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Parents' first moments with their very preterm babies: a qualitative study

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ABSTRACT

Objectives: To assess parents' first experiences of their very preterm babies and the neonatal intensive care unit (NICU).

Design: Qualitative study using semistructured interviews.

Participants: 32 mothers and 7 fathers of very preterm babies (<32 weeks gestation).

Setting: Three neonatal units in tertiary care hospitals in South East England.

Results: Five themes were identified. The first describes parents' blurred recall of the birth. The second shows the anticipation of seeing and touching their baby for the first time was characterised by contrasting emotions, with some parents feeling scared and others excited about the event. The third theme describes parents' first sight and touch of their babies and their 'rollercoaster' of emotions during this time. It also highlights the importance of touch to trigger and strengthen the parent–baby bond. However, some parents were worried that touching or holding the baby might transmit infection or interfere with care. The fourth theme captures parents' impressions of NICU and how overwhelming this was particularly for parents who had not toured NICU beforehand or whose first sight of their baby was on NICU. The final theme captures unique experiences of fathers, in particular that many felt excluded and confused about their role.

Conclusions: This study informs family-centred care by providing insight into the experiences of parents of very preterm infants at a time when they are most in need of support. Clinical implications include the importance of offering parents preparatory tours of the NICU and including fathers.

INTRODUCTION

Preterm birth is the single most important determinant of adverse outcomes for infants and parents in terms of infant morbidity and mortality, the impact on the family (eg, quality of life) and costs for health services. The highest mortality and morbidity occurs in very preterm babies born prior to 32 weeks gestation.¹ In the UK very preterm

ARTICLE SUMMARY

Article focus

- What are parents' first experiences of their very preterm infant?
- What are parents' first experiences of seeing their baby in the NICU?

Key messages

- Highly emotional time, characterised by a 'rollercoaster' of emotions. Parents reported conflicting emotions about seeing their baby, which included feeling scared or excited about their first contact.
- Neonatal intensive care unit (NICU) was an overwhelming environment for most parents, particularly for those who had not seen it beforehand or who did not see their baby until they were at NICU.
- Many fathers felt excluded during the birth and were confused about their role.

Strengths and limitations of this study

- This is the first study to describe the initial experiences of parents of very preterm infants in the UK.
- Findings are limited to the experiences of White European parents. Future research should extend this to experiences of minority ethnic groups.

births account for 51% of infant deaths² despite only comprising 1.4% of births. Very preterm birth raises unique issues for parents and for healthcare services. For example, the birth may be fast and unexpected, and parents may be immediately separated from their baby. The birth of a very preterm baby is often an exceptionally stressful and traumatic time for parents.^{3–6} Clearly this has implications for healthcare services.

Research can inform decisions about the organisation and provision of maternity and neonatal intensive care services.^{7 8} However, there has been little research focusing on parents' initial experiences and reactions to preterm birth. Available information is either

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based on case studies,^{9 10} parents' experiences of care throughout their babies' time in hospital^{11–14} or experiences of parents in non-Western cultures.^{14–16} Themes emerging from qualitative research include the ambiguity of feeling both joy and grief,¹⁷ comparisons made between preterm birth and the 'normal' full-term experience that mothers were denied,^{18 19} and references to the cold and frightening atmosphere of the neonatal intensive care unit (NICU).²⁰ Few studies have examined fathers' experiences of preterm birth. One exception is a Swedish study²¹ which found fathers reported three distinct experiences: (1) suddenness of the preterm birth and feeling unprepared to be a father; (2) their role as responsible for the welfare of their new family and (3) the need to be understood by staff. This highlights the importance of capturing fathers' experiences as well as mothers' experiences. It also indicates the value of healthcare staff being informed and aware of the needs of families at this time.

Although these studies provide insight into the experience of preterm birth, the focus is on experiences over the longer period of the infant being hospitalised. Accordingly, such analyses may explore situations which have already become 'normality' for many parents. This fails to capture those moments when parents may need the most support and care. In addition, the majority of research has failed to include fathers' very first experience of the birth and NICU, which is vital if we are to offer family-centred care at this time. The aim of this research was therefore to explore mothers' and fathers' initial experiences of the birth of their very preterm baby and their first experience of NICU. This was performed using qualitative methods, which are suitable for exploring individuals' experiences in depth.

