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The ROBIN project: A quality improvement initiative in the neonatal unit

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1. Introduction

The Northern Health and Social Care Trust (NHSCT) in Northern Ireland has 3500 babies born annually with approximately 230 infants admitted to the Neonatal Unit (NNU). On average 13% of infants in Northern Ireland are born premature or sick and need care in the NNU (Anderson and Constable, 2018). This is a very stressful time for parents (Malouf et al., 2022; Caporali et al., 2020). An admission into a neonatal unit is not the outcome the parents expected when they discovered they were expecting a baby (Caporali et al., 2020). Kvalvik et al. (2020) identified that 13.1% of infants born to parents after a stillbirth require neonatal care in their Norwegian study. Therefore, it is inevitable that some parents with a previous history of baby loss will require the services of a neonatal unit during their childbearing years.

Miscarriage is considered the most adverse outcome of pregnancy (Simmons et al., 2006), with 10–15% pregnancies ending in this way before 23 completed weeks of gestation (Galeotti et al., 2022). One in 100 women have three or more miscarriages in a row (Tommy's, 2022a). Stillbirth is defined by Westby et al. (2021) as in utero foetal death or death at birth beyond 20 weeks gestation. In the UK approximately eight babies are stillborn per day, equating to one in every 250 pregnancies (Tommy's, 2022b). In Northern Ireland in 2022 71 stillbirths were recorded, and 22 in the first quarter of 2023 (NISRA, 2023).

SANDS (Stillbirth and Neonatal Death Charity) introduced a teardrop sticker to be placed in maternity notes in recognition of a previous stillbirth or neonatal death (SANDS, 2023). However, neonatal staff do not have access to the midwifery notes and infants are admitted under their own identity number. The only information the neonatal unit receives is a paper copy of the computerised NIMATS (Northern Ireland Regional Maternity System) record. There is no space to place a teardrop sticker, therefore the parity of the mother could be easily missed. This is in contrast to the guidance given by the National Bereavement Care Pathway (2020), advising all healthcare professionals caring for families following perinatal loss and who now have another baby.

The emphasis on parental grieving has changed over the years - from encouraging a "letting go" of past experiences to a more modern approach (Tracey, 2022). It is now known it is important to learn to live with loss and memories (NBCP, 2020; Simmons et al., 2006), which has been shown to improve mental health and wellbeing outcomes. Anxiety and depression are still more likely to occur in women who experience the death of a stillborn baby and or a neonatal death (Westby et al., 2021). Depression was considered at greatest risk shortly after the birth (Westby et al., 2021) and is four times more likely to occur in women who have experienced stillbirth or neonatal death (Gold et al., 2016). A systematic review conducted by Westby et al. (2021) found fathers to be at significantly higher risk of developing depression after a stillbirth in comparison to other fathers at follow-ups at two and eight months after the traumatic event. The risk of developing Post-Traumatic Stress Disorder is double that of developing anxiety or depression (Westby et al., 2021) and is seven times more likely to develop after stillbirth (Gold et al., 2016).

The ethos of excellent bereavement care is based on the National Bereavement Care Pathway (Donaldson, 2018) and the Bereavement Care Standards (NBCP, 2020). These documents focus on guiding bereavement care to families in and around the time of death and in the follow up care provision. The principles of "gold standard" bereavement care require an understanding not only of the physical, psychological, emotional, social and spiritual needs at the time of death (Tracey, 2022; NBCP, 2020; Donaldson, 2018), but a foundation knowledge of how previous grief experiences can impact on future pregnancies and life events (Tracey, 2022).

However, there is little mention on how to provide the much-needed

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support necessary during an admission to a neonatal unit following perinatal loss. If not recognised and acknowledged, this could lead to poor mental health outcomes for the families (Tracey, 2022; Law et al., 2021; NBCP, 2020). While psychological support is essential, so too is compassionate and empathetic care (NBCP, 2020; Donaldson, 2018). Galeotti et al. (2022) place significance on empathetic communication by healthcare professionals at the time of miscarriage *and beyond*.

