follow up). However, clarification of such statements are needed. For example, Jocham et al. raise the question ‘is there an assumption that all items in selected QOL questionnaires are of equal significance?’ This question can be interpreted in several ways. First, it will depend on the selected questionnaire. A utility-based QOL questionnaire will be very different from a health profile-based QOL questionnaire. Secondly, whether the questionnaire is developed as single item or multi-item scales will be important in determining whether or not items will be of equal significance. Thirdly, whether the questionnaire is weighted or not, i.e. whether specific items or scales (e.g. symptoms) are given more importance than others (e.g. role functioning). Again, whether this weighting is made by the patient or health professional will have significant implications. Other important methodological issues have not been alluded to in the paper. Issues such as the frequency of QOL assessment, response-shift bias, missing data, the statistical interpretation of QOL data and the clinical importance of QOL information are frequently highlighted as particular problems of QOL assessment in palliative care.

In their conclusion and recommendations, Jocham et al. list a number of valid issues for future consideration including the type of instrument required, the need for placing QOL in context to cultural and pre-cancer life experiences and the potential in adapting existing QOL instruments. However, the limitations of the review must be acknowledged in interpreting the paper. This paper by Jocham et al. has contributed to the growing consensus of opinion that there is a need and demand for QOL assessment in palliative care and have outlined some of the challenges which exist and have been highlighted in previous studies. What is now needed is to move towards developing robust and rigorous programmes of work which address these challenges.

References

COMMENTARY


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The birth of an infant who requires care in the neonatal intensive care unit is highly stressful for all parents. The stress of the delivery, coupled with the unfamiliar environment and uncertainty about the infant’s survival, makes this a traumatic event. The hospitalization period can be quite lengthy which can result in considerable disruption for parents and their families. Hence, nurses play a significant role in supporting parents during this stressful period (Fenwick et al. 2000). In this paper, Mok and Leung (2006) explored the supportive behaviour of nurses as experienced by mothers of premature infants in Hong Kong. They present findings on
parents’ perceived and received support needs in a neonatal unit. The existing research in this area tends to be from North America and Canada, thus this paper is a welcome addition to the body of knowledge.

The literature review revealed that parents of premature infants need information and to be involved in the care of their child. It needs to be noted that Coyne (1995) and Balling and McCubbin (2001) did not conduct research with parents of premature infants. Nevertheless, these studies and many more studies on parent participation have revealed that parents experience a deficit of information which hampers them from determining their role in the hospital setting. Margaret Miles and her colleagues have conducted considerable research in the neonatal area and it would have been more helpful to have a summary of the issues that emerged from this body of research. There was no attempt to analyse the concept of ‘support’, which is a problematic issue in nursing.

The authors used the Miles et al.’s (1999) Nurse Parent Support Model, which is a well-validated questionnaire survey tool, and it is noteworthy that the tool was adapted for the Chinese context. The Cronbach’s alpha test was used to test the robustness and achieved a satisfactory level. The translation of the questionnaire into Chinese was a thorough process. However, the questions were developed for a North American audience and, as such, may not reflect the cultural differences that exist. Furthermore, a factor analysis may have been quite useful as it is difficult to distinguish the concept of supportive communication from emotional support. It is unclear why only 48 questionnaires were distributed to mothers over a seven-month period when approximately 50 admissions occur each month. There is a lack of clarity in relation to the presentation and discussion of the data from the questionnaires. It is unclear what the overall means are being compared with. The authors state that 3.84 indicated a high level of support from nurses because it is higher than the mid-scale point. They would need to show that it is high or higher than the means in other studies and also to have the information about the scale in relation to support ‘categories’, e.g. low = 0–1.5, medium = 1.6–3.1, etc. Overall, there was no indication of whether differences between perceived and received information were significant.

It is commendable that interviews were used with questionnaires as such data collection tools can produce different data. However, there is insufficient information as to why only six mothers from a sample of 37 agreed to be interviewed. The term descriptive study design raises concern as there was no evidence that a systematic content analysis had taken place. It was questionable as to whether data saturation was achieved with such a small sample of mothers.

The six mothers were asked about the ways nurses were and were not supportive of the mothers. These topics have a different focus from perceived support on a selected number of areas. Providing mothers with the opportunity to speak about their needs revealed that they experienced feelings of disappointment, guilt, anxiety and abandonment. The conclusion was that they were in need of support and help. It would have been helpful to have more details on these findings, to understand why parents felt such emotions. Were these emotions linked to the lack of information or the stress associated with having a premature child hospitalized? It was clearly evident that mothers needed open, honest information in simple language throughout their infants stay. Mothers who were interviewed also reported this finding. The questionnaire data revealed that the widest gap between perceived importance and received nursing support were for item 8, ‘included me in the discussion when decisions were about my child’s care’. This is an area that could have been explored in the interviews but the opportunity appears to have not been used.

