

Parent and young person held child health record and advice booklets and their use in Bosnia and Herzegovina

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Parent- and Young Person-Held Child Health Record and Advice Booklets and Their Use in Bosnia and Herzegovina*

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Abstract

Background: To introduce an effective system of health records and to provide appropriate education in health and accident prevention for mothers and children aged 0-18 years in Bosnia and Herzegovina.

Methods: Three trials from May 1994 to June 1995. (1) Of 1630 records for 0-5 year olds accompanying a screening project for all children in Mostar. (2) Of approximately 1000 records given to 0-6, 6-12, and 12-18 year-old children in Tuzla. (3) Of 7175 booklets for all three age groups in Mostar. The third trial included questionnaires of each age group (total 609) before and after distribution of the booklets.

Results: Significant improvements in the knowledge of the interviewees' responses to 7 of 3 questions in the 0-6 years group, to 4 of 13

questions in the 6-12 years group, and to 5 of 15 questions in the 12-18 years group.

Conclusions: Parent-held record and advice booklets appeared to provide knowledge and empower mothers and children in this area of conflict.

Introduction/Background

Parent-Held Records

Parent-held records have been introduced in several countries, both developed (advantaged) and developing (disadvantaged). Early trials were undertaken in Australia¹ and on children of British servicemen and women in Germany.² Patient- (not just parent-) held records have many advantages over health facility-based records: for health professionals in terms of availability, and for parents in terms of empowering them to manage conditions themselves without consulting professionals.³

This is particularly true with mobile families and, as in this study, during war when people move from one area to another, when health care facilities may be destroyed and health care personnel depleted. An objection that these records would be lost or damaged has not been experienced.⁴ On the contrary, they were immediately available whenever and wherever the patient attended, much more readily than, for example, the 60 percent rate of antenatal records examined in one survey.³ They also provide an important saving on administrative costs.

There have been problems, however, in their implementation: in the time taken up without extra resources for their distribution;⁴ in training staff

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involved in their implementation; in cooperation between management and field staff.⁷ Proponents recommend that health promotion will only be effective if combined with national policies that support the health education – the banning of cigarette advertising, for example.⁸

Several studies have evaluated the introduction of records. These include the retention rate, the rate of documentation of immunisations, and the perceived usefulness to parents in Australia between 1987⁹ and 1994,¹⁰ in England,¹¹ and in Scotland,¹² and to general practitioners¹³ and health visitors.¹⁴ These studies have been undertaken only on records for preschool children. Our programme covered new ground in

- Providing not only medical records but also a comprehensive supply of health education, advice on child care and life management, and accident prevention. Previous records have included a small amount of useful advice, but the present booklets provide substantial information and advice similar to the *Facts for Life* booklet.¹⁵
- Providing health record and advice booklets for school-age children.
- Providing personal health record and advice booklets written directly for young persons to manage and implement themselves.
- Providing a questionnaire approach to the evaluation of advice given.

Bosnia and Herzegovina

During the war in the former Yugoslavia, many hundreds of thousands of children have been displaced from their homes. Often this has been in such extreme urgency that all valuables, including health records, have been left behind. In others forcibly displaced, all official documentation may have been taken from them in an attempt to "ethnically cleanse" an area (fascism). In many other cases, the records have been lost or destroyed, as health facilities have in some cases been specifically targeted.

Following David Southall's initial assessment of Mostar for UNICEF, the need for a system of health records and health education was made a priority. The lack of medical personnel and secondary health care facilities made the need for empowering the population to care for their own health and prevent accidents all the more important. Many doctors had escaped early in the war. Those remaining were all the more challenged with injuries due to the conflict and the indirect effects of the collapse of essential services such as immunisation, sewerage, clean water, food, and shelter. The better the population could manage appropriately the early stages of illnesses, and the less they suffered accidents and unwanted pregnancies or their complications, the greater the ability of medical services to reserve resources for the seriously ill or injured. Before the war it was the normal practice for mothers to take their child directly to a paediatrician for even minor complaints. Family doctors were not the usual first call for the sick child, even if it meant travelling to find a paediatrician. Through health education there existed the opportunity also to prevent the inappropriate use of remaining health resources.