Parents feel passionately that their baby should be remembered, while trying to accept the new beginnings of a changed way of life with a new baby (Miscarriage Association, 2023; Tracey, 2022). This transition of life can be exceedingly difficult for new parents (Miscarriage Association, 2023). There is a subconscious human effort to find hope and comfort in a time of loss, of loneliness and despair (Tracey, 2022). Despite the separation caused by the bereavement, the loving bond between the baby and parents remains strong and unique (Miscarriage Association, 2023; Tracey, 2022).

Great sensitivity, good communication skills and a friendly environment are key to easing the parents' journey (NBCP, 2020; Donaldson, 2018). With the anxiety of a baby born too small, sick or at an early gestational age is an additional worry which parents may fear being asked "*Is this your first baby*?" Some parents talk openly about their experiences of perinatal bereavement while others are more reserved and cannot express their grief (Tracey, 2022; Westby et al., 2021).

1.1. Background

The need for this quality improvement (QI) initiative arose from observing an interaction between a consultant and parents in NICU (Neonatal Intensive Care Unit). He asked them a what would ordinarily be a harmless question - "Is this your first baby?" They were unsure how to answer it. The father said yes as the mother stood by his side weeping. Comfort and apologies were offered to the parents. The consultant was unaware that the parents lost a baby who had died as a result of a late miscarriage.

After deep consideration it was hoped that a simple solution could be found to prevent this from reoccurring. A simple sign on the incubator or cot would signify to staff a previous bereavement had occurred, so that the parents could be treated more sensitively. This sign would be small and dignified, but large enough for staff to notice. From this arose the ROBIN Project - **R**emembering **O**ther **B**ereavements **I**n **N**eonatal. This picture represents and acknowledges any previous bereavement the parents may have experienced through miscarriage at any gestation, termination of pregnancy, ectopic and molar pregnancies, assisted fertility loss, intrauterine death, stillbirth, neonatal death, cot-death or child death at any age. On two occasions the ROBIN picture has been adapted to represent the death of a father during a pregnancy and the demise of a grandparent during a baby's stay in the neonatal unit.

The picture of the robin could only be used if the parents gave their permission for their previous bereavement to be acknowledged. If agreeable, they placed a picture of a robin anywhere of their choice on the incubator. They were also offered a similar picture to keep with them in remembrance of their previous baby or child.

1.2. Project aim and objectives

The aim of this project was to increase to 25% over one year the number of bereaved parents (now in the NNU) who were offered a ROBIN picture in acknowledgement and remembrance of their previous bereavement losses.

The objectives were.

- To determine whether the use of such a sign would increase staff awareness
- To initiate more sensitive conversations between staff and parents
- To create an empathetic and trusting partnership with parents, providing positive memories of being treated respectfully and holistically in the neonatal unit.

Some parents avoid mentioning a previous loss, others may not know that they can chat freely about their previous losses, as well as fears and anxieties during their present admission. All parents should be given the opportunity to openly discuss their feelings about their previous losses while in the neonatal unit. If desired, help, support and counselling should be offered to them all regardless of the duration of time since the last bereavement.

2. Method

This project commenced on 1st October 2020 and finished on 30th September 2021. Data was collected in two phases using questionnaires. One questionnaire was distributed to the parents at the point of discharge and one to the nursing and medical staff.

2.1. Inclusion and exclusion criteria

Inclusion criteria for the project were.

- Parents who had experienced loss through termination of pregnancy, miscarriage, stillbirth or neonatal death from a previous pregnancy within 48 hours of admission to the neonatal unit
- Parents who lost a child due to sudden unexpected death in infancy
- Parents who had lost a child at any age, by any circumstance

Exclusion criteria were.

