

Special educational aspects of the quality of life of children with retinopathy of prematurity

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Abstract: *Quality of life has become a very topical scientific phenomenon over the recent two decades and it is reflected in many fields of research. In the context of special pedagogy a very highlighted issue is the assessment of the quality of life of specific client groups in order to establish an adequate level of the provided support and to optimise the complex intervention. This is why there was designed a concept focusing on the research of the quality of life of children with retinopathy of prematurity, which is one of the main causes of blindness in advanced and medium developed countries of the world. This study focuses on the description of the research concept. The whole issue is studied in the context of the theoretical background and practical applications.*

Key words: *Retinopathy of Prematurity, Quality of Life, health related quality of life, visual impairment, special education, children*

1 Introduction – theoretical base

Retinopathy of prematurely born children – Retinopathy of Prematurity, Retinopathiapræmaturorum (“ROP”) is at present on the top of the list of causes of blindness of children in developed countries of the world. ROP was the cause of eyesight loss for ca 70% of the blind children (Rozsival, 2005). This vasoproliferative disease of the retina affects especially prematurely born children with low birth weight. The ROP incidence grows due to the increasing number of extremely premature children, who manage to survive. In the Czech Republic every year 80% of children with less than 1000 g birth weight survive (Štembera, 2004). Every year in the Czech Republic there are registered ca sixty children with serious damage of vision due to ROP (Kuchynka et al. 2007). The contemporary advances in ophthalmology have

significantly improved the prognosis of vision functions of children with ROP, yet its impact can have fatal consequences of total loss of visual perception, which confirms its dominant position among the child blindness causes.

The presented data clearly show, that ROP remains, in spite of the significant scientific and technical advances in neonatology and ophthalmology care, a very pressing medical, social, economic, social-pedagogic and ethical problem. Depending from the level of retained eyesight functions, which range from weak eyesight up to total blindness and in connection with other accompanying complications arising from the degree of immaturity, there was prepared a concept focusing on the quality of life of children, who suffer from retinopathy of prematurity.

The most frequent effect of ROP is serious eyesight impairment, or even blindness. Due to the technical advances in the neonatology and perinatology fields we can expect rising incidence in the category of extremely immature newborns at the very limit of viability, which will mean a rising incidence of retinopathy of prematurity, especially its atypical forms. The loss of vision affects the whole personality of an individual and his/her quality of life. It is also reflected in new trends in access to persons with visual impairment (Růžicková, 2008).

The QOL (Quality of Life) phenomenon is an issue, which is currently highly discussed and widely understood and many fields of science study it (philosophy, sociology, psychology, medicine, economy, ecology, pedagogy, special pedagogy etc.). The wide options of application are reflected in the multi dimensional nature of this problematic. The assessment of QOL of children has become the focus of interest of experts only during the last ten years. A wide range of research is dedicated to the quality of life of the adult population, however the category of children and adolescents is slowly gaining in importance and it becomes an "emerging field of study". In the past there were developed various theories describing the quality of life of children. Mostly the theories focused on only one dominant aspect of a child's world. According to the present view of many authors, the development theories focusing on the psychological aspect (e.g. Limber, Hashima, 1999), or physical aspect (such as Ruštin, Greenberg, 1999), social (e.g. Flakkoy, Hevener, 1997), moral or spiritual growth (such as Thompson, Randal, 1999) do not provide sufficiently complex basis for creation of tools to monitor QOL of children" (Dostálek, Troneček, Hejčmanová, Petrišćáková in Mareš et al., 2006, p. 209). Currently even in this area of interest there dominate the quantitative methods of QOL assessment in the form of questionnaires, which may not be sufficiently sensitive to the specifics of certain groups of children, especially ill children. The questionnaires are also designed for an "average" child, which does not exist. This is why there is a worldwide increase of interest in a qualitative approach and specific instruments of qualitative nature (Mareš, Marešová in Koukola, Mareš, 2007).

