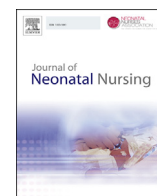




Contents lists available at ScienceDirect

Journal of Neonatal Nursing

journal homepage: www.elsevier.com/jneo

Primary care givers of infants on home oxygen therapy

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ARTICLE INFO

Article history:

Received 7 October 2016

Received in revised form

5 February 2017

Accepted 12 February 2017

Available online 3 March 2017

Keywords:

Home oxygen

parent's feedback

Parents experience

Infants/babies on home oxygen

ABSTRACT

The study was conducted to identify problems experienced by primary care givers of infants on home oxygen and to examine if support given within the neonatal unit and community setting's by health care professionals, made an impact to primary care givers in order to cope with their infant's home oxygen therapy. The results from this study highlight the importance of follow up and support especially when families are caring for their baby on home oxygen therapy.

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Introduction

Having a baby admitted to the neonatal unit can be a huge cost (NCT, 2009), to the National Health Service and also to the family. A randomised trial by Casiro et al. (1993) identified that there is emotional and psychological benefit for the family and infant's development, when the baby is discharged early from the neonatal unit (cited by Bathie and Shaw, 2013). The London Neonatal Operational Delivery Network (2016) recommends as part of their objectives, that mothers and babies should receive the care they need, as close to home as possible. Therefore, the role of the community neonatal nurse plays an important part in facilitating early discharge from the Neonatal Unit as this would increase cot availability and reduce costs for the parents.

Moreover, it is a positive step forward for neonatal units with the support of Community Neonatal Nurses or Children's Home Care Team to aim for early discharge for the complex infant on home oxygen. Although, there is evidence that most parents suffer increased stress during their baby's first year of life, and this could contribute to the infant's behavioural problems later on in their life (Ghorbani et al., 2014). This suggests that, when parents have a preterm baby this could be identified as a source of trauma and distress (Ghorbani et al., 2014). Consequently, the event can be

expressed as an emotional crisis, that would be felt by the parents as a sense of loss and sorrow, lasting for months after the baby is discharged from the Neonatal Unit (Ghorbani et al., 2014).

Our study was conducted to identify problems experienced by primary care givers of infants on home oxygen and to examine if support given within the neonatal unit and community settings by health care professionals, made an impact to primary care givers in order to cope with their infant's home oxygen therapy.

Method

The study was a phenomenology survey, that addressed the lived experience of parents/primary care givers of infants on Home oxygen therapy, through semi-structured questionnaires. The study period was twelve months between January 2010 and April 2011. Based on the nature of the study as a quality improvement project and according to the Trust policy, formal ethical permission was not deemed necessary. The decision for Home Oxygen was based on the local guideline that the infant needed low flow oxygen to maintain saturation above 93%, when feeding, sleeping and playing. Furthermore, may have failed at least one attempt of weaning off oxygen on the Neonatal Unit.

All authors set the questions based on previous verbal feedback from parents' experience when their baby was discharged on home oxygen therapy. Therefore, this was used as a form of piloting the questionnaire, by checking how long it took to answer the questions, and only based on previous parental feedback. The community

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neonatal nurse, reviewed the questions to ensure there were applicable to the specific group setting, unfortunately there was no parent rep linked to the neonatal unit to assist in the survey development. One author had knowledge of discharge process and follow up, including the support given to the families. Another author had reviewed some of the infants on the neonatal unit prior to discharge home. Finally, one author was neutral due to the fact, had minimum involvement in any of the infants discharged, medical care. All authors remained anonymous, in order to avoid any influence in the feedback process.

Study eligibility

The participants were the parents or carers of infants who fulfilled all the following: i- Discharged from our Neonatal Unit on home oxygen; ii- infant less than one-year-old; iii- Residents within the North-East London and iv- Had follow up by the Community neonatal service or local Children's home care team; v- Attended at least two outpatient's oxygen clinics. Parents and/or carers of infants with any of the followings were excluded: i- Discharged from paediatric ward; ii- Nasogastric tube feeding; and iii- Weaned off oxygen as inpatient.

The questionnaires were sent out by post once to all eligible participants with a return stamped addressed envelope included. The questionnaire had twenty-two items, and answers were categorized into agree; strongly agree; disagree and strongly disagree.

The questionnaire addressed the use of portable oxygen equipment and covered wide range of items including discharge planning meetings, safety issues and participant's ability to cope with practical issues that are directly related to administering home oxygen therapy.