Description of Record and Advice Booklets

The third trial in Mostar (see below) included the latest versions of the booklets. There were different booklets for the age groups 0-6 years, 6-12 years, and 12-18 years. Each contained a health record and a section on health education, the latter comprising approximately two-thirds of the 0-6 booklet and three-fourths of the others.

The record section for age 0-6 was larger – containing space for developmental checks, including a series of questions for the parents to think about before a developmental check at each age. This section also serves as a foundation for the professional who undertakes the check. The booklet also contains space for parents to write comments. The second part of the booklet is to be completed by the professional – height, weight, other findings on examination.

There were sections for health checks at 6-8 weeks, 6-9 and 18-24 months, 3 - 3 1/2 years, 4 1/2 - 5 1/2 years, with questions for parents at three and four months, hearing test after 6-9 month examination, and eye test before school. There was also space for family history (including otherwise often forgotten details relevant to children – like photographs and information on their pets), birth details, past medical history, immunisation chart, growth charts and five sides for health professionals to record the results of any visits for medical or surgical attention.

All three booklets had on their front cover a line drawing of the Stari Most bridge of Mostar. There was a hole cut in the front cover to write surname and name. It was realised that waterproof ink was necessary on the cover.

The advice section was comprehensive, including a section on general health with information on immunisation (e.g., "Your child can be immunised even during a cold.") This empowered parents to question health professionals who may have offered out-of-date advice to the contrary. Other general subjects included smoking, hygiene, head lice, scabies, and dental care (with emphasis on starting early to look after primary teeth). In the young person's booklet there were extra sections, including information on puberty, bullying, depression, smoking, alcohol, acne, drugs and solvents, genitourinary disease.

There were three pages on HIV infection and AIDS in all three booklets. This was given prominence as it was a subject that had been largely ignored before the war, with denial of its occurrence in Mostar, lack of access to HIV testing, and arrival of many international aid workers. It was potentially also an area where health education could be particularly effective in its prevention. The last paragraph of the HIV section was entitled "All parents should tell their children how HIV is spread."

The next section for all three age groups was on "Safe Motherhood," with advice concerning pregnancy and childbirth, including information on

contraception and abortion. A section on infant feeding gave suggestions to mothers who chose to bottle-feed, but stressed throughout the advantages of breastfeeding. It addressed weaning practices and included instructions on what to do if a baby chokes.

The next section was on child care, with suggestions to help with the difficult task of bringing up children ("No parent gets it right all the time..."). Advice was included on crying babies, tantrums in toddlers, potty training, bedwetting, passive smoking, and helping children cope with problems in the relationship between parents. This was followed by a section on development and play, including child health checks and a timetable of developmental milestones, helping a child to learn, and two pages on the importance of play (one of the first areas that falters in a war zone).

A large section was provided on common illnesses, including diarrhoeal diseases – a serious problem in the former Yugoslavia following the breakdown of sewerage systems, lack of fuel for cooking, and lack of clean drinking water. This section gave parents and young persons advice about the use of oral rehydration solution (adopting WHO and UNICEF common policy). There was advice on acute respiratory infections, earaches, fevers, fits and convulsions, meningitis, septicaemia, immunisation reactions, spots and rashes.

There was a special section on child protection that included information on prevention and management of abuse, both within the home and in the community. There was a description of child abuse and advice for abused children and young persons to seek involvement and help of an adult whom they trusted.

There were 17 advice points provided on accident prevention, along with a section on firearms. The final section of the booklets gave advice on resuscitation and first aid.

All pages were numbered and there was an index. The 0-6 and the 6-12 booklets were addressed to parents; the 12-18 booklets were written for young persons.

