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PRETERM BIRTH OF CHILDREN: A CURRENT STUDY CONCERNING THE PROBLEMS OF AFFECTED WOMEN AND PUBLIC KNOWLEDGE

ABSTRACT: The issue of prematurity is current as never before. Owing to advanced medical techniques extremely young and light neonates can survive, but the consequences for the child's health and the resulting psychological problems of the affected women are subjects that are often disregarded. In this study the problems of women with preterm children were examined by questionnaire. Additionally, the knowledge and opinion of the public concerning the whole problematic nature of prematurity have been clarified. We found that affected women get most support from their private environment, while social structure of the society seems to fail in some way. The public in Germany have basic knowledge about causes and risks and other topics, but overestimate, for example, the frequency of premature birth. In summary, the results of this approach suggest that both better social support of preterm children and their families, and extensive enlightenment of the public, are needed.

KEY WORDS: Preterm birth – Risk pregnancies – Neonatal intensive care – Ethical and social problems – Public knowledge – Germany

INTRODUCTION

Premature birth of children is an active topic in modern societies and has also been important in earlier times, e.g. the Traufkind¹ situation at the end of the Middle Ages. Modern technology and research allow the survival of children with an extremely low gestational age and/or birth weight. The World Health Organisation (WHO) defines a child born between the 24th and 37th gestational weeks, with a birth weight from 500 to 2500 g, as a premature

birth. The limit of 24 weeks, as well as the lowest birth weight of 500 g, is today undershot in many cases. This is why the risk of lifelong handicap is not falling, despite an approximate constant frequency of premature birth and a decreasing mortality. "Prematurity is [...] known to be a major determinant of neonatal morbidity and mortality in both developed and developing countries" (Chen *et al.* 1996: 53), and the outcome for preterm children is mostly unclear and unpredictable (Sarimski 1996a).

A multitude of studies have investigated the causes and risks of premature birth and examined the results in affected children. A reduction of the occurrence of prematurity is extremely difficult, since it is conditioned by the intense correlation of the different causes and risks (see *Figure 1*). There are different attempts at prevention strategies, for example a self-test by a pH-testing glove, favoured by several German health insurance schemes, or progesterone therapy during pregnancy (Hack, Fanaroff 1999, Spong 2003). However, it is indisputable that the abatement of

¹ In the late Middle Ages and the beginning of modern times the Christian people of Europe thought that infants dying without being christened could not get to heaven and become blessed. New-born or preterm born children were mostly affected. To prevent such a bad destiny, the parents buried their babies under the eaves gutter ("Traufe") of the church, so that the rainwater coming down could christen the children subsequently (Ulrich-Bochsler 1997).

