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Addressing information needs of vulnerable communities about incontinence: A survey of ten CALD communities



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Summary Urinary incontinence is a common and distressing condition. Using focus groups, we explored the views of ten ethnic language groups in Melbourne about knowledge and awareness of incontinence. The 218 participants (with or without incontinence) spoke with trained interpreters. Twenty focus group discussions of single and mixed sex groups were audio-recorded and transcribed into English. Narratives were analyzed using thematic analysis with open coding and also incorporated themes from literature. Participants' knowledge of incontinence was low and incontinence was thought to be an inevitable consequence of ageing. There was little understanding of treatments or assistance available under government-funded programmes. No group was aware of the national continence programme or phone helpline. Sensitivities of the topic plus language barriers in immigrant culturally and linguistically diverse communities may impose barriers to accessing help. Several groups thought they would cope with incontinence by themselves, while all groups suggested they would be able to discuss the condition with a doctor. Various preferences voiced about social limitations and permissible communications with others are described. Nurses should be aware of the needs and communication preferences of ethnic language groups regarding continence information and continence service delivery. © 2013 Australian College of Nursing Ltd. Published by Elsevier Ltd.

Introduction

While incontinence is a common health problem, studies show that many individuals choose not to seek help for this condition (Hagglund & Wadensten, 2007; Harris, Link, Tennstedt, Kusek, & McKinlay, 2007). Incontinence is a highly

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burdensome condition that primarily affects women that is regarded as occurring in older age groups (Hunnskaar et al., 2000). It is often treatable – but if left untreated, can have significant negative impact on a person's quality of life (Shaw, 2001).

Various migrations to Australia since World War 2 have resulted in culturally diverse communities, with many people in these groups now reaching older age: 65 years or more (Migliorino, 2010). African, Middle East and Asian overseas born groups make up in total one-quarter of Australians (Australian Bureau of Statistics, 2006). These culturally and linguistically diverse (CALD) communities present a dilemma for health and social care services in regard to provision of culturally appropriate services (Radermacher, Feldman, & Browning, 2008). There is evidence that individuals with incontinence from various cultural groups such as these have low levels of help-seeking behaviour for incontinence (as will be discussed below), and that they are under-utilizing supportive healthcare services that are available. We report the views of CALD community members from 10 ethnic groups about issues around management of incontinence.

Incontinence is defined as the involuntary leakage of urine (Abrams, Cardozo, & Fall, 2002), with a number of studies using symptom severity as an indicator. Prevalence of incontinence in Australia is estimated at 24%, or 1 in 4 of the population who will experience urinary incontinence at some time in their lives (Australian Institute of Health and Welfare (AIHW), 2006). In this report we refer mainly to urinary incontinence (UI) as this is more common than faecal incontinence in community-dwelling individuals. While recent estimates for UI in Australia report 24% overall prevalence (Hawthorne, 2006), internationally, a number of prevalence studies of UI have been conducted with reports of 10–40% prevalence in adults (Hunnskaar et al., 2000). These figures vary owing to differences in terminology and in the survey methods (Abrams, Andersson, & Birder, 2009). Stress incontinence (leakage on effort or exertion, or on sneezing or coughing) is associated with a weakening of the pelvic floor (Shaw, 2001) while urge incontinence is leakage accompanied by urgency. This results from uninhibited contractions of the bladder (Abrams et al., 2009). A third type of incontinence, voiding dysfunction is a result of poor bladder emptying. Any of these conditions can have considerable impact on a person's quality of life and lead to social isolation through a need for frequent toileting (Hampel et al., 2004).

Risk factors for incontinence in recent investigations have identified, ageing, being female, pregnancy and childbirth, obesity, functional impairment and common chronic health problems such as diabetes (Abrams et al., 2009). Numerous studies have focused on women as the most prevalent UI group. Among ethnic communities there can be both a stigma attached to people with incontinence and a belief that nothing can be done to treat it (Doshani, Pitchforth, Mayne, & Tincello, 2007). Because of these beliefs and a view that it is not serious enough to seek professional help, there is a lack of help-seeking behaviour. A study of over 17,000 incontinent women in France, Germany, Spain and the UK reported a lack of treatment-seeking behaviour, with only around one in three women seeking a consultation with their general medical practitioner (O'Donnell, Lose, Sykes, Voss, & Hunnskaar, 2005). Studies consistently report

this issue. In USA, Harris et al. (2007) found in a study of 459 ethnically diverse women and men with UI, one-third had ever sought medical care for it. A study in the UAE found almost half the women believed UI was caused by paralysis and/or other neurological disorders, with women also perceiving that UI was normal, or untreatable (Rizk, Shaheen, Thomas, Dunn, & Hassan, 1999). Among Chinese women, seeking help from a doctor was often seen as wasting the doctor's time because of the view that UI was a social or hygiene problem (Li, Low, & Lee, 2007). South Asian Indian women in the UK felt that nothing could be done about UI and they would accept it as part of ageing (Doshani et al., 2007). Of 30 Moslem women immigrants living in Holland, 17 had consulted a GP about UI, with others who had not done so being unaware that a GP could offer any treatment (van den Muijsenbergh & Lagro-Janssen, 2006). Swithinbank, Donovan, Shepherd, and Abrams (1997) offered an alternative view: that some people were not bothered by UI and might not wish to receive help. Nevertheless, in a five-country European study, Monz et al. (2005) found that "information about service provision in Europe for women with urinary incontinence is limited and makes it difficult to understand barriers to treatment seeking ... for this widespread and under-recognized condition" (p. 3).

The present study was initiated as a needs assessment regarding local support services for people with incontinence in Victoria, Australia. The study aimed to explore the experiences of various ethnic community members about urinary or faecal incontinence and to further inform professionals in health, ageing and community organizations how to meet the continence needs of people from ethnic communities.

Methods

A qualitative research design using focus groups was chosen to explore incontinence issues. This technique can enable insights into understanding the specific needs of individuals and provides better quality information than other types of survey (Polit & Beck, 2012). Furthermore, the focus group method is particularly suited to use with culturally and linguistically diverse groups to understand their perspectives (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007).

Sample selection was based on analysis of current Victorian CALD populations. Overseas born, age groups and groups with low English proficiency in Victoria were examined (Australian Bureau of Statistics, 2006). The following cultural groups that ranked highly according to indicators were selected for inclusion: Arabic speaking, Chinese, Italian, Greek, Macedonian, Polish, Russian, Spanish speaking, Turkish and Vietnamese.

Recruitment of participants

Recruitment was achieved through liaison with ethno-specific organizations to access social clubs and interest groups. The Ethnic Communities Council of Victoria provided contacts for the respective communities around Melbourne. Translated project information (including purpose of the focus groups and a question schedule) was passed on to

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