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QUALITY OF LIFE IN PREMATURE BABIES

Anca BIVOLEANU¹, Maria STAMATIN²

Abstract

Preterm babies represent a heterogeneous clinical group, whose health state is conditioned by their maturity and the short and long term complications that they sometimes experience as a result of their premature birth. The health and wellbeing of this category of population is the focus of much international effort. Definition of quality of life creates a large debate in medical literature. Since earl's '70, hundreds of questioners and methods have been developed in order to measure and/or quantify quality of life. Measuring quality of life in a former premature child is a real challenge. Most of them, despite their poor neurologic outcome and severe disabilities, rate as normal their quality of life in contradiction with their families and physicians perspective. In our opinion, it is important for the medical community to accept, that even if the stated QoL is at odds with the objective assessment by a clinician, it is the perception of the affected individual that should take priority. QoL measures should be integrated in clinical trials, in assessments of long-term outcome of children with disabilities and chronic health conditions, and in treatment decisions on whether to offer intensive care.

Keywords: prematurity, neonatal behavior, neurodevelopmental morbidities, long term outcome, functional status, quality of life

Background

Progresses in neonatology field lead to an increasing number of surviving babies with low birth weight (LBW) and, especially with extreme low birth weight (ELBW) and very low gestational age. In our days, in modern neonatal intensive

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care neonatal units, limit of survival reaches 23 weeks of gestation, compare to 30 weeks of gestation, thirty years ago (Lau *et al.*, 2013; Blencowe *et al.*, 2012; WHO, 2014; Heron, 2010; Hamilton, Martin, & Ventura, 2012). But decreasing mortality is accompanied by increased specific morbidities: neurological, neuro-developmental, neurosensory, and functional morbidities, proportionally with decreasing birth weight and gestational age (Wilson-Costello *et al.*, 2007; Hintz *et al.*, 2005; Vohr & Msall, 2000; Vohr *et al.*, 2005; Stephens & Vohr, 2009; Mandy, 2012; Fanaroff *et al.*, 2007); even “near term” babies can have effects from preterm birth, such as breathing difficulties, feeding problems, infections and suboptimal brain development (Ramachandrapa & Jain *et al.*, 2009; Santos *et al.*, 2009; McIntire & Leveno, 2008; Adams-Chapman, 2006; Kinney, 2006). For this reason, the specialist must be focused not only on reducing mortality, but also on reducing morbidities caused by prematurity. The consequences of pre-term birth are greater in childhood, but they can be extended into adolescence and adulthood with impact on quality of life (QoL) for these patients. Describing quality of life among survivors is challenging, because QoL is difficult to measure due to its multidimensional nature.

Definitions QoL and HRQoL

To properly assess and study QoL, it is essential to obtain data from the individual’s own perspective, which for the neonate or child is almost impossible. World Health Organization defines Quality of Life as a “state of complete physical, mental, and social well-being- not merely the absence of disease or infirmity”. “It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (WHOQOL, 1994; WHOQOL, 2015). Still, there is no generally agreed definition of QoL”; - a PubMed search of articles published from 1966 to 2005 identified 76,698 articles containing ‘quality of life’ as a Medical Subject Heading or as a title or abstract term, proving the large interest in this concept (Moons, Budts & De Geest, 2006). As a matter of fact, trying to provide a conclusive and universally accepted definition of the concept of QoL and indicating how to best to measure it, are still true challenges. It is essential to clearly define the concept of QoL in order to avoid confounding with other concepts such as functional status, health status, symptoms, disease processes and treatment side-effects.

Measurement of QoL emerged in the 1970s when the focus of health care evaluation moved from traditional clinical outcomes (i.e. mortality, morbidity) to the measurement of broader outcomes, such as function (i.e. execution of routine activities). Due to different perspective- one of the person directly involved and one of person from those opinion is appreciate quality of life, no unitary definition or specific tools has been developed. A wide spectrum of QoL definitions and conceptualizations exist in the literature; people use the term QoL to mean many different things – this can make comparison of findings difficult if not impossible. The absence of a broader definition for the concept of QoL has resulted in describing and evaluation of QoL into more domains, from medical, to social

and/or physical (Holmes, 2005). Health related quality of life (HRQoL) is considered to be a subdomain of QoL, referring to a part of QoL that is associated with health. HRQoL, health status and functional status are terms that are often used interchangeably but they measure different things. HRQoL can be defined as the impact of disease and treatment on the patient's self-perceptions of functioning in a variety of domains (Vivier, Bernier & Starfield, 1994). Health is consistently included as an important aspect of QoL, but a healthy life does not necessarily mean a high QoL. Varni *et al.* (1999) assesses 5 domains of HRQoL: psychological, social, physical functioning, cognitive functioning and disease/treatment-related symptoms (Varni *et al.*, 1999). Assessing HRQoL can be used to provide information about the functioning and wellbeing of a population, identify population groups with special needs, and can measure intervention impact at a general population level as well as in health care settings (Wood-Dauphinee, 1999).

