.010)	0.009	0.068
Treatment control	0.018	(-0.012 to 0.048)	0.24	0.014
Identity	0.007	(-0.028 to 0.043)	0.67	0.002
Concerns	0.018	(-0.012 to 0.048)	0.24	0.014
Understanding	-0.030	(-0.061 to 0.001)	0.061	0.036
Emotions	-0.037	(-0.071 to -0.004)	0.030	0.048
Symptoms	-0.375	(-0.555 to -0.194)	<0.001	0.149
MELD	-0.008	(-0.025 to 0.009)	0.37	0.008
Audit C	-0.009	(-0.028 to 0.011)	0.37	0.008
Age	-0.001	(-0.008 to 0.005)	0.66	0.002
Male	0.143	(-0.023 to 0.309)	0.090	0.029
Married/partner	-0.017	(-0.187 to 0.153)	0.85	0.000
Living alone	0.133	(-0.062 to 0.329)	0.18	0.018
Ethnicity- white	-0.053	(-0.257 to 0.151)	0.61	0.003
Education- degree	0.047	(-0.120 to 0.214)	0.58	0.003
Comorbidities	-0.069	(-0.207 to 0.068)	0.32	0.010
BMI ≥ 30	0.079	(-0.114 to 0.271)	0.42	0.007
BMI unknown	-0.038	(-0.211 to 0.136)	0.67	0.002
Current smoker	-0.231	(-0.396 to -0.065)	0.007	0.073
Employment	0.068	(-0.135 to 0.272)	0.51	0.005

Overall Model: $F(22,97) = 12.91$, $p<0.001$, Adjusted $R^2 = 0.69$

Table 5: **Regression analysis for illness perception and patient characteristics on Quality of Life EQ-5D**

	β	(95% CI)	p-value	Partial R^2
Consequence	0.122	(-0.040 to 0.285)	0.14	0.023
Timeline	0.067	(-0.078 to 0.212)	0.36	0.009
Personal control	-0.086	(-0.221 to 0.049)	0.21	0.017
Treatment control	0.015	(-0.134 to 0.164)	0.84	0.000
Identity	-0.088	(-0.258 to 0.083)	0.31	0.011
Concerns	-0.057	(-0.202 to 0.088)	0.44	0.006
Understanding	-0.135	(-0.286 to 0.015)	0.078	0.032
Emotions	-0.070	(-0.234 to 0.094)	0.40	0.007
Symptoms	-0.915	(-1.799 to -0.031)	0.043	0.043
MELD	0.040	(-0.043 to 0.124)	0.34	0.010
Audit C	-0.042	(-0.135 to 0.051)	0.37	0.008
Age	-0.019	(-0.052 to 0.014)	0.25	0.014
Male	0.001	(-0.818 to 0.820)	1.00	0.000
Married/partner	-0.152	(-0.979 to 0.676)	0.72	0.001
Living alone	0.038	(-0.912 to 0.988)	0.94	0.000
Ethnicity- white	-0.336	(-1.332 to 0.660)	0.51	0.005
Education- degree	-0.010	(-0.828 to 0.809)	0.98	0.000
Comorbidities	-0.647	(-1.320 to 0.026)	0.059	0.037
BMI ≥ 30	0.317	(-0.628 to 1.262)	0.51	0.005
BMI unknown	-0.337	(-1.190 to 0.515)	0.43	0.006
Current smoker	-0.765	(-1.590 to 0.060)	0.069	0.034
Employment	0.765	(-0.223 to 1.752)	0.13	0.024

Overall Model: $F_{(22,97)} = 3.79$, $p<0.001$, Adjusted $R^2 = 0.34$

Table 6: **Regression analysis for illness perception and patient characteristics on Self-management**

a) **SE Chronic**

	β	(95% CI)	p-value	Partial R²
Consequence	-0.067	(-0.229 to 0.096)	0.42	0.007
Timeline	-0.083	(-0.230 to 0.064)	0.27	0.013
Personal control	-0.222	(-0.360 to -0.085)	0.002	0.097
Treatment control	-0.160	(-0.310 to -0.011)	0.035	0.045
Identity	-0.040	(-0.211 to 0.131)	0.64	0.002
Concerns	-0.111	(-0.257 to 0.035)	0.13	0.023
Understanding	-0.137	(-0.290 to 0.017)	0.080	0.032
Emotions	-0.047	(-0.212 to 0.118)	0.57	0.003
Symptoms	-1.841	(-2.721 to -0.960)	<0.001	0.152
MELD	0.067	(-0.017 to 0.150)	0.12	0.025
Audit C	-0.019	(-0.112 to 0.075)	0.70	0.002
Age	-0.007	(-0.039 to 0.026)	0.69	0.002
Male	-0.070	(-0.880 to 0.740)	0.86	0.000
Married/partner	-0.380	(-1.210 to 0.450)	0.37	0.009
Living alone	-0.197	(-1.151 to 0.757)	0.68	0.002
Ethnicity- white	-0.388	(-1.387 to 0.610)	0.44	0.006
Education- degree	-0.139	(-0.952 to 0.675)	0.74	0.001
Comorbidities	0.002	(-0.677 to 0.681)	1.00	0.000
BMI ≥ 30	0.398	(-0.563 to 1.360)	0.41	0.007
BMI unknown	0.187	(-0.660 to 1.033)	0.66	0.002
Current smoker	0.248	(-0.559 to 1.055)	0.54	0.004
Employment	0.154	(-0.847 to 1.156)	0.76	0.001

Overall Model: $F(22,96) = 8.92$, $p<0.001$, Adjusted $R^2 = 0.60$

Continued

Table 6: **Regression analysis for illness perception and patient characteristics on Self-management, continued**

b) **SE Liver**

	β	(95% CI)	p-value	Partial R^2
Consequence	-0.083	(-0.228 to 0.062)	0.26	0.013
Timeline	-0.002	(-0.133 to 0.130)	0.98	0.000
Personal control	-0.054	(-0.177 to 0.068)	0.38	0.008
Treatment control	-0.075	(-0.208 to 0.058)	0.27	0.013
Identity	0.030	(-0.123 to 0.182)	0.70	0.002
Concerns	0.186	(0.056 to 0.317)	0.006	0.077
Understanding	-0.201	(-0.338 to -0.065)	0.004	0.082
Emotions	-0.049	(-0.196 to 0.098)	0.51	0.005
Symptoms	-1.386	(-2.172 to -0.601)	0.001	0.113
MELD	0.000	(-0.075 to 0.074)	1.00	0.000
Audit C	-0.154	(-0.238 to -0.071)	<0.001	0.122
Age	-0.006	(-0.035 to 0.024)	0.70	0.002
Male	-0.976	(-1.699 to -0.253)	0.009	0.070
Married/partner	-0.585	(-1.325 to 0.155)	0.12	0.025
Living alone	-0.584	(-1.436 to 0.267)	0.18	0.019
Ethnicity- white	0.231	(-0.659 to 1.122)	0.61	0.003
Education- degree	0.507	(-0.219 to 1.234)	0.17	0.020
Comorbidities	-0.229	(-0.835 to 0.377)	0.46	0.006
BMI ≥ 30	-0.098	(-0.956 to 0.760)	0.82	0.001
BMI unknown	-0.664	(-1.420 to 0.091)	0.084	0.031
Current smoker	-0.839	(-1.559 to -0.119)	0.023	0.053
Employment	-0.008	(-0.902 to 0.885)	0.99	0.000

Overall Model: $F_{(22,96)} = 6.21$, $p<0.001$, Adjusted $R^2 = 0.49$