How well are parent held records kept and completed?

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SUMMARY. During 1986 and 1987 parents in part of the Oxfordshire district health authority were given their child's health and development records while in the other part of the health district the records remained with the clinic. Between August 1988 and February 1989 an audit was made of a sample of parents attending child health clinics in the two areas: the study examined 284 parents who had parent held records and 168 who did not; how many records were available and if not, why not; how well and by whom records were completed and parents' views on who they felt should keep the record. Interviews revealed that parents with a parent held record liked the scheme and were confident about remembering to take the record to the clinic. Those without experience were less confident and more concerned about losing the record. At the time of the audit 7% of parent held records had been lost or forgotten, but 5% of clinic held records were not available for inspection. Overall, parent held records were more likely to have comments contributed by parents and to be more thoroughly completed by professionals. The results suggest that parent held records are not only workable but desirable.

Introduction

CCESS for patients to their medical records has been receiving increasing attention by international health organizations, the government, professionals and patients. To date research has focused on access to general practitioner records and patient held obstetric records; in both cases allowing access has resulted in high levels of patient satisfaction and few practical problems. A number of other countries have parent held child health records; in contrast the UK is lagging behind with only a supplementary booklet used in some areas. Research has shown these to be well used by parents but less well by professionals, resulting in an incomplete record.

Research from Sheffield and elsewhere^{8,9} indicates that the majority of health symptoms in children are dealt with by their parents without reference to health services, and often within a different value system. ¹⁰ Oxfordshire district health authority has been exploring parent held child health and development records since 1983, based on the belief that parents need appropriate information concerning their child's health and that a parent held record would ensure information was available when needed (including social services and education), and would improve communication between parents and professionals.

Previous work¹¹ has explored the views of general practitioners and health visitors and found that of those who had experience of parent held records over 90% were in favour and

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wished to continue using them. Concerns were raised, however, about loss and completion of records; over 40% of respondents stated that loss was a problem. Work in Australia¹² found that 10% of parent held records were not available after eight to 11 months but there is little knowledge in the UK about loss of records by parents or by the clinics themselves.

The aims of this study were: (1) to establish a loss/forgotten rate for both parent held records and clinic held records; (2) to assess how records were completed and by whom; and (3) to find out to what extent parents made use of the parent held records, for example, by writing in them.

Method

Three types of records are created for each new child in Oxford-shire district: a general practitioner record, a health visitor record and a child health record (often known as the clinic card). During the study the same records were created. During 1986 and 1987 in one part of the district (city of Oxford and south Oxfordshire, covering some 3500 births per annum) the child health record was folded up, put in a plastic folder and given to the parents (subsequently called the parent held record), along with four extra pages for recording the parent's own observations of their child's development. At the same time in the other area (north Oxfordshire, with about 3000 births per annum) the child health record remained in the clinic (clinic held record) and the parents were not given any extra pages for observations. Analysis showed that there were no differences between the two groups of parents being studied in terms of social class distribution.

An audit format was developed, comprising a questionnaire to gauge parents' opinions and assess the issue of lost and forgotten records and an examination of the records to establish who completed what on the record. The questionnaire was piloted with 20 clients in one Oxford city clinic, and minor changes were made before starting the main study.

The audit was carried out between August 1988 and February 1989. The interviews took place during 39 randomly selected regular child health clinic sessions with the interviewer approaching parents (usually mothers) while they waited to be seen by the health visitor or doctor. This represented 33% of all child health clinic sessions during this period. Consent was sought from the health visitor responsible for each clinic. None refused, although one clinic was on the point of closing owing to decreasing attendance. If the clinic involved a doctor the health visitor usually informed him or her of the planned visit. A note was made of the number of child health records that were available for inspection from the clinic held record group or the parent held record group. The checklists which parents could complete on the parent held record were also examined.

The audit of the records looked at the recording by professionals of 15 key items; these included immunizations, prescriptions, information about parents and siblings, information about two and eight month developmental checks, head circumference at key ages and the number of weights plotted on the percentile chart.

A total of 473 parents were approached (representing the parents of 4% of children born during 1986 and 1987), of whom 21 felt unable to take part. Of the 452 parents (96%) who took part in the study, 284 (63%) had been given parent held records and 168 (37%) had clinic held records.