METHOD

Participants

Participants were eligible for this study if they could speak fluent English and had a preterm baby born prior to 32 weeks gestation in a 6-month period (January–June 2011). All eligible parents in three hospitals were sent a letter inviting them to take part (N=123). Thirty nine (32%) participants agreed to be interviewed (32 mothers and 7 fathers). The participants were aged between 25 and 44 years (mean=34.34, SD=5.54), the majority were White European (74%) and married or cohabiting (95%). Babies were born between 24 and 32 weeks gestation (mean=29.31, SD=2.66). Seventy-five per cent of women were primiparous and 61% had caesarean sections. The majority of couples saw their baby at birth (n=21 couples, 66%), and the rest saw their baby for the first time in NICU (n=11 couples, 34%). Two babies died shortly after the birth; six babies (19%) were still in NICU at the time of interview and 24 (75%) were at home. Time since birth ranged from 44 to 344 days (mean=154 days, SD 57). Participants were recruited from hospital A (n=15), hospital B (n=24) but not hospital C.

Design and procedure

After obtaining NHS ethical approval, letters of invitation were sent to eligible parents by research nurses at three hospitals in the South of England. After approximately 2 weeks reminder letters were sent to parents who did not respond, except for those whose baby had died. Recruitment methods also included posters on neonatal units. Parents who responded were contacted and an interview date arranged. Interviews were carried out in a private hospital room or at the participant's home and lasted approximately for 45 min. Prior to the interview the study was explained and a written, informed consent obtained. Most participants were interviewed individually, except for two couples who asked to be interviewed together. The interview schedule contained 12 open-ended questions, three background questions on experiences during birth; three questions examining parents' very first experiences of their baby (see box 1) and six looking at care during labour and delivery (these have been reported elsewhere, see Sawyer *et al*²²). Probes were used to explore parents' responses in more depth. Interviews were recorded and transcribed, removing any identifying information.

Data analysis

An inductive systematic thematic analysis^{23 24} was used to identify themes across interviews. Data were managed using NVivo software.²⁵ Transcripts from the section of the interview examining parents' first experiences of their baby and NICU (box 1) were read and coded for all emerging concepts to generate an initial pool of codes. Codes were extracted across the whole sample of mothers and fathers but unique codes for fathers were also recorded. All codes were examined and discussed by three authors (LA, AS and SA) to identify overarching themes. Codes were removed if they had a single occurrence or were irrelevant to the research question. Remaining codes were checked against the data to ensure reliability of coding and face validity (ie, that they reflected the meaning of participants). A coding schedule was then produced which defined each theme, inclusion and exclusion criteria and examples of quotes. All interviews were then recorded by one researcher (LA) using the coding schedule. Reliability was checked by an independent researcher classifying 25% of coded segments, and was very good (90% agreement). Participants and quotes are referred to by participant number, mother or father, whether the birth was vaginal (V) or by

Box 1 Interview questions

When did you first see/touch your baby?
Can you describe your feelings when you first saw/touched your baby?
What about when you first saw them in the neonatal intensive care unit?

caesarean section (C/S) and whether the baby was discharged (D/C), in hospital (NICU) or deceased (dec).

RESULTS

Five themes were identified. The first four themes portray a timeline of events from the birth through to the earliest moments between parent and baby. The fifth theme describes the unique experiences of fathers. Online supplementary table S1 provides illustrative quotes and the number of interviews in which each theme occurred. Quotes in online supplementary table S1 are referred to by participant number in the text.

Memory: 'trapped in the little world of your own time'

Just under half of parents reported psychological absence and memory loss during and immediately following the birth of their very preterm baby. Several mothers and some fathers referred to the experience of childbirth being a sudden or surreal experience which they did not feel part of. One mother did not even realise when the baby was born (mother 8 C/S, D/C). Even parents who were shown their baby in the delivery room had only vague memories of how the baby looked (mother 31 V, D/C). Some women referred to time itself being distorted (mother 31 V, D/C; mother 11 C/S, D/C). It was notable that medication was not the sole reason for memory loss, as fathers also had difficulty recalling events occurring immediately after the birth (father 6 C/S, D/C). Despite many fathers having blurred recollection of events, women often relied on them for clarification of what happened during labour (mother 9 V, D/C) and after the baby was born (mother 18 V, D/C).