- Parents of infants who were not born in NHSCT hospitals and admitted directly to Antrim Area Hospital NNU
- Parents could not express their thoughts clearly in English.
- Parents who were experiencing the loss of one or more babies in this pregnancy

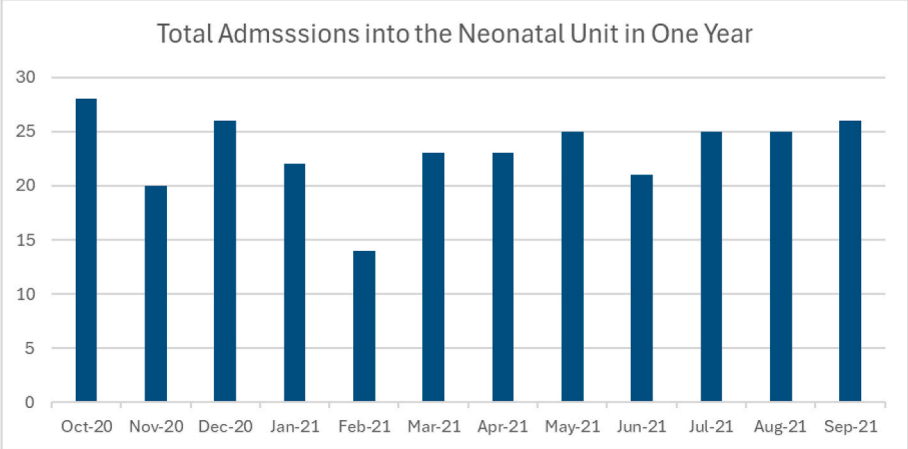
In the incidence of the final exclusion criteria, the Butterfly sign is used to signify this loss (The Butterfly Project, 2023).

During phase one there were 278 admissions (Chart 1) to the neonatal unit despite only working at 75% occupancy during the year from October 1, 2020 to September 30, 2021.

During this period 67 mothers had experienced previous pregnancy related bereavements. The majority of these had been through miscarriage, some more than once. Families were given an explanation of the ROBIN picture and offered provision of the ROBIN picture during their time in the NNU. Despite not being part of the QI project, if parents did not speak English, with an interpreter were offered and accepted the ROBIN sign too. This supported the guidance in the SANDS (2018) audit. Some parents admitted from other neonatal units also used the sign. It was important to continue to deliver a high standard of neonatal care to all families and not create a two-tiered system of care.

To achieve the aim and objectives the project required input from both parents and health professionals within the NNU multi-disciplinary team (SANDS, 2018). Staff support was integral to the project's success (Murthy et al., 2021). They were vigilant in receiving their handover reports so that any bereaved parents could be identified early, as recommended by Donaldson (2018) when parents are cared for in different hospital departments. If the experienced staff member felt it was appropriate to mention the ROBIN project, then it was left for the parents' to choose whether they wished to use a robin picture.

Phase 2 of the project was to establish staff knowledge on the ROBIN



	Oct-20	Nov -20	Dec -20	Jan -21	Feb -21	Mar -21	Apr-21	May -21	Jun -21	Jul-21	Aug -21	Sep -21
Number of admissions	28	20	26	22	14	23	23	25	21	25	25	26

Chart 1. Admissions to neonatal unit from 01/10/2020–30/09/2021.

project. A second questionnaire was produced in January 2021 and distributed to the staff. Information regarding the use of the ROBIN was placed on a parent education board which also substitutes as a staff education board. This was an ideal opportunity to relay the information about this service to both staff and to bereaved parents. In some cases, it initiated conversations between parents in the same room. It also gave bereaved parents who had been admitted from other hospitals the opportunity to ask for a robin, as this was new to them.

3. Results

Only 40 of the 67 (59.7%) bereaved mothers were asked about using a ROBIN sign. This was due to the inexperience of the staff and the lack of awareness of the sign caused by the temporary redeployment of staff. This is in alignment with the guidance in the SANDS audit (2018), highlighting the significance of staff training in regard to bereavement care.

