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Review article

Exploring the experiences of parents caring for infants with developmental dysplasia of the hip attending a dedicated clinic

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ABSTRACT

Specialised DDH (developmental dysplasion of the hip) clinics are developing around Ireland but are, however, variable in how they are operated. A DDH clinic was set up in the South-east of Ireland in 2002 with the goal of achieving an integrated care pathway between the orthopaedic surgical team and nursing team, working to an explicit protocol while also fostering a strong collaboration with the ultrasound department. This paper aims to explore the effectiveness of this dedicated clinic in the Southeast of Ireland.

Introduction

A DDH (developmental dysplasia of the hip) clinic was established in the Southeast of Ireland in 2002 aimed at examining and treating infants referred with suspected DDH. The clinic sees more infants each year with suspected issues, with new referrals reaching approximately 300 both in 2014 and 2015. In addition to recalls, this gives a total number seen in clinic of approximately 2000 per year.

Literature review

DDH, formerly termed congenital dislocation of the hip (CDH), describes a range of anatomic abnormalities in which the femoral head and the acetabulum are aligned improperly or mature abnormally (USPSTF, 2006). DDH is a poorly understood disorder as evidenced by the abundance of literature, both recent and historical, on the topic (Klisic, 1989; Mahan et al., 2009; Bracken et al., 2012; Shorter et al., 2013).

DDH is one of the most common congenital defects in the newborn and is a leading cause of childhood and adult disability (Gelfer and Kennedy, 2008). It accounts for 9% of all hip replacements; a quarter or more being performed on patients under the age of 60 (Engesaeter et al., 2011). What is largely agreed across the literature is that, if DDH is diagnosed and treated early, the risk of significant morbidity is reduced (Stein-Zamir et al., 2008). However, despite best practise, young adults still present with hip dysplasia that was not detected at birth or in the newborn period (Schwend et al., 2014).

Late diagnosis is considered to be DDH which has not been detected in the first 3 months of life (Sharpe et al., 2006; Woodacre et al., 2013); however, interpretation of rates of late diagnosis can often be difficult in relation to the strict definition and age of diagnosis (Sharpe et al., 2006). Late diagnosed or persistent DDH is increasingly recognised as a leading cause of significant long term morbidity including: impaired walking, chronic pain and premature degenerative joint disease, (Holroyd and Wedge, 2009; Sewell et al., 2009; Sewell and Eastwood, 2011; Clarke et al., 2012) and can affect patients socially, functionally and psychologically (Flynn, 2016).

The reported incidence of DDH worldwide varies widely from 1.4 to 35.0 cases per 1000 live births (Mahan et al.,2009). The epidemiologic literature regarding DDH is vast and confusing due to various definitions of hip dysplasia, different methods of diagnosis, ages of the population studied, clinical experience of the examiner, ethnicity of the population being examined and different geographic locations within similar ethnic populations (Bracken et al.,2012). The situation in Ireland is even more uncertain and the literature contains only a small number of papers from the Irish

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setting. While it is believed that there is a high incidence of late diagnosis of DDH in Ireland (Gul et al., 2002), evidence is lacking as to whether this is due to a high natural incidence in the Irish population, or to poor screening and poor early management of the condition.

The overall incidence of DDH in the Republic of Ireland is unknown. However, Phelan et al. (2014) carried out a retrospective study of all cases of DDH in children born between 1st January and the 31st December 2009 in the south-eastern region of Ireland. Of the 8317 live births in the southeast region in 2009, 56 cases of DDH were diagnosed; giving an incidence rate 6.73 per 1000 live births. Donnelly et al. (2015) recently reported an overall incidence rate of 8.5 per 1000 births in a similar population in Northern Ireland.

No international or Irish guidelines or algorithm currently exist for the screening and treatment of DDH (Feeley et al., 2014). The National Clinical Programme for Paediatrics and Neonatology (Paediatric/Neonatal Programme), which is a joint collaboration between the Health Service Executive (HSE) Clinical Programmes and Strategy Directorate and the Royal College of Physicians of Ireland (RCPI), recommended that national guidelines be developed as soon as possible.

The Paediatric/Neonatal Programme has highlighted the concerns of a number of medical and non-medical sources regarding the failure of newborn screening programmes to detect or identify conditions and anomalies at a stage when treatment could be more effective (HSE, 2013). The discrepancy in the management and detection of DDH has been of particular concern. Only 9 out of the 19 hospital units in the Republic of Ireland have access to hip ultrasounds at 6 weeks of age, while the other 10 units have to wait for a hip x-ray at 5 months of age (HSE, 2013), thus losing vital time to treat infants for DDH.

