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高危儿随访情况分析及其父母生命质量调查研究*

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摘要 目的: 了解高危儿随访情况并对其父母生命质量进行调查。方法: 选取 2017 年 5 月~2019 年 5 月于西安交通大学医学院附属三二〇一医院儿童保健科就诊的 400 例高危儿作为研究对象, 分析 400 例高危儿的高危因素, 统计随访次数, 分析随访次数 1~2 次的高危儿的失访原因, 同时采用 SF-36 量表评估高危儿父母与正常儿父母的生命质量。结果: 按照占比从高到低的顺序, 400 例高危儿的高危因素分别为早产、低出生体重、高胆红素血症、窒息和(或)缺氧缺血性脑病、颅内出血、母亲高危因素、吸入性肺炎及其他, 占比分别为 74.00%、18.50%、13.25%、6.75%、2.75%、2.50%、1.25%、2.00%。400 例高危儿中随访次数 1~2 次 183 例, 占比 45.75%, 3~5 次 57 例, 占比 14.25%, ≥ 6 次人数 160 例, 占比 40.00%。183 例随访次数 1~2 次高危儿失访原因主要是有问题再来医院、孩子正常、不了解随访重要性、自己有育儿经验、孩子小, 不方便等。高危儿父母生理机能、生理职能、躯体疼痛、一般健康状况、精力、社会功能、情感职能、精神健康评分均低于正常儿父母(均 $P < 0.05$)。结论: 高危儿的随访失访率相对较高, 其主要原因可能与父母的主观意识有关, 此外, 高危儿父母生命质量降低, 临床工作中可通过加强高危儿系统管理以及对高危儿父母的宣教力度, 从而降低失访率, 提高高危儿父母的生命质量。

关键词: 高危儿; 随访; 失访原因; 生命质量; 高危因素

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Follow-up Analysis of High-risk Infants and Investigation of Their Parents' Quality of Life*

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ABSTRACT Objective: To study the follow-up of high-risk infants and to investigate their parents' quality of life. **Methods:** 400 high-risk infants who were treated in the Child Healthcare Department of 3201 Hospital Affiliated to Medical College of Xi'an Jiaotong University from May 2017 to May 2019 were selected as the research objects. The risk factors of 400 high-risk infants were analyzed, the follow-up times were counted, and the reasons for the loss of high-risk infants with 1-2 follow-up times were analyzed. Meanwhile, SF-36 scale was used to evaluate the quality of life of parents of high-risk infants and normal infants. **Results:** According to the order of proportion from high to low, the high-risk factors of 400 high-risk infants were preterm birth, low birth weight, hyperbilirubinemia, asphyxia and/or hypoxic ischemic encephalopathy, intracranial hemorrhage, high risk factors for mothers, inhalation pneumonia, others, accounting for 74.00%, 18.50%, 13.25%, 6.75%, 2.75%, 2.50%, 1.25% and 2.00% respectively. The 400 high-risk infants were followed up for 1~2 times in 183 cases, accounting for 45.75%, 3~5 times in 57 cases, accounting for 14.25%, and ≥ 6 times in 160 cases, accounting for 40.00%. The main reasons for the loss of 183 high-risk infants were that they came back to the hospital with problems, normal children, understanding the importance of follow-up, they had parenting experience, and the children were small and inconvenient. The scores of parents' physiological function, physiological function, somatic pain, general health status, energy, social function, emotional function and mental function of high-risk infants were all lower than those of parents of normal infants (all $P < 0.05$). **Conclusion:** The follow-up loss rate of high-risk infants is relatively high, and the main reason may be related to the subjective consciousness of parents. In addition, the quality of life of parents of high-risk infants decreased. In clinical work, we can reduce the rate of missing visits and improve the quality of life of parents of high-risk infants by strengthening the systematic management of high-risk infants and educating parents of high-risk infants.

Key words: High-risk infants; Follow-up; Reasons for the loss; Quality of life; High-risk factors

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前言

高危儿指由于早产、低出生体重、宫内缺氧、窒息、感染、营养不良、低血糖、颅内出血、高胆红素血症等各种原因可能引起大脑损伤,从而引起远期智力低下和脑瘫等后遗症发生的新生儿。目前,普遍认为早产,高胆红素血症,颅内出血以及低出生体重等均可能引发高危儿的出现^[1,2]。虽然医疗水平的逐渐提高在一定程度上提高了高危儿存活率,但部分高危儿可能出现不同程度的生长发育障碍问题,其风险高出普通婴幼儿的7~9倍,对其正常生长发育以及身心健康造成了极大的威胁^[3,4]。由此可知,寻找一种有效的干预措施,可能是有效改善高危儿生存质量的重要途径^[5,6]。此外,婴幼儿是父母生命的延续,在家庭中占据着至关重要的地位,其身心健康与否直接影响父母的生命质量。如何有效保证婴幼儿的正常生长发育以及身心健康显得尤为重要,亦是目前围产医学重点关注的问题之一^[7,8]。鉴于此,本文通过研究高危儿随访情况并对其父母生命质量进行调查,旨在明确高危儿的高危因素,加强随访工作,从而为其相关系统管理方案的制定提供参考,现作以下报道。