Methods

Part of Screening Programme for Children in Mostar

A version of the parent-held record for preschool children currently being used in North Staffordshire was adapted for conditions in Mostar and translated into the Bosnian language (dialect of Serbo-Croat) by a refugee doctor from Sarajevo. To this was added a large advice section on health education. The booklet, printed in the U.K., had a card cover and was stapled (rather than the more expensive loose-leaf version in a plastic cover in the U.K.). The booklets were distributed between May and November 1994 to all mothers of 0-5 year-old children seen by international and local doctors as part of a screening programme.¹⁶ Similar booklets were later given at the direct request of a paediatrician in a town (Jablanica) outside the Mostar region.

No formal analysis of the impact of the booklets was made; however, such was the demand and interest shown in them by the paediatricians, nurses, health authorities, mothers and older children that improved versions for the mothers of preschool children, as well as expansion to include mothers of junior school age and young persons themselves, were developed.

Tuzla

In October 1994, the first trial of 1000 records of the three age groups was started in Tuzla, a town in the region of northeast Bosnia, in response to a request from UNICEF for aid to be given to a large influx of people displaced from Serbian-controlled areas. The booklets were distributed in three collective centres for displaced persons and, by local authorities, to people in private houses.

A local doctor and two local nurses, working with an NGO (Italian Consortium for Solidarity), trained nurses, teachers and others to distribute the booklets and give help on completing relevant sections. Parents were subsequently invited to bring their children, at a pre-arranged date, to be weighed,

measured and seen by a doctor. Of 1000 given booklets, 571 children were seen by the first two authors and a local paediatrician in the collective centres and the health centre in Lukavac (a small town just outside Tuzla). All paediatricians and hospital directors were consulted about the booklets and encouraged to request parents to use them. They were well received by the doctors.

Children's heights and weights were plotted on the growth charts and other relevant parts were completed by the doctors, who took a screening history and examination. The latter provided specific details on the health of the displaced population, compared with locals. The results, while not relevant to this paper, are available (unpublished form) from the authors.

Parents and young persons were asked if they had read the booklet, their opinion of it, what parts they found useful and what parts they thought should be changed. This exercise showed that the booklet's format was not offputting, as many had read the entire booklet (even though some had received the booklet only the preceding day). Three mothers and one grandmother (of orphaned children) were unable to read; however, they still appreciated having the record.

Overall, the booklet was seen as helpful. Some frequently made comments included that it was the first time the mothers had seen all the information in one place; that the booklet represented the only papers now held by some of the displaced persons; that the advice provided in the booklets was particularly appreciated by those who cared for orphans. The sections seemingly the most appreciated included infant feeding, caring for young children, common diseases (especially scabies and convulsions), drugs and solvent abuse, child development, pregnancy, puberty, and hygiene.

This method of mass distribution – one without individual support to help parents find their way around the booklets – was not ideal. But it did allow as many children as possible to be seen for medical screening during our time in Tuzla. One associated problem was the relatively low rate of return (57 percent) of children whose parents or caregivers were given a booklet.

Final Trial in Mostar

Feedback from the trial in Tuzla and from the experience of two of the authors (P. McMaster and H. McMaster) who used the booklets were incorporated into a further revision of the three booklets. They were then translated into Croatian by a Professor of English in Mostar, with guidance by V. Simunovic over the medical aspects. The English version was also translated into the Bosnian language by local staff, with the help of N. Selimovic (a refugee doctor). The booklets were developed with financial support and professional input of UNICEF programme staff in the former Yugoslavia. Local adolescents in Mostar, who were involved in the translation process, also contributed to the design the booklets, particularly those for young persons.

A questionnaire (developed in collaboration with experts in public health working with UNICEF and WHO) was devised to assess the booklets. Whilst awaiting funding from UNICEF to print the booklets, the questionnaire was further enhanced by personal interviews with local nurses and doctors who had worked with previous versions of the preschool booklets in the screening programme. Translation was discussed in detail to avoid ambiguity. It was tested on staff working with us, translators, drivers and nurses. Further modifications were made as necessary before the final version was agreed upon in English, Croatian, and Bosnian languages.