The majority of the parents agreed to the use of this symbol (n = 38). Many were grateful that their previous pregnancy had been acknowledged and that all the family members had been included in the celebration of the new life of the baby who was now in the neonatal unit. Several parents thought that the use of a robin sign was a lovely and special way to remember their babies. Two families declined the use of the sign but completed their questionnaires and 38 families accepted the use of this sign.

The number of ROBIN signs in use increased over the last months of this project. This may just be coincidental. However, it could mean staff familiarity of the benefits of the ROBIN project increased, and they tended to ask the parents' permission to use the sign more regularly. The sign has been used successfully in alerting nursing and medical staff of the previous bereavement. It has also been viewed as a positive step in improving the quality of care and wellbeing of the parents by the resident clinical psychologist.

The percentage of parents consenting to use a ROBIN picture during the duration of this project (Chart 2) did show one upward trend between January 2021 and May 2021. The data demonstrated a reduction in the number of parents who were not informed about the Robin picture hence missing out on the opportunity to use it. Realistic live data will always vary due to several factors such as the number of bereaved parents who require the services of a neonatal unit during a future pregnancy and parental choice.

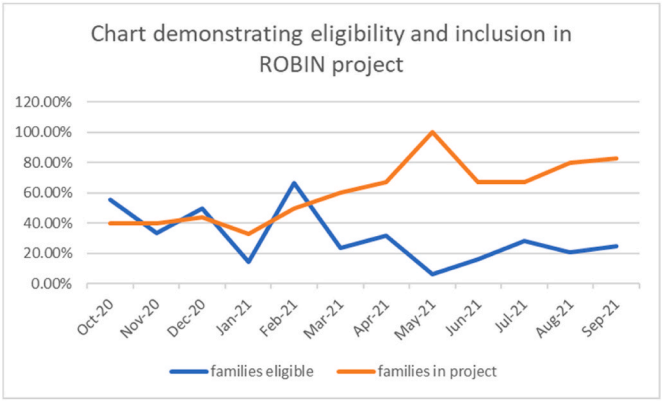


Chart 2. Families engaged in the ROBIN Project.

There were 60 staff (46 nursing staff which included six enhanced neonatal nurse practitioners (ENNP) and two advanced neonatal nurse practitioners (ANNP), ten medical staff, two healthcare assistants, and 2 allied health professionals). There were 20% of the nursing staff off during the project due to sickness and maternity leave. The ANNP and ENNP nurses take on more of a medical role, therefore only 34 nursing staff were more likely to inform the parents about the ROBIN sign. Nursing staff agreed that it helped initiate conversations with the parents which is an achievement when working towards improving good neonatal practice.

Medical staff felt they were prompted to inform parents about the ROBIN. Six found the symbol useful as it drew their attention to the fact that parents had a previous bereavement history when updating them during the ward round. Two allied health professionals found the sign to be an effective prompt during their consultations with the neonatal parents. The others in their roles are not in a position to ask parents about the use of the sign.

All the returned questionnaires were analysed with many positive comments being received. Questionnaires underwent thematic analysis, identifying twelve common themes from the parents' comments (Chart 3).

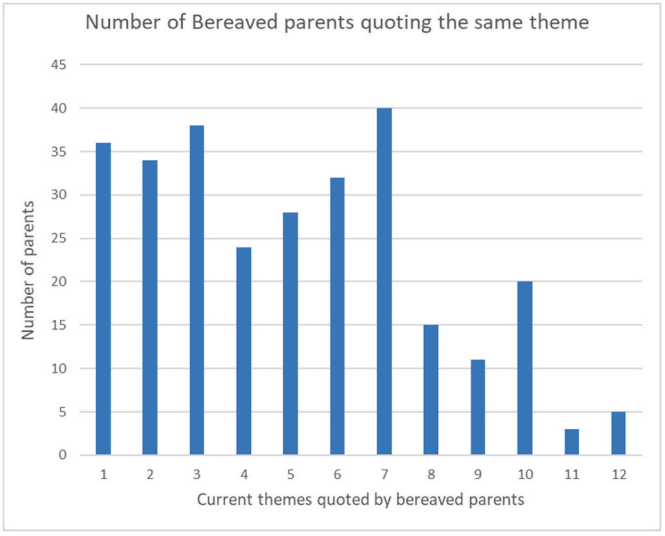


Chart 3. Thematic analysis of questionnaires.