1 资料与方法

1.1 一般资料

选取2017年5月~2019年5月于西安交通大学医学院附属三二〇一医院儿童保健科就诊的400例高危儿作为研究对象。400例高危儿中男277例,女123例,胎龄1~28d,平均胎龄(17.83±4.38)d。纳入标准:所有高危儿均与《实用新生儿学》(第3版)^[9]中所制定的相关诊断标准相符;高危儿父母对本研究知情且签署同意书。排除标准:存在明显畸形的高危儿;出院前死亡的高危儿。高危儿父母791例,纳入标准:年龄18~45岁;孕母为宫内感染高危人群、其新生儿均存在脑损伤高危因素。排除标准:存在人格障碍、吸毒、酗酒、精神病史或伴有特殊药物应用史。另选取同期于我院接受体检的正常儿的父母(n=797)作为高危儿父母的对照,纳入标准:年龄18~43岁,且智力无异常,无高危儿父母纳入标准中的各项高危因素。排除标准:既往有精神疾病史者;合并严重脑器质性疾病史者。其中

高危儿父母年龄23-41岁,平均(27.33±3.72)岁;正常儿父母年龄22-40岁,平均(26.99±3.31)岁。高危儿父母与正常儿父母年龄的比较无差异(P>0.05),具有可比性。此研究已获西安交通大学医学院附属三二〇一医院伦理委员会批准。

1.2 研究方法

(1)高危儿专档管理与随访制度的构建:以新生儿科、儿童保健科和产科共同组成高危儿管理小组。新生儿科主要职责在于对高危儿家长进行健康宣教,并叮嘱出院后儿童进行性保健门诊随访;儿童保健科则负责追踪随访,并设立儿童体检门诊,选用专人进行管理高危儿档案,以发信息或(和)打电话等途径督促家长定期随访;产科主要负责在28d内访视高危儿,并通过开展家长课堂的方式,宣教儿童保健的重要性。(2)随访:出院后即开始随访,每2周行1次随访。参照《0~6岁儿童神经心理评定量表》^[10]完成高危儿发育状况的检查评估。(3)生命质量调查:高危儿父母与正常儿父母的生命质量情况通过健康调查简表(the MOS item short from health survey, SF-36)进行评估,涵盖生理机能、生理职能、躯体疼痛、一般健康状况、精力、社会功能、情感职能、情感职能评分8个项目。每个项目评分均为百分制,评分越高提示生命质量越佳^[11]。(4)质量控制:相关管理科室定期3个月召开1次会议,统一检查与诊断标准,并对随访结果予以讨论、分析。(5)失访原因调查:以电话问卷的形式进行调查,参照我院自制的调查问卷,对随访次数为1~2次的高危儿的失访原因进行调查。

1.3 统计学分析

数据分析主要借助SPSS23.0软件完成,以($\bar{x} \pm s$)进行计量资料的表示,实施t检验。以P<0.05说明差异有统计学意义。

2 结果

2.1 400例高危儿的高危因素分析

按照占比从高到低的顺序,400例高危儿的高危因素分别为早产、低出生体重、高胆红素血症、窒息和(或)缺氧缺血性脑病、颅内出血、母亲高危因素、吸入性肺炎及其他,占比分别为74.00%、18.50%、13.25%、6.75%、2.75%、2.50%、1.25%、2.00%,见表1。

表1 400例高危儿的高危因素分析
Table 1 Analysis of risk factors in 400 high-risk infants

High risk factor	n	Proportion(%)
Preterm birth	296	74.00
Low birth weight	74	18.50
Hyperbilirubinemia	53	13.25
Asphyxia and/or hypoxic-ischemic encephalopathy	27	6.75
Intracranial hemorrhage	11	2.75
High risk factors for mothers	10	2.50
Inhalation pneumonia	5	1.25
Others	8	2.00

2.2 400例高危儿随访次数分析

400例高危儿随访次数为1~2次的人数183例,占比为

45.75%,3~5次人数57例,占比为14.25%,≥6次人数160例,占比为40.00%,见表2。

表 2 400 例高危儿随访次数分析
Table 2 400 follow-up times of high-risk infants

Follow-up times	n	Proportion(%)
1 time	79	19.75
2 times	104	26.00
3~5 times	57	14.25
6~11 times	109	27.25
≥ 12 times	51	12.75
Total	400	100.00

2.3 183 例随访次数 1~2 次的高危儿失访原因分析 183 例随访次数 1~2 次高危儿失访原因主要是有问题再来医院、不了解随访重要性、孩子正常、自己有育儿经验、孩子小、不方便等,见表 3。