In each of the age groups, 100 children (of the 352 children who were part of the screening programme) were randomly selected to complete the questionnaire.¹⁴ Staff attempted to visit the children at their homes (addresses were recorded on the database). It was not always possible to find all the children, however, as some had moved or were now in inaccessible places due to progression of the conflict. As a result, further names were selected at random until we had seen approximately 100 children in each age group. The questionnaires for the children 0-6 and 6-12 were answered by parents; the 12-18 year olds answered for themselves.

We had planned to combine distribution of the records with a wider health education programme in Mostar. This would have included inviting mothers to participate in discussion groups based on various topics in the records. For school age children, there were to have been regular health education sessions added to their curriculum for, say, half an hour a week for the older children and perhaps a simple daily message for the very young children. A child-to-child programme was also developed for children to identify the health problems that concerned them, with time allotted to investigate the problems and to plan, implement, and evaluate a response. Local nurses and a doctor working on the project spent a couple of hours each day for about two months developing this programme and training teachers; the programme was not fully realised, however, due to delays in funding by UNICEF.

At this point in our project, UNICEF decided to print only the preschool booklets; funds from a charity were utilised to provide the 6-12 and 12-18 records.

When the initial 0-6 year booklets arrived in Mostar, we intended to invite parents (via notices in public places and on the radio) to the mobile screening clinics¹⁴ and to other health centres to collect the records. The uptake, however, was slow. The booklets were then distributed through the kindergartens and local community offices. Wherever they were distributed, a record was kept of the names of the children, the names of the parents, and their addresses. It was explained to the parents that this information was needed for ease in finding some of them again to assess the records (questionnaire) at a later date. Booklets for school children and adolescents were similarly distributed through schools and community centres. Information was also given out on local radio stations.

From the lists of families given the booklets, a further 100 from each group were randomly selected and interviewed within a four-month period.

A system of recording the results of several interviews (rather than using a question sheet for each interview) was developed during the

performance of the questionnaires. The data were then entered onto a computer by two international and one national paediatrician, according to an agreed-upon and written code. Two people entered the data (one typing; the other reading the results and checking for correctness of entries).

Although 100 or more interviews were performed for each age group before and after the distribution of the records, the results did not always equal the total because of blanks which resulted when the interviewee did not know the answer (there was not an optional "Don't know" response), or the answer was incompatible with the question.

Before the follow-up questionnaire was undertaken, the interviewers checked that the family had received the booklet. Often it was found that the booklets had been read cover to cover within 24 hours. Each question was taken from a different section of the booklet. For each age-group questionnaire, a different question was asked, even if covering the same general topic.

Answers to questions were entered onto Filemaker Pro database (Macintosh Powerbook), summarised on Excel spreadsheet, and analysed using Instat Statistical Programme. The numbers and distribution of questionnaires in Mostar are shown in Table 1. Results of the questionnaires are shown in Tables 2A, 2B, and 2C. Questions were of two types:

- The first were those with an either/or answer, which provides a percentage of correct answers. This is given in Tables 2A, 2B, and 2C, with analysis by chi square test with Yates correction (and, where the numbers were small, by the Fisher Exact Test). The difference between the two proportions for before and after distribution of the booklets is given (except where numbers were too small - <5).
- The second type of question gives a range of answers. These were non-parametric and hence analysed using the Mann Whitney Test for Unpaired Data (the population who answered the preliminary questionnaire was not the same as the subsequent sample). The null hypothesis was that the two populations means were equal. The median and 95% confidence interval for the results both before and after the booklets, with a probability value for any significance of difference, are also given in Tables 2A, 2B, and 2C.

Questionnaire Results

Of the 39 questions, 18 gave significant positive changes from before to after distribution of the booklets ($p < 0.05$). Two of the questions had to be ignored because of confusion in recording the data.