Anticipation: 'that last hour really dragged'

Two thirds of couples saw their baby at birth but remaining parents saw their baby for the first time in NICU. No parents held or touched their baby until they were in NICU. The anticipation felt by parents prior to seeing and touching their baby for the first time was characterised by contrasting emotions, with some parents feeling scared and others excited about the event.

Anticipating seeing the baby

When anticipating seeing the baby, parents were divided between those who were eager and even desperate to see them, and those who dreaded the experience. Some wished to stay naive to health problems that might be made obvious by the sight of the baby. Their fear was not of the baby itself, but rather of witnessing the seriousness of a situation they would rather avoid (mother 15 V, D/C). This contrasted with the excitement felt by other parents (father 2 C/S, D/C). Being separated from their newborn baby frustrated some mothers who were not only desperate to see their baby but angry and confused about why they could not see them earlier (mother 18 V, D/C; mother 10 C/S, D/C). Others imagined potential medical conditions

and the physical appearance of the baby prior to seeing them in the NICU (mother 24 V, D/C).

Anticipating the first touch

Interestingly, although some parents were desperate to see their baby for the first time, many became nervous and tentative when given the opportunity to touch or hold them (mother 10 C/S, D/C). Parents seemed to do everything they could to avoid potentially harming their baby. Despite a desire to hold their baby many parents chose not to hold them through fear of giving them a harmful infection (mother 20 V, NICU; mother 21 V, D/C; mother 27 C/S, D/C).

Similar to the anticipation of first seeing the baby, there was a clear-cut distinction between parents who worried about touching them and those who were more confident and excited about this experience. One father described longing to hold his baby and painted a vivid picture of the disappointment he felt from being able to look at his son but not being allowed to touch him (father 2 C/S, D/C). Parents described a conflict between wanting to touch their baby and the belief that, by satisfying this wish too early, they might hinder their baby's chances of survival and good health (mother 22 C/S, NICU).

Interestingly, the anticipation of events was different for some first-time parents compared with those with other children. Some first-time parents confronted the situation as it occurred rather than building hopes or worries. They often relied on and trusted the choices of medical staff and perhaps were more psychologically protected by their inexperience of a 'normal' childbirth and its aftermath (mother 14 C/S, D/C).

First moments between parent and baby

The first contact between parent and baby was characterised by turbulent emotions, whether it occurred immediately after birth or later in NICU. The first time parents held their babies was often weeks after the birth and clearly illustrated differences in parents' bonding with their infants.

Physical description: 'like little baby sparrows'

When asked about the first sight of their baby, half of parents focused on their baby's physical appearance. The majority referred to their tiny size implying that this was overwhelming and what they felt was most characteristic of very preterm babies (father 2 C/S, D/C). Others emphasised how small their baby was by repeating that point (mother 31 V, D/C). Some parents referred to the size of the infant in addition to other aspects such as the fragility of their skin (mother 30 V, D/C).

Some parents compared the appearance of their baby to that of 'normal' babies in terms of colour and size (mother 24 V, D/C). The shock of the first sight was emphasised by the metaphoric language used, with occasional comparisons to baby animals (mother 23 V, NICU) or difficulty acknowledging that this was a real

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baby (mother 19 C/S, D/C). Many parents, although confronted with a sight they may not have anticipated, looked beyond the physical appearance of their baby. One mother described her relief at discovering that her baby was actually healthier than she originally thought (mother 12 C/S, D/C). Parents also compared holding their preterm baby to holding those born at full-term (mother 5 V, NICU). Some felt detached during this experience and the baby's discomfort frequently meant the first cuddle was over very quickly (mother 31 V, D/C).