From another perspective, the aforesaid authors speak about other problematic aspects of measuring the quality of life of children – we, the adults, ask children from our point of view, using our methods and our words. Vaďurová (2006) notes the attention span and points out, that in reasonable cases there is no other alternative than “proxy rating”, when the quality of life is assessed by a parent, doctor or other relative. This brings us to the question of the evaluator of the quality of life. Vaďurová (2006) considers the assessment of the source of information as a very important aspect of the QOL assessment. The source of information may be the patients (clients), nurses, medical staff. Each of the groups clearly provides a different point of view about the quality of life of a child and interprets the situation from its own perspective. One of the variants is the “proxy rating” – assessment done by the parent or nurse. The parent’s opinion about the quality of life of a child may not be quite relevant, it may be distorted for instance due to different perception of the present situation of the child and anticipation of its future and it can be significantly determined by emotional influences. In this context Salajka (2006, p. 68, 69) notes, that the “tools assessing the HRQOL of children have until recently almost always been based on data from the relatives, usually the mother.” In this context Růžicková (2007) emphasizes the role of counseling, especially with psychological counseling.

Measurement of the quality of life of handicapped children may be even more complicated. QOL of specific client groups must be assessed so we could improve the quality and optimise the complex individualised intervention in order to achieve the maximum possible social integration of a handicapped person into the intact society. Růžicková (2006) states, that the subjective assessment of quality of life is the current trend in support for people with special needs. Even in this context the total QOL cannot be described only by health indicators. An illustration of this is the definition of health created by the National Institute on Disability and Rehabilitation Research – “Being handicapped does not equal being ill.” The international classification of functioning, handicap and health according to WHO on the other hand emphasises the social dimension of a handicap and the limitations arising from that (Vaďurová, Mühlpachr, 2005). In the recent decades there has been spreading an attitude, that the handicapped people themselves identify the elements of the “disabling environment” instead of the axiom, that the organic damage is the primary source of their problems. This has led to a significant change of paradigm, when the functional limitation was replaced with a model of a minority group, which faces basically the same problems as other disadvantaged groups (Hahn in Vaďurová, 2006, p. 88).

1.1 Underlying ideas of the research

The quality of life issues can be defined by several attributes, which illustrate the contemporary state of scientific research in this area – wide applicability, multi-dimensional nature, vague terminology, strong interdisciplinary overlaps, differing interpretations, fragmented concepts and multifactor conditionality. In spite of a great diversity in the theoretical background, models, approaches and terminology, the unifying element is the attempt to present a complex view of a person on various levels, which reflect the overall quality of life with an accent on the subjective feelings and the person's preferences instead of objectively measurable attributes. From what has been said above, from the fragmentation of the whole concept up to the subjective specifics of the quality of life, it leads us to the key question – Why should we study the quality of life anyway? Spilker (1990) notes that on the individual level the answer is self evident – the purpose is to optimise the intervention directed to a specific individual. This is the context, in which the concept of QOL assessment of children with ROP originated. Some characteristics of the eyesight disability may be an obstacle in the path towards life satisfaction, well-being, and can significantly affect the key pillars of the quality of life in the widest sense.

Depending from the extent of the retained eyesight functions and in relation to other accompanying complications arising from the degree of immaturity, there came an idea to assess the quality of life of children with this specific eyesight impairment. In this sense it is required to identify and fully analyse the specifics of the given target group and perform its thorough description in order to optimise the complex intervention process, which might, in an ideal case, lead to an improvement of the quality of life. The main goal of the research was subjective evaluation of the ROP impact on the quality of life of individuals, with the focus on child population. One of the partial objectives was to identify relevant QOL indicators specific for children with this type of eyesight impairment.

1.2 Survey design

Though the present dominant trend is to use quantitative methods to measure QOL, such as generic and specific questionnaires, the presented research is conceived as qualitative. So far the experts have not clearly solved the question, how can quality of life be assessed quantitatively and to what extent the used questionnaires are suitable for this purpose. In the context of the target group of our survey there is also the specific and so far not scientifically preferred field of QOL measurement of children, modified for children with health disability, often combined with other disabilities. Not only due to the aforesaid factors, the worldwide interest in the qualitative methods and qualitative approach as such is rising. We decided to reflect this trend and

conceive a qualitative design for our survey. Due to the character of the researched subset we consider qualitative methods as the most relevant.