Table 1. NUMBERS AND DISTRIBUTION OF QUESTIONNAIRES IN MOSTAR

0-6 Years	Before	n = 86	E = 70 (81%)	W = 16 (23%)
	After	n = 100	E = 80 (80%)	W = 20 (20%)
6-12 Years	Before	n = 106	E = 74 (70%)	W = 32 (30%)
	After	n = 98	E = 78 (80%)	W = 20 (20%)
12-18 Years	Before	n = 110	E = 84 (76%)	W = 26 (24%)
	After	n = 109	E = 70 (64%)	W = 39 (36%)

E = East Mostar; W = West Mostar

Table 2A: RESULTS OF QUESTIONNAIRES
(CI = Confidence Interval)

0-6 Years Q	Before	95% CI		After	95% CI		P	95% CI of Difference	
	Median	Lower	Upper	Median	Lower	Upper		lo	hi
1	3	6.5	11.2	2	3.1	5.7	<.001		
2	10	9.27	11.98	8.5	8.70	10.62	0.1912		
3	21	17.00	23.07	12	18.84	27.14	0.6972		
4	76%	(n = 65)		88%	(n = 88)		0.0436	0.0140	0.2343
5	8	7.61	8.51	10	8.75	9.47	0.0006		
6	1	67%	(n = 56)	69%	(n = 69)		0.8578	-0.1121	0.1588
7	2	81%	(n = 70)	93%	(n = 93)		0.0241	0.0211	0.2110
8	2	2.05	2.76	3	2.72	3.35	0.0086		
9	3	2.30	2.98	3	3.23	3.91	0.0006		
10	4	3.62	4.17	4	3.47	3.83	0.2497		
11	1	85%	(n = 73)	99%	(n = 99)		0.003		
12	-	-		-					
13	1	16%	(n = 14)	27%	(n = 27)		0.1138	-0.0123	0.2267

Table 2B: RESULTS OF QUESTIONNAIRES
(CI = Confidence Interval)

6-12 Years Q	Before Median	95% CI		After Median	95% CI		p	95% CI of Difference	
		Lower	Upper		Lower	Upper		to	
1	53	(n = 56)		57%	(n = 56)		0.6329	-0.0936	0.1798
2	2	1.61	1.88	2	2.05	2.31	<0.001		
3	83%	(n = 86)		94%	(n = 92)		0.0165	0.0225	0.2012
4	89%	(n = 94)		94%	(n = 94)		0.0690		
5	45%	(n = 48)		68%	(n = 67)		0.0015	0.0946	0.3671
6	81%	(n = 86)		89%	(n = 87)		0.1854	-0.0222	0.1751
7	81%	(n = 86)		83%	(n = 81)		0.9205	-0.0907	0.1211
8	8	7.98	8.99	9	8.25	8.99	0.4253		
9	76%	(n = 81)		86%	(n = 84)		0.1312	-0.0150	0.2010
10	39%	(n = 41)		64%	(n = 63)		0.0004	0.1187	0.3934
11	72%	(n = 76)		68%	(n = 67)		0.7143	-0.0925	0.1591
12	-	-		-	-				
13	63%	(n = 67)		72%	(n = 71)		0.7933	-0.0993	0.1525

Table 2C: RESULTS OF QUESTIONNAIRES
(CI = Confidence Interval)

12-18 Years	Before Median	95% CI		After Median	95% CI		p	95% CI of Difference	
		Lower	Upper		Lower	Upper		to	
1	75%	(n = 82)		89%	(n = 97)		0.0096	0.0421	0.2468
2	60%	(n = 66)		83%	(n = 90)		0.0004	0.1058	0.3456
3	3	3.02	3.72	3	2.44	2.94	0.0144		
4	95%	(n = 105)		100%	(n = 109)		0.0597		
5	97%	(n = 107)		98%	(n = 107)		1.0000		
6	64%	(n = 70)		75%	(n = 82)		0.0864	-0.0062	0.2380
7	2	1.33	1.74	2	1.52	1.95	0.2851		
8	85%	(n = 94)		96%	(n = 105)		0.0084		
9	75%	(n = 83)		81%	(n = 88)		0.4348	-0.0568	0.1624
10	82%	(n = 90)		89%	(n = 98)		0.1688	-0.0181	0.1649
11	23	22.17	23.63	23	21.91	23.06	0.2847		
12	67%	(n = 74)		88%	(n = 96)		0.004	0.0976	0.3184
13	88%	(n = 97)		97%	(n = 106)		0.0169		
14	75%	(n = 82)		71%	(n = 77)		0.6199	-0.0791	0.1572
15	7%	(n = 8)		30%	(n = 32)		<0.0001	0.1080	0.3207