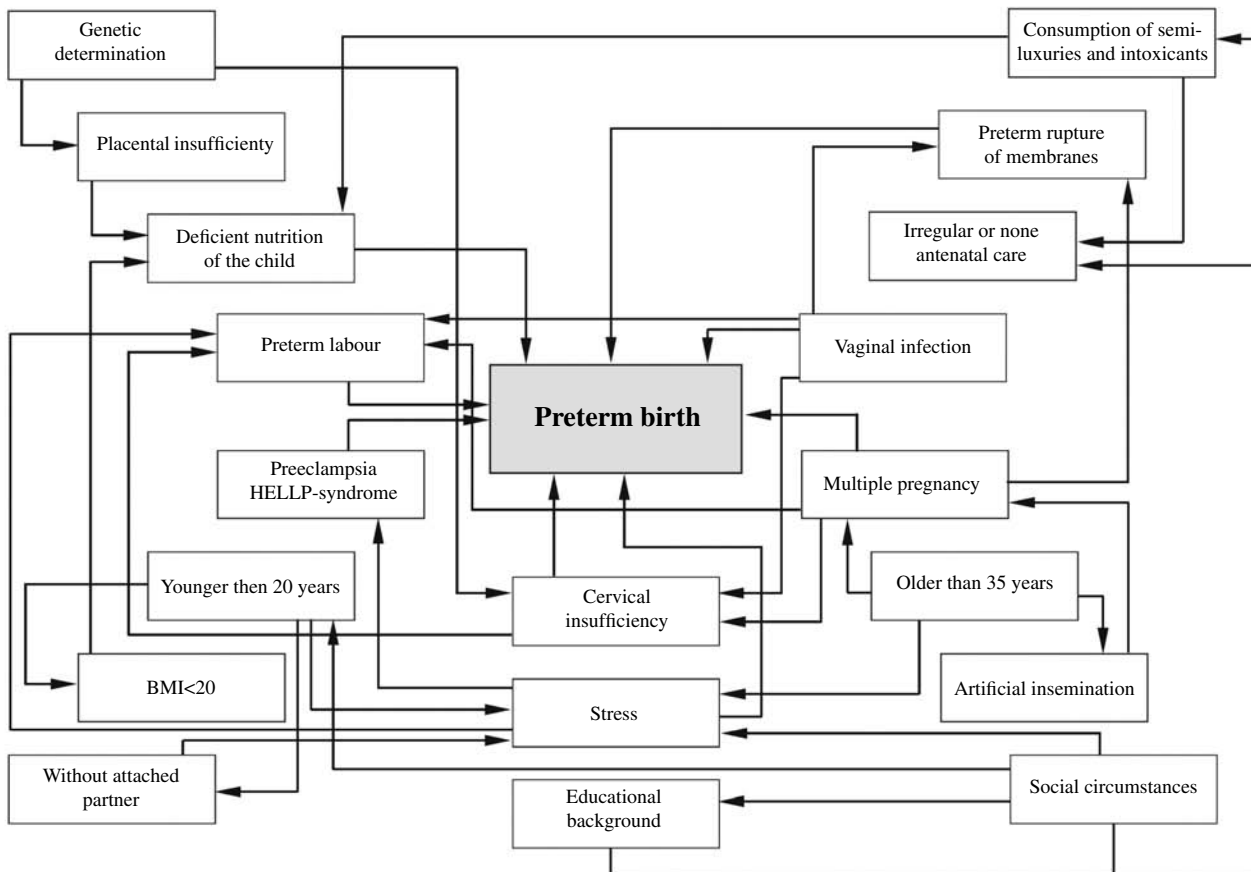


FIGURE 1. Correlation between causes, risks and other influence factors for prematurity.

one risk factor is not adequate for reducing the frequency of preterm birth. It is also very important to achieve a better enlightenment of the public because there is not enough public information concerning this subject (Massett *et al.* 2003, Hardt 2005).

The incidence of prematurity and its social importance is not the same among different industrial countries. For instance, this problem is 12 % more common in the USA than in European countries (Massett *et al.* 2003), where the rate ranges from 5 to 7 % (Kristensen *et al.* 1995, Martius *et al.* 1998, Rudanko *et al.* 2003), and the consequences are therefore more distinct. Reasons for this imbalance of the distribution of prematurity vary with different influences of the various risk factors and the diverse public health systems. Nevertheless "prevention of preterm delivery is of financial and social value" (Krymko *et al.* 2004:160) in all affected countries; the clinical costs for the early months amount in average 30,000 to 70,000 Euros (similar costs appear normally in the gerontological stage of life).

Consistent with the influence of prematurity, the effects that a preterm child implies for the life-planning of the parents are also remarkable. They are closely related to the concept of the human child as a physiological preterm birth, and the reduced extra-uterine time for development of locomotion, as opposed to the maturity of the nervous system and senses. Neither should the impact of a preterm baby on the parents' life be underestimated. "Preterm birth

is a dramatic event for the infant born early, causing distress for child and parents while also burdening both parents and society" (Moutquin 2003: 33). Emotional strains are closely connected with a huge variety of problems that emerge in combination with prematurity of a child (see *Figure 2*). For affected parents psychological aftercare is indispensable and should, amongst other things, involve the current state of the baby, the relationship between mother, father and child, reactions at the intensive-care unit, and the experience with social support (Sarimski 1996b). Another problem in this context is the parental situation, beginning with support during the pregnancy and the integration in nursing the babies, and ending in psychosocial aftercare.

