An audit of patient and carer views and experiences of prevention, early intervention and treatment pathways for alcoholic liver disease in Wandsworth

Introduction

The incidence of liver disease continues to rise in the UK with alcohol use seen as a significant factor in this upward trend. Alcoholic liver disease is preventable and where the disease does occur outcomes are significantly improved with early identification and effective treatment. For those who graduate to more severe ALD the focus is on improving quality of life and life expectancy and where required choice and dignity in end of life care.

The main predictor of outcome for those with severe liver disease is complete abstinence from alcohol. For many patients there are many obstacles, both practical and psychological to meeting this requirement. Chronic patterns of alcohol use often to lead to the complete breakdown of family relationships and wider social networks can lead to social isolation or social contacts limited to other entrenched drinkers.

Effective strategies for the prevention and treatment of require a comprehensive response within a shared care framework involving a wide range of hospital and community services. More importantly an effective response to ALD can best be delivered within an integrated and coordinated ‘share care’ framework.

Objectives of Patient/Carer Audit

1. To measure from a patient and carer perspective the quality and effectiveness of existing responses to ALD in Wandsworth including interventions provided by primary, secondary and community care, addictions services and carer support.

2. To review from a patient and carer perspective areas where systems for prevention, early intervention and treatment (including palliative care) could be improved.

3. To identify possible patient carer/identified minimum standards for improving the prevention and management of ALD in a way that promotes improved outcomes and quality of life for affected adults and their families.

4. To contribute to the wider treatment pathways review for Wandsworth for the prevention and treatment of alcoholic liver disease.

Methodology

Semi structured interviews

A sample of no less than 40 adults with a diagnosis of alcoholic liver disease will be interviewed. The sample will be recruited though a number of sources including:

- Secondary care – hepatology, alcohol liaison nurses including ALD liaison nurse
- Wandsworth Integrated Drug and Alcohol Services (IDAS)
- Wandsworth Carers support centre
- Battersea alcohol service
- Local liver disease patient support group
- General Practice
- Community health services
- Hospice care teams

A semi-structured interview framework will be used to capture a range of common data and personal experiences. Interviews will cover the following areas:

- Basic demographic data including age, gender, ethnicity, housing status, family support networks.
- Alcohol history including current status e.g. abstinence, controlled drinking.
- Treatment journey from first diagnosis through to current interventions
- Experiences of different services and their response to (a) liver disease (b) alcohol use.
- Suggestions for improvements to particular interventions and the overall treatment response including areas such as communication, coordination and family support.

The questionnaire/interview schedule will be developed using a range of national standards/evidence frameworks including those for alcohol screening and subsequent clinical investigation, chronic disease, family support and palliative care.

The questionnaire will also be informed through a focus group discussion with ALD patients and carers.

1. Each interview will last 30-40 minutes.
2. Patients/carers will be sent a copy of the interview schedule, with a letter outlining the objectives and processes of the audit and ensuring them of confidentiality
3. Where feasible be held at times and locations suitable to patients and carers e.g hepatology outpatients, IDAS, BAS etc.
4. Where requested interviews will take place by phone
5. Efforts will be made to organise interview sessions at a number of venues.
6. Each patient/carer will be paid £15 for their time and any travel costs will be reimbursed.

Focus Groups

The overall findings of the interviews will be presented to two focus groups made up patients/carers. These will focus on translating data from interviews into a set of core standards and improvements in existing system/responses.

All participants will be paid for participation in a 1 hour workshop.

Required outcomes

1. A report outlining the experiences and views of patients and carers
2. A range of patient and carer proposed improvements to existing responses and pathways and suggested standards for service responses
Timescale

Interviews will be completed in February 2013 with key findings presented to (a) focus groups and (b) a clinical partnership review group in early March 2013 which will also consider the conclusions recommendations of the wider pathways audit.

A full report will be drafted and sent to Wandsworth Health and Well Being Board and Clinical Commissioning Group.

The consultants

The patient/carer audits will be completed by Alcohol Concern accredited consultants.