‘Such a bleeding nuisance’: A qualitative study into the female patient experience of mild bleeding disorders

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BACKGROUND AND OBJECTIVES

- Women represent the largest number of newly registered patients per annum in UK (UKHCDO, 2012).
- A literature review (OVID, CINAHL PLUS & PSYCH INFO) highlighted that the burden of disease within women is not well reported; studies addressed medical issues rather than psycho-social aspects of mild bleeding disorders (MBD).

A qualitative study was undertaken as follows :

1. To gain an understanding of a woman’s experience of bleeding symptoms prior to referral to a haemophilia centre (HC).
2. To obtain a woman’s perspective about the process of being diagnosed with an MBD.
3. To explore how women feel about being referred to a HC for assessment and diagnosis of MBD.

METHODS

Full Ethical and Research & Development was obtained.
Study Design – Symbolic Interactionism – analysis of symbols of shared meaning (Blumer, 1966).
Study Setting – A HC with 650 registered patients. The researcher is a clinical nurse specialist who has worked at the centre for 5 years.
Data Collection – Semi-structured interviews, recorded and transcribed verbatim, guided by a list of key topics for reliability purposes.
Sampling – 20 women were purposively selected; 8 women consented within the study’s academic deadline (see TABLE 1).
Piloting – not performed due to small scale of study and academic submission deadline.
Data Analysis – ‘Framework analysis’ as devised by Spencer *et al* (2003) using the Analytic Hierarchy of data management, descriptive accounts and explanatory accounts.

TABLE 1. SAMPLE CHARACTERISTICS

Age (in years)	Bleeding disorder	Time registered at HC (in months)	Referral method to HC
22	Factor VII	11	GP
52	Von Willebrand (type 1)	60	Haematology Conultant
42	Platelet function defect	72	GP
67	Factor XI	14	Surgical Consulstant
62	Dysfibrinogenemia	30	Orthopaedic Consultant
46	Von Willebrand (type 1)	8	Haematology Consultant
61	Platelet function defect	34	Cascade diagnosis of other family member at HC
29	Von Willebrand (type 1)	120	Medical Consulltant

RESULTS

FIGURE 1 – THEMES IDENTIFIED THROUGH FRAMEWORK ANALYSIS OF PARTICIPANT INTERVIEWS

Description and Impact of Symptoms
- Physical symptoms - menorrhagia, bruising, anaemia, depression
- Agreement with description of bleeding disorder as 'mild '
- Negative impact on work, relationships, friendships
- Concerns over siblings, daughters, grandchildren
- Self-discount of symptoms

Diagnostic Odyssey and Medical Uncertainty
- Complex testing process, possible denial of symptoms by Health Care Practioners (HCP)
- Possible incorrect advice and diagnosis
- 'Trial and error' with treatment
- Patient's high level of involvement managing with medical care

Varied Experiences within health care services
- Patient monitoring of health care advice
- Greater risk of recieving inappropriate care
- Disengagement- cancelled procedures, dismissive attitudes from HCP
- Positive views of care delivery through HCs and endorsement of registration with MBD

CONCLUSIONS and RECOMMENDATIONS

- Women are affected physically and psycho-socially by MBD. Diagnosis may be difficult due to pre-existing health beliefs of symptoms as normal.
- Women’s services need to be integrated into the current UK health service model to audit and commission further research into patient care.
- Activity within specialised models of care needs to incorporate educational and advisory services to external stakeholders to improve provision of care for women with MBD.

REFERENCES:

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