表 3 183 例随访次数 1~2 次高危儿失访原因分析
Table 3 Analysis of reasons for missing follow-up visits of 1-2 times in 183 high-risk infants

Reasons for missing	n	Proportion(%)
Come back to the hospital with problems	175	95.63
Understanding the importance of follow-up	170	92.90
Normal children	162	88.52
They had parenting experience	157	85.79
Children are small and inconvenient	145	79.23
Busy with work	74	40.44
Difficult to see a doctor	65	35.52
Traffic inconvenience	59	32.24
Forget follow-up	50	27.32
Family financial tension	41	22.40
Others	30	16.39

2.4 高危儿父母与正常儿父母 SF-36 评分比较 见表 4。
高危儿父母各项 SF-36 评分均低于正常儿父母 (均 $P < 0.05$),

表 4 高危儿与正常儿父母 SF-36 评分的比较(分, $\bar{x} \pm s$)
Table 4 Comparison of SF-36 scores between parents of high-risk infants and normal infants(scores, $\bar{x} \pm s$)

Projects	Parents of high-risk infants (n=791)	Parents of normal infants (n=797)	t	P
Physiological function	84.28± 12.15	88.56± 10.39	7.510	0.000
Physiological function	51.03± 31.29	56.94± 34.11	3.611	0.000
Somatic pain	80.27± 12.23	84.12± 13.92	5.877	0.000
General health status	78.29± 14.23	83.05± 15.75	6.343	0.000
Energy	71.94± 15.76	76.92± 17.40	6.000	0.000
Social function	81.09± 12.95	85.92± 13.29	7.362	0.000
Emotional function	76.41± 14.23	79.83± 19.20	4.048	0.000
Mental health	72.19± 11.92	76.42± 15.57	6.101	0.000

3 讨论

随着我国近年来二胎政策的全面开放,每年约有 2000 万的新生儿出生,其中高危儿占比约为 10%~20%^[12-14]。迄今为

止,临床上尚无一种有效的手段用于胎儿期或出生时或新生儿早期准确预测各类高危因素对婴幼儿的危害,亦无法准确判断高危儿脑损伤程度^[15-17]。因此,针对高危儿应予以系统管理,从而给予及时有效的干预,达到缓解以及改善高危儿生命质量的

目的^[18-20]。随访是高危儿系统管理的重要途径与保障,然而针对高危儿医学监护的现状不容乐观,存在较高的失访率^[21-23]。

本文结果显示,高危儿的高危因素主要为早产、低出生体重、高胆红素血症、窒息和(或)缺氧缺血性脑病、颅内出血等。提示早产、低出生体重、高胆红素血症、窒息和(或)缺氧缺血性脑病、颅内出血可能是导致高危儿出现的最主要原因。而陈志玮^[24]等人研究发现高危儿高危因素前4位分别为低出生体重、高胆红素血症、窒息和(或)缺氧缺血性脑病、颅内出血,两项研究结果存在一定差异,而导致上述差异的原因可能和纳入对象地域不同有关。此外,本文发现,随访次数 ≥ 6 次人数占比为40.00%,提示高危儿的失访率不容乐观。183例随访次数1~2次高危儿失访原因主要为有问题再来医院、孩子正常、不了解随访重要性、自己有育儿经验、孩子小、不方便等。分析原因,笔者认为可能包含以下几点^[25-27]:(1)医务人员在宣传相关保健工作过程中以及对家长的健康教育力度不够,从而使得家长对于儿女发育问题方面的相关知识掌握程度较差。(2)在首次高危儿评估中医务人员未和家长进行良好的沟通,从而导致家长不重视儿女的预后。(3)部分家长的受教育程度较低,难以理解高危儿定期随访的重要性,从而影响了高危儿的随访工作持续开展。(4)部分高危儿居住地距离医院相对较远,加之父母工作时间调配不易,从而无法及时有效地定期参与随访。

另外,高危儿父母各项SF-36评分均低于正常儿父母,这与高永嘉的报道基本相符^[28],表明高危儿父母的生命质量显著下降。究其原因,笔者认为高危儿父母普遍存在担忧、焦虑、紧张等负性情绪,从而对其健康状况产生不利影响。而随着健康状况的下降,机体生理活动功能以及精力亦会受到影响,从而表现出不同程度的疲劳、失眠等不适症状,继而影响精神健康以及社交活动,最终导致生命质量的降低^[29,30]。由此,建议在临床工作中应重视对家长的健康教育,提高家长定期随访的依从性。同时,对高危儿进行规范化系统管理,针对部分因客观因素无法前来的儿童需进行电话随访管理,及时了解儿童现状,并为家长答疑解惑,保证随访工作的落实。

综上所述,高危儿的随访失访率较高,其主要原因可能与父母受教育程度较低、对孩子的随访重视程度不高、时间紧张等有关,高危儿父母的生命质量较正常儿父母降低,临床工作中可通过加强高危儿系统管理以及对高危儿父母的宣教力度,从而达到降低失访率的目的。

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