Response to baby: 'rollercoaster of emotions'

The first moments between parent and baby evoked a variety of feelings, described as a 'rollercoaster of emotions' (father 2 C/S, D/C). Parents described the confusion of feeling both elated and devastated (mother 5 V, NICU). Others were filled with guilt and continually questioned whether they could have prevented the negative outcome of the pregnancy (mother 23 V, NICU). Some parents felt guilty of putting their babies through pain with only a small chance of survival and, shocked at their vulnerable appearance, briefly considered whether it was right to continue their care (mother 24 V, D/C).

Typically, parents were more optimistic when it came to touching and holding their babies for the first time. Of parents who discussed this, the majority viewed this first touch in a very positive light, perhaps because they had often waited weeks and prepared themselves for this moment (mother 30 V, D/C; mother 13 C/S, D/C). One mother of twins, when finally given the chance to hold her babies, could not choose which one to hold first. The long anticipation of holding her babies and the equal love she felt for them meant she was unable to choose one over the other even in an outwardly simple decision like this (mother 4 C/S, NICU). Fathers described the experience of holding the baby as unparalleled to anything else (father 2 C/S, D/C).

Half of parents who talked about touching and holding their babies felt they immediately bonded when they first touched their babies. One mother felt connected to her baby as soon as he was taken out of the incubator and she could recognise that he was hers (mother 14 C/S, D/C). Many parents felt so connected while holding their babies that putting them back in the incubator and disrupting the bond they felt was upsetting. A mother of twins felt an instant bond with both her babies (mother 8 C/S, D/C). One mother, when allowed to touch her baby, became desperate to take the next step and hold him (mother 24 V, D/C). Nevertheless, some parents found the experience of holding their baby an ordeal and took a while to feel comfortable (father 5 C/S, D/C). One mother acknowledged that she found it difficult to bond with her baby in case the baby died (mother 23 V, NICU).

NICU: 'a little hidden world, full of poorly babies'

Parents' exposure to and understanding of the NICU environment was crucial to their first impressions of NICU, as it

lessened the shock of their first exposure and contributed to the reassurance that their baby was in safe hands.

First impressions of NICU

The majority of participants had some forewarning that their baby would be born prematurely and around half had a tour of the NICU prior to the birth. Most parents who mentioned this were thankful for the opportunity and said it prepared them and helped relieve the apprehension felt before they saw their baby there (mother 15 V, D/C). Many parents had not seen a preterm baby prior their tour of NICU. Therefore the experience prepared them for the sight of their baby in addition to the atmosphere of the ward (mother 4 C/S, NICU). A few parents had experienced NICU previously with an earlier child (mother 2 C/S, D/C) or through working in a hospital. However, one ex-nurse explained that regardless of her professional experience, her experience of NICU was completely different when it was her own baby being cared for (mother 8 C/S, D/C).

When compared with parents who did not visit the NICU prior to the birth, it was clear how beneficial a prior visit could be for easing some of the worry and confusion brought about by a lack of knowledge of what would happen to the babies. One mother, whose giving birth early came as a complete shock, was not even aware of the existence of NICU until her baby was taken there (mother 6 C/S, dec). A few parents were offered the chance to tour NICU but made various excuses not to. Some of these regretted their decision once their baby was born. For these parents, two first experiences had to be faced simultaneously: their first sight of their baby and their first sight of NICU which was shocking (father 4 C/S, D/C). One mother acknowledged that she had a chance to visit NICU but didn't do so. In hindsight, she wished she had been made to do so, as an absence of choice would have prevented her from taking the easier option of avoiding the anxiety-inducing situation (mother 20 V, NICU).

Describing the NICU

When describing their first experiences on NICU, parents regularly referred to quality of care, from the cleanliness of the environment to the high nurse-to-baby ratio. However, the majority of those who mentioned this found the atmosphere of NICU and the machines overpowering (mother 1 C/S, D/C; mother 23 V, NICU; father 1 C/S, D/C). One mother described the NICU as a secret and mysterious ward, hidden from the rest of the hospital (mother 20 V, NICU). Another mother explains how incomprehensible the experience of the NICU was to her, despite endless descriptions from others about what to expect (mother 16 C/S, D/C). Lastly, some parents felt like a danger on NICU, finding it hard to trust themselves around all the equipment which was saving their baby's lives (mother 6 C/S, dec).