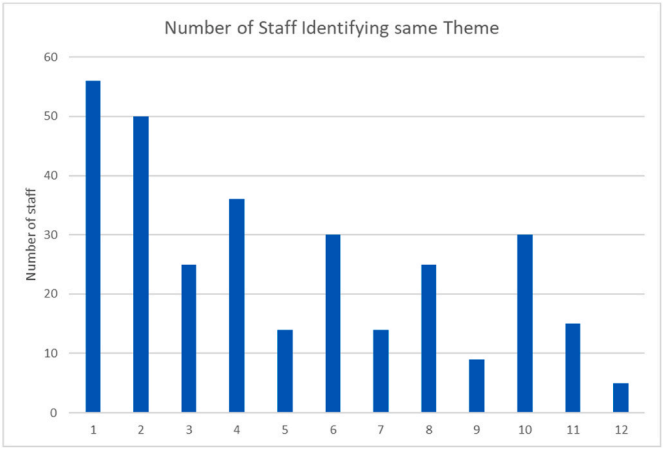


Chart 4. Thematic analysis of staff responses to questionnaire.

(1) Special way to remember our baby.
(2) Feels as if all the family members are included.
(3) Don't have to explain my story over and over.
(4) Nurse included my baby in the conversation.
(5) My previous loss has been acknowledged.
(6) Such a special and thoughtful thing to do.
(7) A lovely idea.
(8) Shows the staff are caring and compassionate towards us.
(9) Appreciate the memento in remembrance of our baby.
(10) Helps us to feel more at ease, more relaxed during our visit.
(11) Felt less isolated after observing other parents had the same sign.
(12) Showed others thought about my baby too.

Parents stated that they felt more at ease, as they did not constantly have to remind the nurses and doctors that they had previously experienced the death of a baby. Some parents felt that the staff who had the foresight to initiate the conversation were experienced nurses who had shown sensitivity and the parents felt that they were actually cared for as well as the new baby. This provided them with a more positive outcome and great memories of the standard and quality of care given to them all as a family (Chart 4).

Only on two occasions the parents decided not to use the picture. One mother wanted to forget that she had a previous early miscarriage, as it had occurred several years ago. The other parents were going to call their newborn daughter Robyn, but they stated that they thought it was a lovely idea and wished every success with the project.

(1) Helped recognise parents previous experience	56
(2) Initiated conversations with parents	50
(3) Eased conversations with parents	25
(4) More time spent listening to parents	36
(5) Provided more support to parents	14
(6) Showed greater sensitivity when speaking with parents	30
(7) Staff more aware of parents feelings	14
(8) Initial approach likely to be more cautious	25
(9) Made more allowances for parents being uptight	9
(10) Good to acknowledge the parents grief	30
(11) Helped form better relationship with parents	15
(12) Felt that full integrated family care was offered	5

4. Discussion

Some parents are forced to relive their previous trauma when their newborn baby is admitted into a neonatal unit (Law et al., 2021). This unique grief of losing a baby is the worst type of grief as often all the parents' dreams and aspirations are lost (Tracey, 2022). Not only is there a deep sense of sadness, feelings of guilt, anxiety, blame, loss of self - esteem, loss of self - control, feelings of failure as parents and isolation which can leave bereaved parents feeling more vulnerable (Caporali et al., 2020; NBCP, 2020; Ong et al., 2019). This grief is often overlooked, misunderstood, or not acknowledged by family, friends, or the wider community, unless by another parent who has experienced a child death. Even then each individual parent's grief is different.

All bereaved parents need to feel valued and cared for during their stay in the neonatal unit This care must include meeting the needs of each individual family to the best of our ability, and at a high standard (SANDS, 2018). Although neonatal units are in the business of saving lives it is important to recognise all the needs of the parents and provide fully-inclusive parent centred family integrated care which includes recognising their past experiences as parents (NBCP, 2020).