Also important is the ethical component of prematurity. This refers to the question to what extent medical care on the neonatal intensive-care units is necessary, and its possible harming impact (Marcovich, de Jong 2003). It is also questionable in which cases maximum medical care for a preterm child is wise, and who should decide whether such care should be continued or not. Regulation by law is for example very different among the European countries. In Germany the "Einbecker Empfehlung", written by lawyers and ethical societies is valid. They commit that a baby should get neonatal intensive care if it shows signs of life, and that parents and doctors should make decisions about the duration and intensity. Other European countries, e.g. The Netherlands or Switzerland, do not intervene for

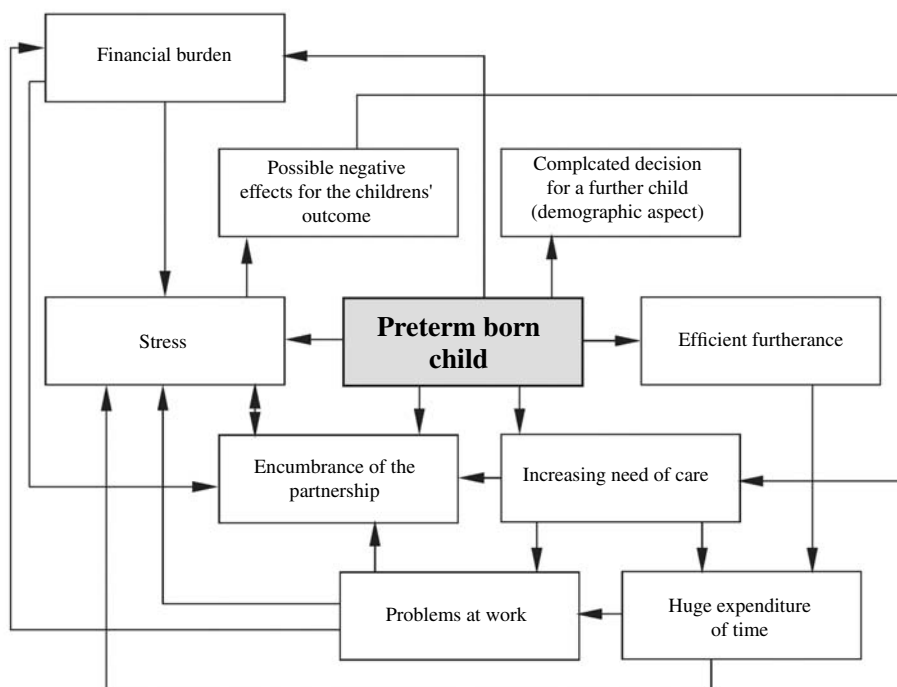


FIGURE 2. Possible effects of a preterm child on the parents' life.

children born before the 25th week of gestation. So this is a highly controversial topic which requires discussion.

MATERIAL AND METHODS

The inquiry here is restricted to German people and is divided into two parts: an inquiry about women with children born preterm, and an examination of public knowledge about this subject.

By means of an online questionnaire completed by 133 female members of an internet group (www.fuehchen-netz.de), information was collected about the social status, the family expectations, medical doctors and social institutions, problems during the pregnancy, and additional perinatal data of the preterm child.

TABLE 1. Occurring causes and risk factors in the present sample (a selection).

Causes and risk factors decisive for premature birth
Vaginal infection → preterm labour, preterm rupture of membranes
Preeclampsia/HELLP-syndrome
Deficient nutrition of the child → growth retardation
Pathological heart sound → danger to life
Former pregnancy ending with a miscarriage/abortion
Primiparous women vs. women who already gave birth
Multiple pregnancies
BMI<20
Short or long period between the pregnancies
Stress and other problems

The anonymous inquiry of 291 participants by a questionnaire (directly or online) was used to elicit the knowledge and opinions of the public concerning prematurity.

Both datasets were evaluated by SPSS®, and summarized by graphs and tables to show present trends. Additionally, the results were compared with an American study carried out by Massett *et al.* (2003), to point up possible differences.