The American Academy of Pediatrics (AAP, 2000) also suggests that early intervention resources be utilised and that key disciplines are brought together to provide a high quality skilled service for children who are at risk both developmentally and medically. The successful use of integrated care pathways (ICPs) has been shown to have a positive influence on the quality of service that is enabled by the enhanced communication between all members of the multidisciplinary team which in turn can lead to improved patient satisfaction (Beazley and Brady, 2006).

The literature lacks information on parental issues and attitudes regarding DDH services and caring for a child being treated for DDH (Hassan, 2009). Parents play a pivotal role in the doctor-parent-child relationship, where parents are relied upon as the source or voice of information about their child's health status (Tates et al., 2002). Satisfaction with health services is known to be associated with positive patient behaviour, including the use of preventative health services (Halfon et al., 2004). Satisfaction is, in turn, considered to be an important predictor of health related behaviour by, for example, influencing parents' commitment to, and effectiveness of, recommended treatment for DDH (Witting et al.,2012). It has also become an important factor in the evaluation of health services (Bergenmar et al., 2006).

The psychosocial consequences for parents regarding the screening and treatment policies of DDH are potentially important in the management of DDH. Parents will often feel overwhelmed when a new diagnosis of DDH is made or when a treatment is initiated. A lot of information is given to them regarding diagnosis, treatment, possible failure of treatment and possible surgery if early treatment fails which can be a lot for parents to absorb (Causon, 2010). Coming to terms with the diagnosis of DDH and the need for treatment may invoke feelings of guilt and stress that their child has been affected (Causon, 2010). The role of the nurse as a support person is often critical for a successful outcome to be achieved (Hart et al., 2006).

The condition poses tremendous challenges for caregivers and impacts on nearly every aspect of parent and family lives such as work, transportation, skin care and feeding (Gardner et al., 2005; Hart et al., 2006). Continuity of nursing care in a specialist nurse led paediatric clinic for hip dysplasia, from the first consultation and throughout treatment to on-going follow-up visits has been shown, in a previous study, to yield high levels of satisfaction among the parents of the infants (Lee, 2005).

It can be concluded that DDH remains a poorly understood disorder despite a great deal of research being carried out on the subject. To date, there is very little literature pertaining to the parents' perspective in relation to caring for a child in a Pavlic harness or Boston brace. Furthermore, much less is known about the impact of caring for a child with DDH within the Irish healthcare setting. Consequently, the aim of this study was to investigate the experience of parents of infants with DDH attending a dedicated clinic in the south-east of Ireland.

Method

Following a review of the literature and with consideration of the aim of the study, it was deemed that a mixed methods framework was most suitable, integrating quantitative and qualitative tools to foster a greater understanding of the experiences of parents attending a DDH clinic with their infants.

A twenty-three question parent satisfaction survey including a Likert scale was constructed. The questionnaire was modelled on Lee's (2005) satisfaction survey and Gardner et al.'s (2005) Hip Worries Inventory. With permission, both instruments were modified to suit the study. It was hoped that the questionnaire would elucidate the experiences of parents of children revieving treatment in the dedicated DDH clinic.

Ethical approval was granted from the local Regional and College Ethics Committees in May 2014. A pilot study was undertaken in the clinic in October 2014 involving ten parents of infants with DDH to assess the acceptability of the questionnaire, to check for ambiguities in relation to the understanding of the questions and to investigate the length of time for completion of the questionnaire. Following evaluation of the pilot questionnaire, minor editing changes and revision of the overall layout were made prior to the main study. Nonprobability convenience sampling was used to select study participants. A three-month data collection phase between November 2014 and January 2015 was agreed upon. Mothers and fathers who attended the clinic for the first time during this period were invited to complete the questionnaire. Due to the high volume of weekly and fortnightly repeat visits, an average of 10 new families attended the clinic per week during this time frame. After three months, one hundred questionnaires had been administered. A response rate of 100% was achieved as one hundred questionnaires were returned to the researcher.

To establish internal consistency and reliability of the research questionnaire in this study, the Cronbach's alpha was calculated. The result (0.80) indicated the questionnaire as an accurate measuring tool. Statistical analysis included the Mann-Whitney *U* test which was carried out using a two-tailed significance of 5% using the statistical packages SPSS 21.

Findings

Demographic details of infants attending DDH clinic

Eighty percent of the infants attending the clinic were female. Table 1 illustrates the age of diagnosis of infants who attended the clinic. The majority of infants were diagnosed within 13 weeks of

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