Assessment of QoL and HRQoL for a child and neonate

As for a child, health state encompasses physical, mental, emotional and social well-being, from infancy through to adolescence. "Children health is the extent to which individual children or groups of children are able or enabled to (a) develop and realize their potential, (b) satisfy their needs, and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments" (National Research Council and Institute of Medicine, 2004; Schor, 1998). Assessing QoL for a former premature child is more estimated than real evaluated, because for these children it isn't possible to make an exact evolutive prognostic; specially when is about children born before 28 weeks of gestation, short and long term outcome is marked by the development of severe complications that can affect QoL for them and their families (Saigal & Doyle, 2008). For a former premature newborn, QoL is linked to health status and his or her physical and neurologic development, but for their parents HRQoL is impacted by the stress associated with taking care of a baby who may have problems. Some data suggests that parental ratings of the quality of life of their child can be mediated by their own level of distress (Eiser, *et al.*, 2005).

Even though QoL and HRQoL are related and often used interchangeably they are not identical, as QoL is a broader concept referring more to a child's feelings and appraisal with his or her life whereas HRQoL refers specially to a child's functional status as impacted by his or her state of health (Davis *et al.*, 2006). Functional status may be defined as "the child's ability to perform daily activities that are essential to meet his or her basic needs, fulfill roles, and maintain health and well-being" (Drotar, 2004). Functional status /child acquisitions are more complex while child is growing, so this lead to changes in standards from which QoL is appreciated. Although pediatricians have assumed that parents can provide information about the impact of the disease and treatment on the child, it is increasingly acknowledged that the child's perspective is different. In general, parents perceive an illness to have more negative consequences than children themselves perceive. Parents are more able to rate the child's HRQoL in relation

to domains of physical functioning or physical symptoms compared with less visible domains such as social or emotional functioning (Koot, 2001; Vohr & Msall, 1997; Als & Gilkerson, 1997). The application of HRQoL in pediatrics is complicated by the need to incorporate the diverse developmental and emotional stages underlying children's health and disease states (Wallander, Schmitt & Koot, 2001). For neonates, it could be assessed a relative QoL through information from neonatologists and/or families. In Neonatal Intensive Care Units (NICU) there are specific parameters such as: (a) vital signs, (b) physical symptoms, (c) neurobehavioral assessments and (d) pain scores, which could be adapted in order to estimate HRQoL for these patients (Scheinberg, 2011; Boss, Kinsman & Donohue, 2012).

1. Vital signs are influenced by a multitude of disease present in babies admitted to neonatal intensive care units. Respiratory distress syndrome represents the most frequent pathology in the neonatal period, especially for premature. The presence of this pathology and the need for respiratory support in the form of mechanical ventilation or supplementary oxygen beyond 34 weeks postmenstrual age for preterm infants and at any time for near-term and full-term could be a parameter in quantifying quality of life. In fact, respiratory symptoms are commonly included in HRQoL measures for adults and older children; measures of respiratory status reflect both infant maturation and health status.
2. There are a number of symptoms included in adult and pediatric HRQoL measures, which could also be quantified for neonates admitted to the NICU. The most relevant for premature newborns is feeding tolerance. In fact, feeding tolerance is an indicator of well-being at all stages of life. In older children and adults, quality of life related to enteral intake is a function of both nutritional benefit and enjoyment. In neonates, feeding intolerance is related to immaturity, malformations or various pathologic entities. Feeding intolerance leads to delay in the time to full enteral feedings; prolonged inadequate nutrition is associated with failure to thrive and cognitive delay (Vlaardingerbroek, van Goudoever, & van den Akker, 2009). Measures of feeding tolerance, time to full enteral feeds, and time to full nipple feeding could all be included in measures of HRQoL.
3. There are several scales used to evaluate neonatal behavior: Neonatal Behavioral Assessment Scale (Beeghly *et al.*, 1995). Neonatal Intensive Care Unit Network Neurobehavioral Scale (Lester & Tronick, 2004) and the Newborn Individualized Developmental Care and Assessment Program (Als *et al.*, 1994), which provide multiple-item scoring of central nervous system function and infant behavior, including also interaction with environment. Although these scales may provide helpful information about a neonate's current behavior, clear correlations between scores on these scales and long-term neurodevelopment have not been consistently demonstrated.