Their baby in the NICU

Just under one third of parents talked about their impressions of their baby in NICU. On their first visit,

the majority of these parents were preoccupied with the NICU and equipment covering their babies. Most found it very difficult to focus on their baby when there was so much going on around them (mother 28 C/S, D/C; mother 16 C/S, D/C). It was particularly difficult when distinctive features, like the baby's face, were covered by masks as it was hard for parents to feel a connection to an infant they could barely see (mother 18 V, D/C). When first holding their babies, some parents felt they were interfering with the care and were daunted by the life-saving technology (father 2 C/S, D/C). The process to hold their baby was lengthy and parents often felt guilty of taking up staff time. However, the experience was generally thought of as worthwhile (mother 7 C/S, D/C).

Unique experience of fathers: 'it's different being a man...'

This final theme looks at the unique, yet often ignored, experience of fathers, which was mentioned by over a third of parents. While both male and female participants contributed to this theme, it is distinguishable by its focus on the father's role and involvement in events from labour to the first moments with their preterm baby.

First, parents referred to the awkwardness and exclusion felt by fathers, particularly during emergency caesarean sections. They were torn by a desire to help out and witness the event but also feared getting in the way (mother 5 V, NICU). One father thought that men were often stereotyped as uninterested, which was detrimental to those who wanted to be involved in the birth and informed of their partner's progress (father 2 C/S, D/C). Paradoxically, despite fathers feeling excluded during labour they were often the first to see their preterm babies and typically experienced this alone while the mothers were recovering. For some fathers the first sight of the baby was both frightening and disappointing (father 2 C/S, D/C). One father interprets this reaction as representative of many fathers having greater difficulty bonding with their babies, as they do not experience the same connection as the mother during pregnancy (father 5 C/S, D/C). Despite many fathers feeling emotionally detached from their babies, most went to see them in NICU for the first time by themselves and reported information back to the mothers, trying to put their minds at ease (father 6 C/S, D/C). For some fathers, given that they had undergone the isolation of seeing the baby without their partner, it was upsetting when mothers were typically given the first chance to hold them (father 3 C/S, D/C).

Fathers also referred to confusion over their roles in caring for mother and baby. Although they wanted to help, they thought the control was in the hands of the professionals (father 2 C/S, D/C). Tensions in the parental relationship were often attributed to the difficulty of fathers finding their role in the situation. A few mothers criticised fathers for acting tough and hiding their emotions (mother 24 V, D/C) or for being overemotional when she needed him to be strong

(mother 21 V, D/C). Some mothers admitted blaming their partners for their distress (mother 24 V, D/C). Despite this, fathers seemed to accept being a forgotten entity in the short-term; their more pressing concerns being the health of their new family (father 1 C/S, D/C).

DISCUSSION

This is the first in-depth study of initial experiences of parents of their very preterm baby and NICU. Results show that parents have difficulty remembering aspects of the birth and experience a rollercoaster of emotions during this time. Individual differences in emotions were most apparent between the birth and seeing their baby in NICU when parents were either nervous and fearful, or eager and excited. NICU was initially overpowering for parents, especially those who had not visited it previously or who saw their baby for the very first time there. However, being able to touch and hold the baby in NICU was important in triggering or strengthening the bond between parents and their baby. Parents who are anxious and avoidant of initial contact with the NICU or their baby are at risk of poor attachment and mental health²⁶ therefore parents need help to overcome this. Interestingly, a few first-time parents appeared to be protected by their inexperience of a 'normal' birth and reported considering situations as they occurred, relying on staff to guide them. In contrast, many fathers felt awkward and excluded during the birth and struggled to find their role.

These results support and extend previous research. There is now consistent evidence that parents report blurred memory of the birth, a rollercoaster of emotions and are initially overpowered by the NICU environment.^{9 17 18} Difficulty remembering aspects of the birth is also reported by women who experience difficult or traumatic births²⁷ and is consistent with the view that fragmented memories are characteristic of a post-traumatic stress response.²⁸ The positive impact of prenatal visits to NICU on parents' is consistent with evidence that such visits decrease fear and reassure parents about the care their infant will receive.²⁹ The finding that touch is important for the parent-baby bond supports the principles of kangaroo care. Parents' worries about consequent infection or harm to the baby are in contrast to evidence that kangaroo care may lead to reduced infant morbidity and mortality.³⁰ Although very preterm babies can become stressed by repeated contact and stimulation, the evidence suggests comforting touch (such as from parents) does not adversely affect the baby and may result in benefits when done carefully and taking account of infant behavioural cues.³¹