Mareš (in Mareš et al., 2006) characterises qualitative approach to QOL assessment as an approach, which does not attempt precision and generalisation. Qualitative methods in general enrich our view of the examined problem and allow us to generate new hypotheses. “Svatoš, Švarcová (in Mareš et al., 2006, p. 174) point out to methodological difficulty, when a child subjectively assesses the quality of its own life – “Unlike adults here it is methodologically more difficult to get reliable data about quality of life from a self assessment – especially in case of little children, in general it can be said, that with falling age our diagnostic options decrease.” This is one of the reasons for combining a subjective self- assessment performed by children with ROP and proxy rating provided by parents or nurses.

Due to the problematic aspects connected with the assessment of QOL of children with visual impairment, the chosen data acquisition method is semi-structured interview, which should reflect the aforesaid problematic nuances so the interpretation imprecision is as reduced as possible. At the same time this method should contribute to a truly subjective assessment of the child's life quality and it should allow for identification of the subjectively important elements of the child's every day life.

1.3 Interpretation of the research outcomes

Our survey should help as a primary research about the development of children with ROP. The result is an integrative description based on authentic opinions and statements of the respondents, so we could paint a maximally complex picture about the life experiences of children with ROP in the context of their quality of life. During the realisation of the survey we chose the following research questions, whereas some of them emerged spontaneously from the data only during the very research:

- What are the characteristics of the quality of life with retinopathy of prematurity?
- In what way does retinopathy of prematurity affect the quality of life of children?
- What is the subjective perception of the quality of life of children with retinopathy of prematurity?
- Is retinopathy of prematurity subjectively viewed as something connected with worse quality of life?
- What areas of quality of life are considered by children with retinopathy of prematurity as subjectively problematic, or which are the most determined by eyesight impairment?
- How do children with retinopathy of prematurity view their quality of life and how does their view differ from the one of their parents?
- What is the role of the overall health condition in the assessment of the quality of life of children with retinopathy of prematurity?

Concerning the first of the research questions (What are the characteristics of the quality of life with retinopathy of prematurity?) our objective was to define the individually specific and subjectively assessed level of the quality of life. At the same time we wanted to define the specific predictors of QOL improvement based on identification of any specific indicators.

Though we used general measurement instruments to create the concept of the assessed QOL areas, the tool we designed can be considered as adequately sensitive. The spectrum of indicators corresponds to the empirically verified areas of QOL of the intact population, so we can expect that it captures all the relevant attributes. Schalock (2009, p. 5) confirms our approach on a more general level: "Individual quality of life is a multidimensional phenomenon consisting of key areas affected by both personality and environment. These key areas are the same for all humans, though they may differ individually according to the relative value and importance." The general measurement instruments thus reflect even specific indicators for the category of people with visual impairment, who however have different individually specific characteristics. Due to a relatively wide range of the used indicators, they can be expected to cover all the subjectively important aspects of the quality of life. At the same time the assessed indicators are identical with the determining factors of the quality of life of each individual, regardless the existence of any health problems. However the resulting profile of the quality of life bears the specific characteristics of a disability, in this case a visual disability.

The second of the presented research questions (In what way does retinopathy of prematurity affect the quality of life of children?) has a very wide scope – from individually specific characteristics of health condition – concerning the retained vision functions there are two extreme positions, when comparing the case studies and authentic interviews – through other anamnesis data confirming the aforesaid variability of the overall health condition; up to the characteristics of mental and social dimension related to the visual or even combined disability. Authentic statements, or individual QOL profiles allowed us to capture and describe all the differences in the individually specific quality of life indicators.

These aspects can be further connected with the interpretation of results related to the third and fourth question (What is the subjective perception of the quality of life of children with retinopathy of prematurity? Is retinopathy of prematurity subjectively assessed as something connected with worse quality of life?). It is clear, that ROP and complications connected with prematurity affect the quality of life. On the individual level, the question is, how to determine the subjectively perceived well-being. International research concerning the quality of life of people with disabilities examined a representative sample and proved specific features identified by a wide range of disabled people – a communication and information barrier between the intact population and the community of the disabled, which has implications

for social integration, acceptance and non-acceptance by the intact society and also identification with the community of the disabled. These characteristics are, due to the age range of the respondents, especially in the casuistic studies made by us.