These factors must be taken into consideration when deciding whether to adapt them for use in measures of HRQoL.

4. A substantial literature describes neonatal pain perception at varying gestational ages, including also long-term outcomes. Symptoms like tachycardia, facial movements, crying and oxygen desaturation episodes can be quantified using a variety of validated pain measures, such as: Neonatal Infant Pain Scale, Neonatal Pain Agitation and Sedation Scale, CRIES score (Crying, Requires Oxygen, Increased Vital Signs, Expression and Sleepless Scale) (Lawrence *et al.*, 1993; Hummel *et al.*, 2008; Gruenberg *et al.*, 2006).

These metrics for neonates could be considered when developing HRQoL measures. Another important aspect, with influence on QoL of former premature is length of hospitalization. Extremely preterm infants are more likely than children or adults to have hospital stays lasting weeks or even months. For an adult patient, a prolonged stay in intensive care unit is defined as a length of stay >95th percentile, that is more than 7 days (Gruenberg *et al.*, 2006) and for a pediatric patient, a prolonged stay is more than 12 days (Marcin *et al.*, 2001). In contrast, approximately 70% of neonates in the NICU have a length of stay of 20 days or more (Kornhauser & Schneiderman, 2010). This prolonged hospitalization, frequently associated with many NICU specific interventions has a double impact: on premature infants and on their parents, with reflection on QoL.

From birth to childhood, socio-economic factors play a key role in HRQoL compared to adulthood, because low socioeconomic status in childhood influences anthropometric and neurodevelopmental status and impacts morbidity (Klassen *et al.*, 2004; Hoff *et al.*, 2004). Despite high rates of chronic health condition, former premature infants rated their QoL similar to controls, whereas their parents reported poorer health for their children compared with parents of controls. The presence of a disease, or the absence of a certain ability, is not perceived by the child as affecting his/her QoL (Johnson *et al.*, 2003; Sweeting & West, 2008; Harris, 2004; Glascoe & Sandler, 2005). No longer true, that in first years of life a child didn't realize with what is different from other children and isn't able to compare his/her acquisitions with children of the same age. (Ironically, it may be especially in these situations that information about the child's QoL is most pertinent). In addition to mortality and morbidity, QoL has become an important outcome measure of neonatal care. This has led to the development of, questionnaires to monitor the infant's QoL and HRQoL.

Quality of life is assessed in the literature using various methodologies including quantitative, qualitative and/or combined methods. Ideally, QoL assessment should include both objective and subjective evaluation. Quantitative assessment of QoL includes the use of questionnaires composed of questions or statements that are evaluated by the respondent. Most scales will convert the answers into a numerical score and these scores may be further grouped into scale scores or summary scores. This allows the researcher to evaluate a numeric figure that attempts to quantify the measured concept of QoL (Glascoe, 1997; Streiner & Norman, 2008). Qualitative assessment of QoL can be achieved by in

depth interviews, observation, focus groups, consensus methods, case studies or with written open-ended questions. Qualitative investigation enriches data that are received from the quantitative surveys and gives a narrative description to the life experience and views of the participants (Taylor, Wray & Gibson, 2010; Wright, 2000). Measurement of QoL in pediatrics presents unique challenges related to the various developmental stages encountered and the need to utilize proxy assessments. Scales used to measure QoL in children need to consider developmental stages of children relative to cognition, emotions and ability to foresee the future (Pope & Mays, 1995).

When children are too young, too ill or cognitively impaired, it is necessary to use a proxy for a child's QoL measurement; preferably the primary caregiver who has the most intimate knowledge of the child's well-being. Unfortunately this prevents the researcher from truly acquiring the child's perception of his own QoL. Parents' views and proxy assessments are impacted by a number of factors that could potentially interfere with a true assessment of what the child is experiencing. This includes knowledge of different information than the child, the parent's own past experiences, expectations, mental and physical health, cultural expectations, educational and social backgrounds, personal knowledge of normal development and whether the parent has already had his or her child developmentally assessed (Varni, Seid & Rode, 1999; Hack, 1999).