Two questions had small changes in the opposite direction to the advice given in the booklet, but neither of these was significant, either statistically ($p=0.7$ and 0.6 , respectively) or clinically.

Discussion

This study has demonstrated the value of these booklets in educating parents and children caught up in a prolonged war in Europe in which, as usual, civilians including mothers and children have endured immense suffering. In conditions of war or severe socioeconomic deprivation, decisions within the family are likely to have the most relevant effects on the well being, including the health and even the survival, of children. Empowerment of heads of families and of children themselves in knowledge regarding health and accident prevention is always important, but no more so than in situations where both primary and secondary health care facilities have been damaged or destroyed.

Generally, the booklets were well received with ubiquitous demands for more copies to be distributed to all the families in the area. They were appreciated by parents, children, teachers, paediatricians and health authorities. Before being accepted as local or national policy, a more objective assessment was demanded of their usefulness. A scientifically sound research design (controlled trial) was not considered ethical, possible or desirable, however, given the conditions. Efforts were made to limit the potential effects of the different interviewers on responses. Differences between the interviewers should have cancelled out as the same interviewers undertook similar number of interviews before as after the distribution. The interviewers were not specifically told the expected answers, but all were local nurses who had spent many hours of training in teaching the use of the booklets; hence, they knew the contents well. Most of this teaching was undertaken before the first questionnaires, thus any bias from the nurses knowing the answer would be the same before as after distribution.

The questionnaires were not designed to test health knowledge generally, but purely to assess the

impact of the records. A proportion of questions addressed attitudes and practice with respect to health issues. For a sustained change in practice to be recorded, a questionnaire would need to have been used after a longer period than the security situation in Bosnia allowed. The period from distribution to follow-up questionnaires ranged from four days to three months. There were no other major health education programmes underway in Mostar between the time of questionnaires before and after the distribution of the records. The knowledge of mothers of preschool children, however, may have already been enhanced by the 0-5 year booklets distributed as part of the screening program.¹⁶

Health education and accident prevention was an important part of these records, providing the opportunity of reaching a large part of the population with up-to-date information. The use of records for school children as well as young persons under 18 years is a new strategy that could be introduced elsewhere in the world, particularly in areas of conflict and poverty. It may also be appropriate to extend the concept to the remainder of the population (adults).

Our results suggest that the printing and distribution of similar records for all children in Bosnia and Herzegovina should be considered as soon as possible. Most appropriately, support for this should come from the international community. In this respect, we were disappointed that UNICEF would not support the printing of records for school children, particularly the adolescents whose health knowledge and attitudes are so important in terms of the next generation. With attempts being made in Bosnia and Herzegovina to rebuild the health service, it might be appropriate for these record and advice booklets to be distributed to help initiate a comprehensive and integrated child health service.

Our study also suggested that similar records and advice booklets could be of value in the (too many) other areas of severe socioeconomic deprivation and conflict around the world. The booklets would clearly have to be designed in specific ways relevant to the literacy and cultural, medical, and educational needs of the different communities using them.

Programmes to introduce the booklets and to best sustain the messages within them (similar perhaps to those attempted but unfortunately not fully implemented in Mostar) would also require careful thought and development.

[Copies of the PHRA booklets, in English, Bosnian and Croatian languages, are available from Professor Southall.]

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