

The Experience of Bedwetting in Adolescents and Young Adults

Master's research proposal by Glenice Wilson.

AIM

The aim of this study is to describe the experience of nocturnal enuresis (bedwetting) in adolescents and young adults.

Specific Research Objectives

To describe the experience of nocturnal enuresis with regard to:

1. Education, work and social activities,
2. Relationships and social interactions within the family,
3. Relationships with friends.
4. The establishment of personal and intimate relationships.

BACKGROUND

Many health care professionals lack in-depth knowledge about the causes and management of incontinence and bedwetting, and passively accept the symptom in people who come into their care. All nurses deal with incontinence at some time in their career, and recognise only too well the wet bed, the puddle on the floor, and the tell-tale odour (Norton, 1996). In recent years with the advent of Continence Foundations and Nurse Continence Advisors in the United Kingdom, Europe and Australasia, both the public and professionals are talking more about the subject. Nurses are at the 'coal face' of dealing with bed wetting, and other incontinence problems, which are often disclosed to them during assessment. Where Nurses at one time provided 'custodial' care to keep the patient as clean and comfortable as possible there is now a wide range of nursing interventions and equipment available. The Nurse is in a prime position to inquire of the patient their bladder/bowel habits, and it is the empathy, understanding and knowledge that it essential to assist the person who is reluctant to seek assistance.

Nocturnal enuresis is defined as the involuntary loss of urine at night when the individual is sleeping Norgaard (1991). The problem is common in childhood, with most children growing out of it by school age. In a small number of otherwise usually healthy individuals the problem continues through the teenage years into adulthood. Nocturnal enuresis is often classified into primary nocturnal enuresis where full urinary continence has never been achieved by age five years; and secondary nocturnal enuresis in which the person has had at least three months of dryness at night.

In Australia the prevalence of adult nocturnal enuresis (ANE) is unknown. There has not been a study of nocturnal enuresis in adults in Australia, but a survey in Scandinavia suggests that 1-2% of young adults are affected and in many instances the problem persists as long as they live (Djurhuss, 1992). This result was supported by McInerney et al. (1991) who estimated that nocturnal enuresis affects about 10% of six year olds, 3% of 12 year olds and 1% of adults. Belmaker & Bleich (1986) estimated the prevalence of nocturnal enuresis in men 18-20 years in several studies to be 2-3% and noted that all of the cases had suffered considerable adverse social consequences.

Of the two most comprehensive population studies to date, Yeung et al. (2002) investigated the prevalence and characteristics of ANE in Hong Kong, using a random sample of 8534 subjects aged 16-40 years, who were interviewed by telephone. To decrease the social sensitivity of the study and to establish rapport with the respondents the first part of the study questionnaire covered only general demographic background factors. The more sensitive information was collected using a confidential information line service that was pre-recorded and allowed the respondents to key in their responses. This section included ANE symptoms and the social and psychological impact of ANE on the affected individual. The authors concluded that 1.9% of Hong Kong adults aged 16-40 years had symptomatic primary nocturnal enuresis with 53% wetting more than three nights per week, and 26% wetting every night. Yeung et al. reported that 40% of respondents with ANE felt that there was some effect on their choice of work, work performance and social activities, whilst 23% felt the condition affected their family life, intimate relationships and making friends.

The second of the studies by Hirasings et al. (1997) was a population based study in The Netherlands on The Prevalence and characteristics of Adult Nocturnal Enuresis. 13,081 adults were randomly chosen from 6 million community dwelling non-institutionalized residents. 11,406 (87%) agreed to participate in the study and were visited at home by trained interviewers. To provide privacy the respondents operated a personal computer to answer 23 questions about enuresis. Questions included those of

symptoms, treatment and perceived impact on quality of life. The authors found that ANE was associated with great psychosocial impact, stating that 30% of respondents were concerned & saddened about wetting the bed at night and reluctant to go on holiday and 23% commented on complications with relationships. Despite the impact on their lives 40% had never consulted a care provider, although 30% believed that nocturnal enuresis was treatable.