Though it is not possible to reach a truly relevant generalisation, there is no denying, that ROP significantly determines the quality of visual perception and secondarily even the whole development of an individual concerning the possible strong vision impairment with all the described negative impacts and limitations. Another complication is the etiology factor of the ROP formation – prematurity implying a number of health complications, often life endangering, and late polymorbidity. The above mentioned attributes certainly contribute to the personal well-being and in the general sense they affect the quality of life of each individual.

The generally accepted view is that health disability implies a lower quality of life, however regardless the resulting health condition, which may or may not be affected by these factors, we would like to highlight an empirical confirmation of the “disability paradox” which brings also one of answers to the fourth research question (Is retinopathy of prematurity subjectively viewed as something connected with worse quality of life?) – it is a disparity between the objectively documented serious diagnosis and its expected serious impact as viewed by the exterior evaluators on one side and the subjectively positive evaluation of quality of life by the persons, who lives with health problems (Mareš, Marešová in Řehulka, Řehulková, Blatný, Mareš et al., 2008). Mareš, Marešová (in Řehulka, Řehulková, Blatný, Mareš et al., 2008) call it a paradox of the beneficial influence of health problems.

The research of this phenomenon has shown, that people with various types of health problems claim to have the same or even higher quality of life than people, who are healthy or “intact”. So we cannot a priori anticipate a lowered quality of life, even though serious scientific studies (Silva, Oliveira, Ferreira, Pereira, 2005) proved a significant impact of health impairment on the quality of life of an individual – as we have emphasised several times, in case of QOL it is a multifactor conditioned concept, which needs not necessarily be affected by health condition, or the limits arising from it. The authors also present an explanation for this divergence, as shown by Albrecht and Devlieger (in Řehulková, Řehulka, Blatný, Mareš et al., 2008, p. 11) using the theory of balance: “Many people with a serious disease can find a balance among the physical, mental and spiritual segment of their lives. They are helped also by the positive influence of their environment, whether it is social or nature environment.” This explanation can be applied also to the problem of health or visual disability. Our findings are more optimistic, than we had anticipated originally, not only concerning the retained visual functions, but also concerning the assessment of the overall development and the related social factors. In this context Salajka (2006) points to a very careful and reasonable interpretation of the data acquired from the QOL assessment. Also, considering the disability paradox, he warns about

the possibility of data distortion due to the prejudice, which automatically expects the health problems to have a negative impact on the quality of life. In this sense he highlights the individual hierarchy of life values, the level of adaptability to changed conditions and the ability to “perceive various aspects, which form the rich tapestry of everyday life, to what extent this influence will manifest, how much it is perceived by the ill person” (Salajka, 2006, p. 105). On the level of the third research question (What is the subjective perception of the quality of life of children with retinopathy of prematurity?), apart from the aforesaid disability paradox we can only highlight the individually specific profiles of the quality of life of each respondent.

Of all the proposed indicators of the quality of life, the most highlighted one – not only by our respondents – is the psycho-social dimension, which is – in compliance with the outcomes of the international handicapped person QOL assessment projects – the main troublesome dimension of a disability – which opens the question of the attitude of the intact population to disabled persons, the question of social integration, influence of the disability on the process of socialisation of an individual, the level of acceptance and non-acceptance of the handicap and identification with the community of the handicapped people and a number of other long term topical all-society issues – the influence of family and the upbringing attitudes of parents, social determinants (wider environment, other members of the same age group, contact with the community of the disabled) and other nuances. On this level we have actually answered the fifth question (What areas of quality of life are considered by children with retinopathy of prematurity as subjectively problematic, or which are the most determined by eyesight impairment?).