RESULTS

Inquiry of affected women

Traceable risk factors

Some of the known causes and risk factors for prematurity (see *Table 1*) occur in the present set of affected women. These are mainly consistent with diseases resulting from the pregnancy (e.g. preterm labour or HELLP-syndrome), foetal problems (e.g. growth retardation) or increasing stress. It is important to remember that all the occurring causes and risk factors can appear simultaneously or be influenced by each other (see *Figure 1*). Consequently in the present data it is hard to say which was the main reason for the preterm birth.

Present problems and complaints

Looking at the problems the women had to handle during pregnancy, *Figure 3* shows that physical complaints occur more often than psychological ones; this distinction disappears when the focus is on the last third of the pregnancy (see *Figure 4*). Along with typical pregnancy problems like sickness, heartburn or pain in the back,

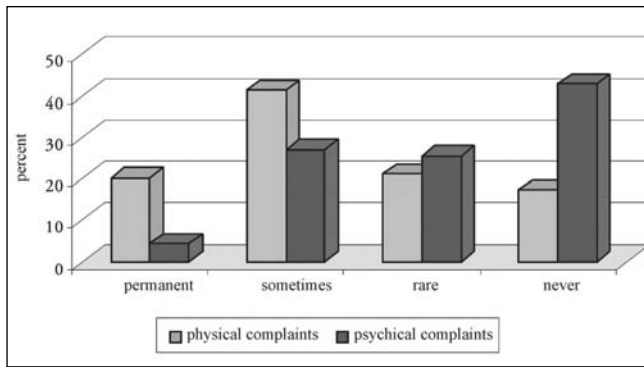


FIGURE 3. Frequency of physical and psychological complaints. (n=133)

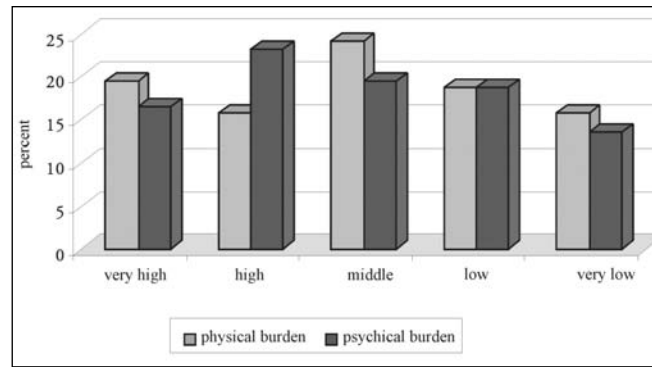


FIGURE 4. Intensity of physical and psychological complaints during the final third of the pregnancy. (n=125/122)

problems typical of preeclampsia (e.g. high blood pressure, oedema) occur more often. Such things can cause a preterm birth. In fact, looking at the distribution of causes for prematurity of the children in this set, the listed complaints and their frequencies are as expected. The psychological problems occur mostly in connection with the diagnosis of "risk-pregnancy", which is subsequently followed

TABLE 2. Stress factors emerging during the pregnancy (succession given by the frequency of quoting).

Main stress factors cropping up during pregnancy
Problems at work
Family problems, for instance concerning care of siblings
Fears and psychological complaints
Problematic course of the pregnancy
Sorrow, anxiety and uncertainty regarding the child
Problems in the partnership
Increased susceptibility to stress
Financial unease
Diagnosis of the doctors and their insensitivity, low empathy and partly incompetence and little attention respectively
Result of the preceding pregnancy
Physical problems like bleeding, preterm labour or oedema

by gloomy thoughts about a chaotic pregnancy or the development of the child. Additional stresses at work, in the family or the partnership, worsen the situation (see Table 2).

Absent aid, occurring assistance and actual problems

Table 3 summarizes the assistance affected women could rely on and the aid they wished to have, both during pregnancy and after the birth. It is obvious that the partner gave most of the support, followed by the family and friends. Information and enlightenment have also been important, as well as contact and dialogue with other affected persons. After the birth the women mainly get help from contact with and nearness of their child (e.g. breastfeeding, further providing). Psychological support, more information concerning the risks and causes of preterm birth and the occurring problems of the child and medical measures, as well as financial relief from the health insurance schemes, was also absent. Doctors were not regarded with great confidence. *In toto*, the affected women in this set mostly got help from their private environment, while there seems to be a general lack of support in the social structure of German society.