In other reviewed literature, Feneley (1987) concluded that the prognosis of ANE was poor; that is, symptoms persisted for years and perhaps for life with little prospect of spontaneous resolution. In a qualitative study by Hindmarsh & Bryne (1980) the hidden nature of ANE was found to be due to a reluctance to seek help, embarrassment about the problem and ignorance of the help available. They found that people suffering from ANE generally perceived their problem as one to be dealt with personally in private rather than a proper target for medical intervention. In fact, evaluations of treatments for nocturnal enuresis in adolescents and young adults such as multimodal therapy with antidiuretic hormones in combination with equipment such as bell and alarm mats have been favourable. Lackgren et al (1998) in a seven-year follow-up of 25 patients aged 11-21 years concluded that oral medication had a 76% success rate. A personal paper by DeGraff (1992) in the *Lancet*, gave the perspective of a bedwetter who had sought assistance for his problems from general practitioners, urologists, psychologists, neurologists and the alternative health fields, to finally at the age of 41 years find cure with the use of medication.

Of great significance to this study is the research completed to date by Richard Butler, a researcher from the Department of Clinical Psychology, Leeds Community and Mental Health NHS Trust, Leeds, UK. Butler's earlier findings (1994) strengthened the view that the child's attitude, outlook and stance towards nocturnal enuresis needs to be taken seriously, for example beliefs about bedwetting, impact on lifestyle, self image, perceived tolerance by their parents and the implications for becoming dry. More recently however Butler (2001) in his review of understanding the psychological impact of nocturnal enuresis, suggests that some children do appear more vulnerable to the effects of bedwetting, including boys, those with severe socioeconomic disadvantage, and those with associated daytime wetting.

In Western Australia children aged 5-14 years with nocturnal enuresis are offered treatment and community awareness of avenues for help are well established. However, anecdotally it is believed that many children fail treatment or relapse later in life, although the exact magnitude of such failure or relapse is unknown. By comparison, the avenues for helping young adults with nocturnal enuresis are poorly defined, despite the fact that new modalities of treatment may be effective.

RATIONALE & SIGNIFICANCE

A small qualitative pilot study performed by the researcher in 1996 has highlighted the deleterious impact of this condition on affected individuals. Eleven participants aged 16 to 47 years (average 27 years) with known ANE were interviewed using a purpose - structured questionnaire. There was a family history of nocturnal enuresis in 7 of 11 participants (64 %). The ages at which the participants first sought medical attention ranged from childhood to 32 years. Five of the 11 had sought medical attention by the age of 20 years. Most of the participants had presented to their GP due to social pressures such as embarrassment at school camps, boarding school or sleep over parties. The participants who first sought attention at an age older than 20 years attributed the delay to embarrassment, and thought they would eventually 'grow out' of the problem. Two participants had only recently become aware that medical help was available for their problem. Participants reported that ANE had a significant impact on their quality of life. For example, ANE led to divorce for two people, isolation in the workplace for another, homelessness for yet another, and an inability to form intimate relationships for one participant. It was widely reported by participants that ANE had a substantial impact on educational, work, and social activities.

There is no literature that has investigated the psychosocial impact of bedwetting on adolescents and young adults. The knowledge and understanding gained in this project will make a significant contribution to creating awareness among nurses and other health professionals. It will also contribute to future clinical pathways to nursing care.

RESEARCH PLAN AND METHODOLOGY

As there is little published literature concerning the psychosocial impact of nocturnal enuresis on adolescents and young adults, a phenomenological approach is the methodology of choice. Following the appropriate Ethics approval, this would allow the researcher to investigate the study's intended

objectives by interviewing participants concerning their experiences. The phenomenological method has value in exploring the meaning and perceived structure of any event or experiences that affect human beings. It has been implemented in many areas, and draws meaning from complex realities through careful analysis of narrative, subjective materials. Essentially the goal of qualitative research is to document and interpret as fully as possible the totality of whatever is being studied in particular contexts from the peoples' viewpoint or frame of reference.

Participants between the ages of 18 and 25 years will be recruited through advertisements placed in community newspapers in Perth, Western Australia. After obtaining informed consent, participants will be asked to recount their personal experience of bedwetting as an adolescent or young adult. Tape recorded interviews will be conducted with all participants, tapes will be transcribed, common words and phrases will be grouped together, and various themes will be identified.

In summary, due to the the 'taboo' nature of the subject, the impact of ANE on the quality of life of adolescents and young adults is unknown, although there are grounds to suspect that the impact on psychosocial functioning is significant. Consequently the loss of quality of life of those suffering from ANE and the cost to society through the impact on education, work and social activities is likely to be substantial.

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