Concerning the sixth research question (How do children with retinopathy of prematurity view their quality of life and how does their view differ from the one of their parents?), there was assessed the hypothetically different viewing angle of the parent and the child about the ROP impact and the related QOL aspects. From the view of the researcher the parents were able to adequately and relative rationally assess the impact of the health problems and the disability on the life of the child. The realised interview also allowed them to reflect on the development of the child and to get a feedback. Schalock (2009) points out, that except providing the feedback there are also other ways, how the data can be useful for the parents – it can create their expectation that change is possible and it can occur on several levels. At the same time it confirms functionality of organisations in the sense of a holistic attitude to the client and comparison of the subjective and objective dimension. In this context it also clarifies the importance of the use of personal data, either in the form of individual or summary information on the organisational level – it highlights the need to allow sharing of information about the client’s outcomes and changes on various levels of support, to incorporate the information about the outcomes and the findings arising from that to the theory of scientific disciplines, and last but not least,

to define the individual, organisational and community factors, which may indicate the prospective development.

The specific features of the health care of the surveyed group usually have the attributes of a combined disability in the ROP context and also complications connected with prematurity, however some of the contacted respondents feel only minimum negative impact of the aforesaid factors. The level of retained visual functions seems relatively positive in this respondent group, compared with the anamnesis data from the case studies. In the sense of the last research question (What is the role of the overall health condition in the assessment of the quality of life of children with retinopathy of prematurity?) we can, again, only point to the individually variable influence on the quality of life.

Concerning the visual impairment and its negative impacts on the independent and his/Her well-being, the answer to the last question is clear – if the outcomes of ROP reach the dimension of visual impairment, the psycho-social indicators of QOL are modified in the above presented way.

As part of a specific module intended only for the parents, there was assessed not only QOL of their children in the sense of proxy rating, but we were also interested in the attitudes, feelings and knowledge of the parents concerning the options for the optimal development of the child. Again, we cannot reach a relevant conclusion with an adequate value, but in a number of specific examples we noted very rational democratic approach of the upbringing. However talking about the acceptance of the disability by the parents or by their children, proved to be embarrassing for the parents, as well as the topic of the options to identify with a group of disabled people in order to form an adequate identity of a disabled person. This issue of course has implication for the area of personal self-perception, but in a wider dimension also to the social integration area. From the interviews and the casuistic studies we can see an emphasised role of the family and family influence towards adequate socialisation, or social integration and the overall psycho-social dimension of the disability.

In general, our research aimed to become the first survey of a “new or complex area” and initiated a quantitative research while “proposing measurement procedures or acquiring a deeper insight into the specifics” (Hendl, www.kpg.zcu.cz/capv/HTML/5/5.pdf, p. 5). Our objective was not to create a generalising theory, but to provide a relatively complex picture of the quality of life of children with ROP so as to allow subsequent deep analysis of a quantitative nature.

2 Conclusion

What was the premise of our work, from what idea did the research design originate? These questions have been answered in the previous text, however, several characteristics will serve here for final balancing:

- Quality of life – multidimensional, broadly interpreted, multifactorially conditioned scientific concept attracting in the last three decades attention of expert public within the intentions of social disciplines.
- Retinopathy of the premature babies (ROP) – one of the main causes of sightlessness of children in the economically developed world, a specific disease characteristic for premature babies with low birth weight, which may and, at the same time, due to technological advance in the field of interventional procedures, does not have to lead to fatal consequences in the form of meaning loss of sight perception, respectively to sight disability.
- Extreme prematurity of a new born baby – factor carrying along a very wide spectrum of life threatening complications and late consequences, situations evoking a number of ethical dilemmas, key etiological factor of origin of ROP.
- Sight disability – attribute determining overall development of an individual, factor conditioning the socialization process and social integration process, one of key determinants of quality of life and the life satisfaction.

We decided to reflect these phenomena of contemporary scientific research on various levels of knowledge – the result is a concept of evaluation of quality of life of infant population with ROP with accent on subjective evaluation of impact of above presented factors, mutual interaction of which and determination of complexly understood quality of life in the sense of well-being – personal well being integrating in itself indicators of psychical and social health.