The use of a questionnaire can be defined as a form of psychometric instrument, to measure an aspect of the human psychology (Greenhalgh, 2014). Therefore, the key is to aim for more than 70% of people to have properly completed the survey (Greenhalgh, 2014). A few of the possibilities of achieving this would be by having a clearly designed and simple, thoroughly piloted and tested questionnaire, personalised invitations for participants, researcher on hand to answer questions and if using a postal questionnaire, a stamped addressed envelope included (Greenhalgh, 2014). Evidently, our study choose to post the questionnaires to the primary care givers, in order to gain as much openness from primary care givers, especially for collection of sensitive data.

Results

24 infants were identified for the study and had all been discharged on home oxygen therapy during the survey period. They were 15 females and 9 males and 3/24 had a sibling who was twin. 21/24 were born at less than 32 weeks' gestation and the remaining 3/24 were term infants. 16/24 (66.7%) infants were weaned off oxygen at home by the end of the study. They were 23 biological mothers and one foster parent. 6/24 (25%) participants did not response to the questionnaire. The remaining 18/24 (75%) responded to the questionnaire and all met the study eligibility.

All participants knew who to contact, if needed, in case of any questions regarding the infant's home oxygen therapy. All participants agreed/strongly agreed that the safety issues regarding home oxygen were explained and their queries were addressed to their satisfaction. 3/18 (16.5%) participants felt alone regarding the needs of their baby and would appreciate more support. 5/18 (27.5%) agreed were overwhelmed by their baby's needs and felt emotional strain. 6/18 (33%) participants agreed their family was greatly affected by the needs of their baby on home oxygen. 7/18 (39%) participants felt supported by the community neonatal nurse/

children's home care team. 4/18 (22%) participants reported difficulty with using portable oxygen outdoors.

8/18 (44.5%) participants experienced ≥ 2 of the following: i- Inability to handle emergency situation; ii- Felt alone regarding the needs of their baby; iii- Overwhelmed by their babies' needs; and iv- Life was greatly affected by home oxygen. Of these eight participants, only seven participants felt supported by the Community Neonatal Nurse or Children Home Care Team and only one felt unsupported by the either teams.

The remaining 10 participants experienced none of the above issues. Of these, nine participants felt supported by the Community Neonatal Nurse or Home Care Team; four participants reported difficulties with using portable oxygen therapy outdoors; one participant felt not supported with using portable oxygen therapy outdoors; one participant wanted to do everything on their own and one participant stated that home oxygen therapy affected their life.

Discussion

Evidently, having an infant on home oxygen is a complex process that requires planning and communication, it is therefore important to support and give information to the family when needed (Moss and Bond, 2002). Hence, the role of the health care professional is to support many of these parents during the hospital to home transition, which can be extremely beneficial to the family (Affleck et al., 1989). In addition to this, Bliss (2009) argues that parents should have access to health professionals that can provide emotional/psychological support.

Our study identified that coordinated discharged planning enabled safe home discharge and allowed parents opportunity to gain effective home oxygen teaching. Although, it is important to acknowledge that infants with complex needs require in-depth discharge planning and awareness of the difficulties the parents and infants may face at home (Reid and Scherf, 2006). The argument would be, the teachings should be tailored to specific needs of the vulnerable infant (Reid and Scherf, 2006). Consequently, the feedback from our study was mixed especially based on the statements given, other primary care givers seem to cope with outdoors, while others it was a struggle. In comparison, the Cleveland study found that mothers had experienced uncertainty in coping with their infant's care, and felt there was limited services from the community nurses in relation to follow up information, home visits and management of the baby's medical conditions (Cleveland, 2008). In contrast, our study found that support was given however some of the issues the Community Neonatal Service/Children's home care team had limited control.

Accordingly, the POPPY Project found that when mothers are discharged home with their babies they tend to feel depressed, anxiety and isolated, especially when they have been on their own all day. It is therefore, advised that they go and meet other people to be able to break up the day (POPPY Project, 2009). This point is also sustained by, the experience of a clinical psychologist, after his son was delivered 10 weeks early, stated that the Neonatal Unit can be compared to the battlefield, as it feels like a life and death experience which one becomes disorganised and upset for months or at times even for years (Hynan, 1991). In addition to this, a study by Arzani et al. (2015) found that mothers who received peer support, found it unique and learnt skills to care for their infant from each other, as it was another form of asking for help as long as it was not stressful information. In contrast, the study done by Professor Mason (1963) cited Rubin, who identified that maternal behaviour is a learnt behaviour, evolving and changing, largely dependent on nature and kinds of intimate interpersonal experiences and on the individual mother's evolving self-concept.