It was reported that the mothers felt involved in their infants care, yet the statement ‘Made me feel important as a parent’ was ranked 17 in the order of importance. The link between involvement and retaining a feeling of control and restoring confidence in parenting skills was made in the Discussion section. It is generally assumed that involving parents in the delivery of some aspects of care helps restore parents’ confidence in their parenting skills. For mothers who already have children, the experience of parenting a premature infant may not threaten their parenting skills. Instead, they may find it frustrating because they are unable to have close contact because of their infant’s vulnerability and illness. For parents who are new mothers, involvement may help to establish confidence in newly formed parenting skills. What concerns me is, the assumption that involving mothers in care giving is always going to have a positive effect on all parents. Some research has indicated that parents can find it more stressful to participate in care when their child is very ill and receiving multiple medical interventions.

In this paper, it is concluded that mothers found meeting other parents beneficial and thus nurses should encourage communication among parents. Was it only the six mothers who stated this finding and, if so, caution should be taken even if this finding confirms other research findings? It is generally assumed that parents find it beneficial to talk with other parents and hence parent sitting rooms have evolved as a device to encourage communication among parents. However, there are instances where parents do not want to meet other parents in similar situations because they do not want to be confronted by other people’s troubles when they are feeling stressed or
potentially they do not want to have to share experiences with other potential strangers when they are, by nature, shy and reserved individuals. It does highlight a significant issue that parents may draw support from other parents because health professionals are not meeting their needs.

The qualitative data indicated that mothers experienced guilt, anxiety and feeling of abandonment. There was also indication that parents’ experienced inconsistencies in what nurses allowed them to perform for their child. The opportunity to analyse these issues was not realized which was disappointing. It would have been more interesting to go one stage back and find out the mothers’ perceptions of what constitutes support without being ‘led’ by a questionnaire. Nevertheless, Mok and Leung (2006) have conducted the beginning of work which will give them the opportunity to examine such ideas in more detail. As no previous study has examined the support needs of mothers of premature infants, this paper contributes to the research in this area.

Reference


RESPONSE

The authors appreciate the thoughtful analyses of the commentator. The commentary has provided the authors with important insights on the research study (Mok & Leung 2006).

The authors fully agree with Coyne (2007) that the studies of herself (1995) and Balling and McCubbin (2001) focus on the parents of children rather than on the parents of premature infants and that the literature review should focus on the parents of premature infants instead. As for the conceptualization of support, this is a term that is often overused and is difficult to define. The authors have defined the concept of nursing support based on Miles’ conceptualization of it as the interpersonal interaction with nurses that parents of preterm infants perceive as helpful. The Nurse–Parent Support Tool developed by Miles was based on House’s conceptual definitions of social support (1981). Four overlapping aspects of support are included: supportive communication and the giving of information, emotional support, self-esteem support and instrumental support. The nurse support model does not conceptualize nursing support as similar to, or a replacement for, social support (Hupcey & Morse 1997). However, the concepts used to define social support have some relevance to professional intervention.

The authors would like to clarify that, as only 37 questionnaires were returned, it might not be appropriate to conduct a factor analysis on the scale of the study. Only 48 questionnaires distributed over the seven-month period because other cases admitted to the unit did not meet the criteria for inclusion in our study. Either the infants admitted were not preterm babies or they were not hospitalized for more than one week.

The authors agree with Coyne (2007) that we cannot claim the parents of premature infants in the current study perceived that they had received a high level of support. According to Fielding (1999), for ordered categories data, the cut-off point can be set at three when scores range from one to five. In our study, the score was 3Æ84, which is highly significant compared with the cut-off point, but we cannot claim that 3Æ84 is very much above the average. Therefore, we would instead like to re-state that the level of support perceived by the parents of premature infants was significantly higher than the average in the study. Compared with Miles et al.’s (1999) study, which reported a mean of 4Æ12, the level of perceived support received by the parents of premature infants was lower in the current study.

The authors were only able to recruit six parents to participate in the interviews. We agree, if the study is to be conducted again, it would be a good idea to interview the parents first to prevent their perceptions of what constitutes support from being influenced by the questionnaire. The authors support Dr Coyne’s view that it would have been helpful to provide more details on the qualitative findings of the study to help readers understand why parents had negative emotions. Because of the word limit for the article, the authors did not elaborate on the qualitative findings in detail. Perhaps another paper focusing on the qualitative