The objective of the research has been to formulate subjective influence and impacts of ROP onto the sphere of regular everyday life and the rate which determines its quality. We tried to evaluate to which extent ROP, and its consequences and other related aspects, influence the quality of life – physical and psychical state, way of life and the feeling of life satisfaction. Respectively we wanted to confirm empirically correlations between its consequences and altered quality of life. A partial objection was in this matter to find subjective importance and meaning of proposed indicators of quality of life for target group, while, at the same time, identifying other subjectively important factors. In this sense an analysis of the statements of children was a premise. The subject to measurement of quantitative nature was a category of children with ROP, whose current quality of life was evaluated.

The proposed indicators are, according to our opinion, relevant in relation to studied issues and, at the same time, these are identical with the determinants of quality

of life of each individual despite the presence of the health disability. However, the resulting profile of quality of life carries just the specific features of health disability, in our case sight disability in particular. Despite it is not possible to reach really relevant evaluation, it is evident that ROP significantly determines quality of sight perception and secondary the entire development of an individual in the sense of potential severe sight disability with all described negative consequences and limitations. As another complication factor comes to the front line the etiological factor of occurrence of ROP – prematurity implicating a number of health, often life threatening, complications and late polymorbidity. The outlined features are undoubtedly taking part in the feeling of personal well-being, in the most general sense of the word these influence quality of life of every individual. However, without taking into account the health state, which may or may not be influenced by these described factors, we would like to stress the empiric proof of, so called, disability paradox – illustrating case may be case study of Lukas, on the basis of which we may predict his positive future development towards self-reliant, independent and satisfactory life. Of all the proposed indicators of quality of life psychosocial dimension is accented, not only by our respondents. It is in line with the conclusions of international projects evaluating quality of life of persons with disability, the main acrid dimension of disability – here comes a question of the approach of intact population towards the persons with disabilities, The area of social integration, influence of disability on the socializing process of socialization of an individual, level of acceptance and not acceptance of disability and identifying with a community of persons with disability and a number of others long term topical society-wide topics.

The results of empiric research would, in ideal case, be reflected in optimizing of special pedagogy intervention process with the observed category of individuals with sight disability – both on individual levels, towards improved quality of the approach of professionals, and on the level of organizations in the sense of interdisciplinary cooperation. An integral part of this requisite represents enrichment of theoretical base of special pedagogy of person with sight disability by the phenomenon of the quality of life and especially by the problems of ROP, to which adequate, and from the point of view increasing incidence ever more accenting, attention has not been paid so far. We expect that applicable potential of the research output may be found not only in the field of social pedagogy, but also in medicine, respectively in neonatology and ophthalmology practice. The presented proposals for practice aim also to this conclusion. At the same time the resulting findings may project into the process of creating of a standardized specific tool for measuring the quality of life for the category of persons with ROP. In association to this was one of partial objections checking the extent of proposed concept of evaluating of quality of life of children with this specific disease on a relatively small group and its viability and its use for further applied research.

In general approach our research sought primary acknowledgement “with a new and complicated field of science” and initiation of quantitative research “with proposal of measuring procedures or reaching of deeper insight into peculiarities” (Hendl, www.kpg.zcu.cz/capv/HTML/5/5.pdf, p. 5). Our objection was not to establish a generalizing theory, but rather to present a relatively complex picture of life of children with ROP.

The key objection of this work was to broaden theoretical base of special pedagogy for persons with sight disability on the basis of longitudinal quality oriented research by, so far never reflected, issues of quality of life of persons with ROP and to open space for related applied research. Secondly, these efforts should lead to optimizing of complexly understood intervention towards the given target group.

On individual level our objection was not only to present particular life histories, but, at the same time, using this self-evaluation secondarily provide to respondents, respectively to their parents, a feedback, opportunity for self-reflection. On the level of cooperation with professionals should these features, related from distribution of information, to adequacy of approach of experts, and the level of empathy, via interdisciplinary cooperation as far as optimized accessibility of services on various levels, illustrate a very real picture of used services, which should be a premise for further applied research aiming towards saturation of specific needs of individuals with sight disability resulting from ROP and towards increased quality of their everyday life. The pivot point of this idea is achievement of independent, self-reliant and satisfied life on various levels in the sense of well-being.

Conclusion of this work is not based on rough scores or statistical data, not even on generalized theory – it is based on description of images of particular authentic life histories of children with ROP.

3 Literature

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