Although, Discharge planning meeting screening toolkit could be used, to identify the parents that need extra support. The DOH -

Table 1

Comments made by primary care givers.

Participant A “makes it awkward to go out and you can't take two babies on oxygen out on your own”
Participant B “home oxygen is mildly irritating but considering what it is for it is worth it”
Participant C “it takes longer to prepare and to be ready to go out”
Participant D “coped well and managed to do most of what is needed on my own”
Participant E “I have to stay home and take care of him because I did not want to expose him to cold and infection”

Toolkit for High-Quality Neonatal Service (2009) emphasise there should be plans to support and monitor vulnerable families in order to safeguard and promote the welfare of the baby. Our study highlighted the need to increase the specialist community neonatal nurses/home care team. In addition, our findings identified 7 primary care givers that felt supported by the Community Neonatal Nurse/Children's home care team, although some expressed the use of home oxygen equipment a bit of a challenge. However, our study found that 8 primary care givers felt at least two or more identified issues, of feeling alone, overwhelmed, inability to handle emergency situations and greatly affected by the home oxygen. Similarly, a study by Ghorbani et al. (2014) found that mothers of preterm infants had significantly higher Post-Traumatic Stress Disorder level compared to mothers of term infants. Furthermore, the effects of parents' post-traumatic stress disorder are that it could be a strong predictor of the infants' sleep and behavioural problems (Ghorbani et al., 2014). Evidently, Post-Traumatic Stress Disorder in parents of preterm infants, seem to be a challenge for a longer period than one would imagine or expect.

Similarly, the study by Kersting et al. (2004) found that PTSD in mothers of preterm infants compared to term, was significantly higher (1–3 days, 14 days, 6 and 14 months after the delivery of the infant) cited by (Ghorbani et al., 2014). For these reasons, this reveals the existence of mental health problems in parents, especially during the first 18 months of the infant's life (Ghorbani et al., 2014). The recommendation would be for health professionals to aim for more parents' consultations in order to support them during this challenging time (Ghorbani et al., 2014) (Table 1).

Clinical implication and conclusions

The relevance of this study, at the present changing National Health Service, would be that more babies will be discharged home with oxygen. What services would be of benefit to support the parents/primary care givers in order for them to feel confident to care for their vulnerable baby. Reviewing these findings, actions were taken to support parents more, by recruiting more community neonatal nurses and expanding the service to 9 am – 5 pm (7 day working). Furthermore, the guidelines were reviewed to ensure that more intense and frequent home visits the first 3–4 weeks at home, then weekly home visits from 5th week. Although, this would be depended on the infants needs and parent's ability to cope with their infant health needs and home oxygen equipment use. The Neonatal Unit has a Clinical Psychologist from the Perinatal Service, who works closely with the families to give emotional support especially during these challenging times. The Neonatal Unit also has family care nurses based on the unit – Monday to Friday, to focus on the complex infants, needing the extra support prior to discharge.

Findings from the study by Arzani et al. (2015) identified that mothers should not be forgotten after their baby has been discharged

from the hospital. However, the health service should put some support in place to teach, guide and develop the parents coping strategies, especially if the baby was born premature (Arzani et al., 2015).

Limitation

Our study had a small sample size, only recruited from one geographical area (that covers three boroughs). The method of recruitment would be the limitation, however based on that the neonatal outreach records used, any other method would have required more time and maybe funding. Furthermore, lack of participant personal details made it difficult to identify those that needed extra support.

Our study also identified issues that were not formally addressed however seem to have been contributing factors to the findings. Such factors include traumatic birth; may have been a previous bereavement; single parents; less support from family or partner; history of depression or mental health; multiple births; one or more children under the age of 5 years' old; housing problems.

Funding

This research received no specific grant from any funding agency in the public, commercial or not for profit sections.

Authors contribution

Tendai Nzirawa: literature review, study design, data collection and writing manuscript.

Mas Ahmed: questionnaire design, data analysis/interpretation, study design, writing manuscript.

Abul Haque: study design and data collection.

Acknowledgements

We would like to thank the Community Neonatal Nurses, Children Home care team, Family care team and Consultants for their continues dedication in supporting and following up the babies discharged on home oxygen within our Trust.

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