TABLE 3. Assistance affected women had, or wished to have, during the pregnancy and after birth (a selection).

	During the pregnancy	After the birth
Available assistance	<ul style="list-style-type: none"> - Support and aid of the partner - Support of the family - Support of friends - Competent medical doctors, nursing staff and midwives - Dialogue/contact with other affected persons 	<ul style="list-style-type: none"> - Support and aid of the partner - Support of the family - Contact with and bonds to the child (e.g. breastfeeding) - Contact and dialogue with other affected persons - Information and education
Missing assistance	<ul style="list-style-type: none"> - Confidence in doctors with regard to the result of the pregnancy - Better education concerning the risks and causes of premature birth - Employers and colleagues should show more regard; earlier maternity support - Financial relief from health insurance schemes (e.g. for help in the household) - Psychological help to be better prepared for the situation 	<ul style="list-style-type: none"> - Support of health insurance schemes regarding reimbursement of expenses for measures of furtherance and travelling expenses - Psychological aftercare to work up the premature birth - More appreciation of the medical doctors for sorrow and fears, a confident focus with regard to the children's outcome - Explanations pertaining to possible problems and medical measures - Dialogue with other affected persons; self-help-groups

Most women need more help in understanding the development of their child, more sensitivity and insight from the doctors, a better extended network of self-help-groups and less bureaucracy (e.g. simplified application forms for travelling expenses or help in the household). Apart from the fear regarding the welfare of their child, the women complained of insufficient psychological or financial help. This resulted from their lacking information and enlightenment, and their increasing isolation as a consequence of the absence of support and understanding.

Public inquiry

Present trends

The self-estimation of the respondents makes it obvious that they do not feel very proficient on this subject and have not engaged themselves in this topic. This inquiry shows clearly that TV or printed media (see Figure 5) predominantly influence knowledge concerning prematurity. So it is not surprising that the majority of participants cannot give a distinct definition what a premature birth is. Mostly they defined it with an inaccurate statement of the gestational age, and in few cases does the definition given include both the gestational age and the birth weight.

In the same way only few knew the frequency of premature birth in Germany, the average of which is about 17%. Approximately 71% believe that the number of preterm births per year has risen in the last 10 years. Both estimates are not appropriate; in reality the frequency of premature birth has stayed steady at about 6 to 7% for the past 10 years.

Prematurity appears to be a greater problem in the industrial countries than in the developing ones, taking the opinion of the questioned sample (76.3 vs. 22.0%). Within the industrial countries the participants believe that the USA/Canada have the greatest problem with premature birth.

When asked what group of women has the highest risk for a preterm birth, the respondents answer that they are women older than 35 (57.7%) or those who are pregnant for the first time (79.7%). Women younger than 20 years, and those who have had a stillborn child, are expected to have the lowest risk.

Looking at the reasons believed to be causal for premature birth, it is clear that the consumption of semi-luxuries and intoxicants like alcohol, tobacco or illegal drugs, is estimated to have an extremely high influence (see Figure 6). Stress is also rated as an important factor. The influence of health factors that arise throughout pregnancy, and of environment and inheritance, is estimated to be less strong. The importance of stress is underlined by the

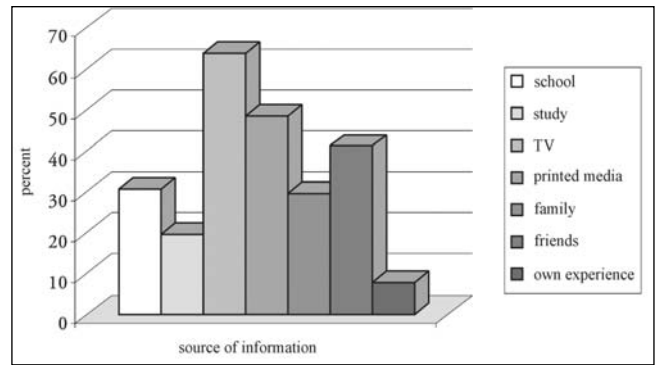


FIGURE 5. What are the sources of information concerning the topic of premature birth? (n=291)