In addition, the results extend research by providing original insights, such as the opposing emotions felt by different parents prior to seeing and holding their baby. The finding that parents were either anxious/avoidant or desperate/excited is consistent with research showing

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different individuals have approach or avoidant coping styles and this affects both responses to care and outcomes.³² Fathers' experiences were consistent with the Swedish study of fathers²¹ in identifying feelings of responsibility and needing to be understood and included. However, this study showed that fathers also struggle to find their role in the situation and tensions in the parental relationship can arise. A recent metasynthesis of qualitative studies of fathers' experiences of maternity care throughout pregnancy, birth and postpartum similarly identified themes of feeling excluded, fear and frustration and issues of support. The authors summarise this as fathers being 'not-patient and not-visitor'.³³

The strengths of this study include the qualitative methods, which provide a detailed insight into the experiences of parents, and the inclusion of fathers. Methodological rigor was ensured in a number of ways, including careful construction of interview questions, consecutive sampling, the use of appropriate and well-established analytic techniques; discussion of results between team members; and checking reliability of coding with an external rater. Ethical rigour was ensured by informed consent and using an experienced interviewer who was not associated with the hospital, which enabled parents to freely express their opinions. Descriptive vividness was ensured through careful description of the study and results, as well as sending a summary to participants. Heuristic relevance is apparent from the coherence of the results with previous empirical and theoretical literature. Aspects that could be addressed in future research include that, although the study had a good response rate for this kind of recruitment, the sample mainly consisted of white, married women. Recruitment of fathers to the study was low (23% of couples) and the sample was small, so it was not possible to examine factors that might influence parents' perceptions of their experiences, such as time since birth or infant status. Research is therefore needed to see whether the experiences reported here are applicable to parents from different backgrounds, to extend the research on fathers' experiences and examine other influences on parents' experiences.

This research has a number of clinical implications. Recommendations for family-centred care include recognising critical steps for parents during the care pathway and being aware of their needs, the emotional impact and individual differences in responses.³⁴ This study shows the birth of the baby and first contact with NICU are critical steps and the impact of this varies between individuals. The buffering effect of prenatal visits to NICU, alongside the regret expressed by parents who did not take up this opportunity, suggests all parents should be encouraged to visit NICU prior to birth if possible. If this is not possible then providing parents with a photograph of the infant before they visit the NICU may lessen the impact of seeing their baby in NICU for the first time and improve bonding.^{35 36} The importance of touch means that parents who worry

about negative impacts on the baby's health should be educated, reassured and taught to recognise infant cues so that touch can be enabled while avoiding stress on the infant. Finally, it is clear that we need to involve fathers more, particularly during the birth.

In conclusion, this study contributes to our understanding of parents' first experiences with their very preterm babies. Subsequent studies are essential to further improve knowledge and care offered to parents during this unique personal and emotional 'rollercoaster ride'. To offer truly family-centred care we first need to understand individual differences in experiences and responses, which the current study addresses. Going forward, research needs to explore and understand the care needs of different individuals and groups, such as fathers, or anxious and avoidant parents. This can be used to inform and guide practice in maternity and NICU services.

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Contributors LA analysed the data and contributed to the writing, revision and final approval of the manuscript. AS contributed to the protocol, coordinated the study, interviewed the parents, supervised analysis of the data and contributed to the revision and final approval of the manuscript. HR and JA and GG (representatives from parent groups) contributed to the protocol and contributed to the revision and final approval of the manuscript. LD and SA designed the study, contributed to the protocol and the revision and final approval of the manuscript. SA designed the study, contributed to the protocol, supervised the analysis of the data and contributed to the writing, revision and final approval of the manuscript.

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Data sharing statement The coding schedule and coded segments from the dataset are available from the corresponding author at Susan.Ayers.1@city.ac.uk. Consent was not obtained from participants for data sharing but the presented data are anonymised and risk of identification is low.

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