Parents and staff benefited from the development of such a simple initiative. The aim was achieved, and this has become a recognised symbol within the NICU. Parents and staff formed a better working partnership when the parents received more of the much-needed support and reassurance during their stay with their "sunshine baby". Parents stated that they felt they were respectfully and compassionately treated. They trusted and appreciated the genuine warmth and care shown to them and their much-loved precious baby during what could have been another very stressful life event for them. Some of the parents who read the story about the Robin commented on the fact that they were left with hope and comfort for the future. All who received the token gesture of the robin candle greatly appreciated the sentiment.

The staff were pleased that such a small and simple gesture helped to improve the overall care and well-being of the parents. The NNU staff are determined to continue to use the Robin sign not only as a symbol of a previous loss but of hope and encouragement to the parents and each other who too have experienced losses so that brighter days are ahead.

5. Conclusions

Robins were always considered a sign of hope and life. They have now developed this similar meaning in the NNU. The ROBIN project has gained momentum in NHSCT NNU. Valuable information was gleaned

during this project which will improve the quality of care and support given to previously bereaved families. It has proved successful in directing all staff to the sensitivities required while conversing with bereaved parents. It has become embedded into everyday practice, as part of the holistic care all staff offer parents with previous perinatal loss.

It is recommended that staff continue to use the ROBIN picture as a symbol in the neonatal unit. It has become a recognised symbol in the NHSCT NNU during the past two years. Family centred policies including better care provision for parents with previous bereavement experiences should be adopted. This will foster a culture of collaboration between all health professionals and parents. To do so, support is needed from those in a position to influence policy development and implementation. This will then encourage a consistency in care provision and implementation of the ROBIN project which is essential.

An area of future study could be involving siblings in the ROBIN project. Infant siblings at home may be worried about their brother or sister in the NNU. This will be heightened if they, too, have experienced loss perhaps due to stillbirth or if they have been aware of a late miscarriage. This would support the family integrated care ethos of the NNU.

As suggested in NBCP (2020) guidelines, staff training is of utmost importance. More bereavement education is required for junior and new staff, especially if they are expected to broach this subject sensitively. Upskilling staff to communicate empathetically and sensitively is vital, particularly if they are inexperienced in this area of care.

It is suggested that the ROBIN project could be replicated and disseminated to neonatal staff in other neonatal units. In conjunction with using the picture of the ROBIN, a booklet will be produced and given to each family as a keepsake token of remembrance of their previous loss, along with a white candle with a ROBIN picture transferred on to it. They can be used to supplement the care provided to grieving families. The story of the ROBIN will be remembered not only by the parents who have received a copy. It will also be available to all those passionate, caring neonatal staff working in neonatal units, who may also work with the ROBIN project.

Ethical approval

Ethical approval was not required.

Funding

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Authors' contributions

EO led the conceptualisation and design of the project. EO wrote the manuscript, with input from VC. Both authors approved the final version of the manuscript.

Declaration of competing interest

VC is a PhD student supervised by Dr Breidge Boyle, co-editor of the Journal of Neonatal Nursing.

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Appendix 1. Parent questionnaire

Parent Questionnaire

The use of the Robin sign is a fairly recent development in the Neonatal Unit.

ROBIN means Remembering Other Bereavements in the Neonatal Unit.

Have you chosen to use a Robin picture?

Yes ☐

No ☐

If Yes,

How was it for you?

If No,

Any reason why not?

Appendix 2. Staff questionnaire

Monkey Survey

Do you know what  means?

Yes ☐

No ☐

Where have you seen it before?

Have you used a Robin picture before?

Yes ☐

No ☐

Did you allow the parents to choose the location of the picture on the cot or incubator?

Has this improved your communication with the family?

If so, how has it helped?

Please tick which group of staff members you belong to?

Medical ☐

Nursing ☐

AHP ☐

Other ☐

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