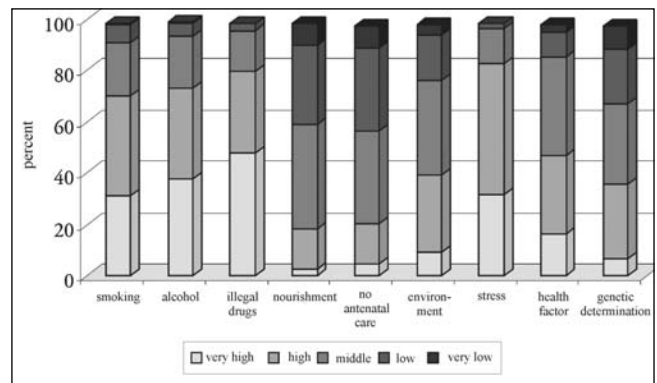


FIGURE 6. How strong is the impact of certain reasons on premature birth? (n=287)

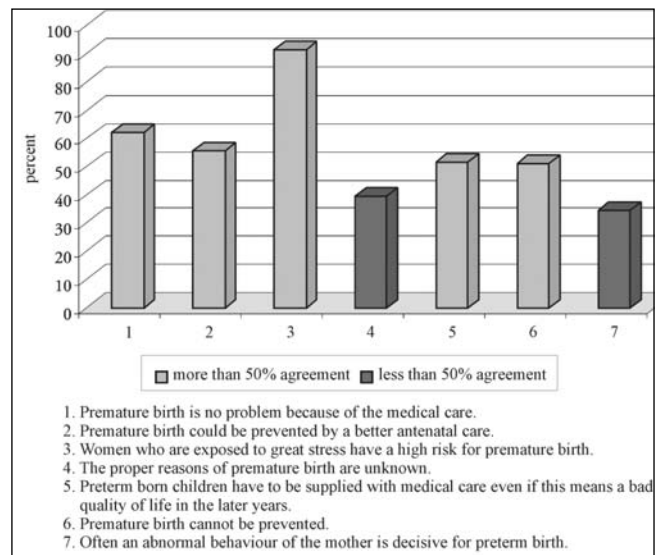


FIGURE 7. Statements the participants agreed to. (n=284)

TABLE 4. Consequences of shortened duration of pregnancy for the life and outcomes of the children (values in percent).

	Child dies in the hospital	Child dies during the first year	Child survives with health problems	Child survives without appreciable problems
34 weeks	0	0.3	10.0	89.0
24 weeks	15.1	13.7	62.9	5.8

fact that 91% can agree to the statement "women who are exposed to great stress have a high risk for a preterm birth" (see *Figure 7*). The majority of the respondents only disagree with the statement "the true reasons are unknown" and "often an abnormal behaviour of the mother is decisive for the prematurity of the child".

Concerning outcomes the picture drawn by the participants is realistic (see *Table 4*). 89% suppose that a child with a gestational age of 34 weeks will survive without problems, while 62.9% believe a 24-week-old child will only survive with health problems.

Comparison with the American study

Knowledge and opinion in terms of premature birth is basically the same in the two studies. The definition, the frequency, the statements regarding the causes and other subjects, and opinions about the outcome for the children, are nearly the same. One big difference lies in belief whether "abnormal behaviour of the mother causes the child's prematurity". While German respondents rejected this statement, the Americans consented. It is remarkable that both Germans and Americans think that stress is an important release for premature birth.

DISCUSSION

Results within a social and ethical context

It is remarkable that the most frequent causes of prematurity in this set are infections that arise during the pregnancy. The participants in the public inquiry to have high to mediocre influence estimate these reasons. The question of why such conditions (e.g. preeclampsia, HELLP-syndrome) occur, and lead to preterm birth despite the fact that in most cases physical indications like oedemas, becomes evident. Among the reasons for this is the lack of antenatal care, in particular with regard to the enlightenment of the pregnant. On the other hand, antenatal care in Germany seems to be very professional and cautious. About 60 to 80% of pregnant women are classified as having a "risk-pregnancy". These women have to go through a number of examinations, in most cases without sufficient explanation. This means an increasing stress, which is also a risk factor for premature birth.