Methodology

The analyses in this article are based on comparison of literature studies regarding assessment of QoL and HRQoL for a child and neonate by using specific questionnaires and observational tests. Quality of life is assessed in the literature using various methodologies including quantitative, qualitative and mixed methods. Because quantitative assessment of QoL includes the use of questionnaires composed of questions or statements that are evaluated by the respondent is difficult to use in case of neonate and critical paediatric patient. A questionnaire has to have: (a) reliability, defined by Guyatt *et al.*, as the ratio of variability between patients to the total variability (Guyatt *et al.*, 1997); (b) validity is whether the instrument is measuring what it is intending to measure; (c) responsiveness is the assessment of a tool's ability to detect both clinically important and real changes in a specified concept over time; (d) Sensibility includes information such as the original purpose of the tool, its target population and setting, examination of the actual items, review of response options, and feasibility.

Qualitative investigation enriches data that is received from the quantitative surveys. Qualitative assessment of QoL can be achieved by in depth interviews, observation, focus groups, consensus methods, case studies or with written open-ended questions (Wright, 2000; Taylor, Wray & Gibson, 2010). For neonates and small babies, it is necessary to use a proxy for a child's QoL measurement; preferably the primary caregiver who has the most intimate knowledge of the child's well-being (De Civita *et al.*, 2005). Unfortunately this prevents the

researcher from truly acquiring the child's perception of their own QoL. Parents' views and proxy assessments are impacted by a number of factors that could potentially interfere with a true assessment of what the child is experiencing. Regarding this aspect, Peter Rosenbaum provided commentary on a European study investigating QOL in children with Cerebral Palsy and he noted that "It is important to separate the disorder from the person, and not make assumptions about what life must be like for that child or their family" (Rosenbaum, 2008).

Discussion

Although is a widely used, the concept, of "quality of life" remains difficult to define (Holmes, 2005, Moons, 2006). Many authors, instead of providing a conceptual definition of QoL, use it as an indicator. In fact "description" of QoL begin with first respiration and first scream, quantified through Apgar score. It is well documented that children born preterm are at risk for developmental disorders like cognitive, emotional, behavioural and school performance problems (Hintz *et al.*, 2005, Vohr *et al.*, 2005; Mandy, 2012). For neonatologist, health-related quality of life (HRQoL) is a more useful concept, because it combines physical, psychological, and functional well-being from perspective of a parent or from the child itself- or better both (Eiser *et al.*, 2005). HRQoL identifies population groups with special needs, and can be used to measure intervention impact at a general population level as well as in health care settings (Koot, 2001).

Measurement of QoL in pediatrics represents a difficult task- challenges are related to the various developmental stages encountered and the need to utilize proxy assessments (Varni, Seid & Rode, 1999). Scales used to measure QoL in children need to consider developmental stages of children relative to cognition and emotions. Questions that are developed for children must be asked in a manner that uses appropriate language and level of understanding for the child. When children are too young, too ill or cognitively impaired, it is necessary to use a proxy for a child's QoL measurement; preferably the primary caregiver who has the most intimate knowledge of the child's well-being. Unfortunately this prevents the researcher from truly acquiring the child's perception of their own QoL. Parents' views and proxy assessments are impacted by a number of factors that could potentially interfere with a true assessment of what the child is experiencing. This includes knowledge of different information than the child, their own past experiences, expectations, mental and physical health, cultural expectations, educational and social backgrounds, personal knowledge of normal development and whether they have already had their child developmentally assessed. Parents have been found to find illness more significant than kids do (De Civita, 2005). Further studies needs to establish the proper age for a child to complete a questionnaire on his or her own QoL, or should it be done together?

Conclusion

Despite the international focus on improving the health and wellbeing of children living in lower-income countries, there are no population-based studies of HRQoL in these countries. For region of Moldova, which is the region in Romania with the largest number of births per year and highest incidence of prematurity, no previous study has been made on this matter. The authors plan to develop a questionnaire to be applied to mothers of children who were admitted as premature infants to a level III intensive care unit, which may help to evaluate the outcome of neonatal care and therefore help in the counselling of parents. It is important for the medical community to accept, that even if the stated QoL is at odds with the objective assessment by a clinician, it is the perception of the affected individual that should take priority. QoL measures should be integrated in clinical trials, included in long-term assessments of outcome of children with disabilities and chronic health conditions, and in treatment decisions about whether to offer intensive care.

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