In the present sample of women stress is repeatedly named as a psychological problem, particularly during the last third of the pregnancy. Likewise the respondents to the questionnaire suppose stress to be of very high influence on the risk for preterm birth. And beyond medical diagnosis and insufficient explanation, financial and vocational problems have to be added. This hints that, for instance, an earlier maternity support is needed to reduce stress. Also, more assistance by health insurance schemes concerning financial relief (e.g. for help in the household) is required. In this context, the question has to be asked how far social networks and, in particular, the family as an institution, still work in this society. Many women in the present sample wish to have more support from family and friends, but even

more from public institutions. Thus it seems that in modern society social competence for dealing with such problems is missing, maybe not only as a result of growing egoism and/or ignorance, but as a consequence of increasingly reduced social states.

Another question is about costs and benefits and, in consequence, how much every single person is willing to do and pay, respectively. Remembering that intensive care in the early months is relatively expensive (Krymko *et al.* 2004), continuing intervention in later years is in most cases very cost-intensive, too. Serious support of affected children is not only a request of the mother, but was also demanded by the questionnaire respondents. Nevertheless, some participants voice ethical doubts whether life-extending methods are needed and reasonable in all cases. In both parts of this study there are only a few concrete statements about this critical subject. This shows the unclear situation of the law and the frequent exceeding of the defined lower limit of premature birth.

Psychological problems among the mothers commonly arise as a result from the difficult and mostly unpredictable outcomes among the children (Sarimski 1996a, 1996b). Beside problems that arise through the situation itself, medical care at the neonatal intensive-care units can lead to an insufficient contact between mother and child, and thus result in poor or even nearly missing bonds. In addition to this emotional factor it is a question whether those intensive-care units should not better be influenced by humans than dominated by technical machines and instruments (Marcovich, de Jong 2003).

It is apparent that in many fields there is not enough information and education. Thus, more energy has to be invested to inform the public in general and pregnant women in particular about causes and risks, the prevention of preterm birth, and the outcomes among premature children. This involves increasing research on each of these topics.

Critical remarks about this study

Both of these inquiries could be optimised. In the questionnaire study the most important point is to increase the rate of return (76% in the present study). The main criticism of the second inquiry is that there was no comparative group of women who had a normal pregnancy. Thus there is a problem with the data validity, because the answers cannot really be put in a causal relationship with the prematurity of the child, although the incidence of the problems named seems to be quite typical for affected women. Direct questioning of those women would have been desirable for several reasons. For this would not only avoid misunderstanding, but would also lead to acquiring more extensive information. Such a proceeding was initially planned, but could not be realised for organisational reasons and data protection. In summary, this study serves as a pilot project, and can be used for optimizing further investigations. In fact the participating women gave some suggestions concerning interesting ways to proceed, for example by profiling psychological

aftercare, and the impact of the premature birth of the child on the partnership.

CONCLUSIONS

Although the public is aware of the subject of premature birth, its knowledge is limited. Nevertheless, the majority of the public is interested in this subject, and seems to know and discern the necessity of taking suitable measures. The clinical inquiry shows that the affected women get together and develop a certain self-confidence, in particular in this time of the World Wide Web and the possibilities of forums and online self-help groups. It is desirable that critiques of medical doctors, health insurance schemes and the environment of those women, should help to change the focus and to improve the situation. Current research, and especially reports in the television and newspapers, should not only yield information about the so called "infant prodigies", but also provide a realistic picture of the situation and supply basic scientific insight.

It is crucial to recognize that the present study can only deliver a little insight into the wide field of the problematic nature of prematurity. The information collected cannot give a complex image, but does serve as a platform for further research. The mode of questioning, as well as the questions, needs to be more direct and intensive. It remains, for example, uncertain how people see the effects of premature children in relation to actual social problems such as the reduction of social benefits or an increasing rate of old and diseased persons. Especially, the ethical question about "saving the life at the cost of health or psychological problems" has to be a central subject of future research. Further, it is important to show precisely where deficiencies of education require an altered and enhanced kind of information. Improved communication, with a closer dialogue between affected people and their environment, will help them to react adequately, with proper assistance for parents and children alike.

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