Results

Parents' views of records

When asked who they thought should keep the child health record three quarters of parents who had experience of the system thought they should hold the records compared with only one quarter of parents whose clinic held the records (Table 1).

The two groups were asked why parents should hold or not hold the child health records. This was an open question, the results of which were then grouped. The most common positive comments (Table 2) were concerned with the ability of parents to keep themselves and their family informed about the child's progress. Other comments included such things as liking the parents' checklists, being able to give the record to the child when he or she is older and the convenience of being able to use more than one clinic and have the record available. Only three parents (one clinic held and two parent held group) stated that the record was safer with parents than the clinic. The two commonest negative categories (Table 2) focused on worries about losing the record but also raised the issue of access to clinic held records. Other negative comments included those who saw the record as the property of the clinic, or saw no value in it and three who did not know it existed. There were also a number of miscellaneous comments concerning size, format and legibility of entries.

Table 1. Parents' responses to the question of who should keep the child health record (closed question).

Who should keep the record? Parents Clinic Don't know	Number (%) of parents				
	Parent held record group (n = 284)		Clinic held record group (n = 168)		
	17	75) (6) 19)	43 63 62	(26) (38) (37)	

Loss/forgotten rate

This was assessed on the basis of whether the record was available for the researcher to see at the audit. Two hundred and fifty seven (90%) of records held by parents and 159 (95%) of the records held by the clinic were available.

Of the 27 (10%) parent held records not available, 19 had been forgotten, although several parents did give reasons, such as not having had time to go home to get it between an earlier activity and coming to clinic. Six parents said they had left the record at home deliberately. All six were interviewed at one clinic in the clinic held record area where the audit was carried out after the expiry of the study period and where the health visitors were gradually giving parents records that had been clinic held. Originally they had been given a small booklet which they had all brought to this (health visitor) clinic to record weights, health visitor advice and so on. They saw the child health record as a 'medical' record to be used only when they attended clinics at their general practitioner's surgery. Two records had been lost or stolen from handbags and were being replaced on the day of the interview.

Of the nine (5%) clinic held records which were not available, three were normally stored at that clinic but could not be found for the audit. One of the cases was a child recently moved to the area with no Oxfordshire record. Five of the records were 'kept elsewhere'. If a client wishes to use more than one clinic and the record is clinic held then a choice must be made about which clinic to store it in.

Two hundred and sixty eight (94%) of the parents holding records said that they had never lost the record; 12 (4%) had

Table 2. Parents' responses to the question of why parents should/should not hold the child health record (open question).

	Number (%) of parents				
-	Parent held record group (n = 284)		Clinic held record group (n = 168)		
Why should parents hold records	?				
I like to watch child's weight Record provides information,	99	(35)	13	(8)	
useful for reference	43	(15)	13	(8)	
I can see what is written	31	(11)	7	(4)	
I can show record to spouse and family	23	(8)	0	(0)	
I can read record at leisure,					
clinic too busy	20	(7)	2	(1)	
Record acts as a reminder I feel more involved, secrecy	11	(4)	2	(1)	
is reduced	11	(4)	2	(1)	
Why should parents not hold red	ord?				
I worry about loss/record safer at clinic	19	(7)	43	(26)	
I prefer clinic to keep record if it can be viewed on demand	4	(1)	23	(14)	

More than one answer could be given and only the most common are given here

mislaid it temporarily and four parents (1%) had lost it permanently and had had it replaced. Ninety four per cent of the parents holding records said they 'always' or 'nearly always' remembered to bring the record to the clinic compared with 72% of those with no experience of parent held records who thought that they would 'always' or 'nearly always' remember it.

Completeness of records

On the part of the record designed for professional rather than parent use it was encouraging to find that 13% of parent held records had additional comments by parents. Overall, the parent held records were more thoroughly completed by professionals than were the clinic held records. Two of the 15 items audited were completed in a higher proportion of clinic held records, for four items there were no difference but for nine items a higher proportion were completed in parent held records than in clinic held records.

Immunizations were well recorded in both parent held (96%) and clinic held records (93%). The prescription section was completed less often on clinic held records (60%) than on parent held records (77%). There were few differences in the type of information recorded about parents and siblings. In the section on birth information slightly more of the clinic held records were left blank (18%) than parent held records (8%). The two month developmental check was well recorded in both groups (91% for clinic held and 93% for parent held records) although there was a tendency for the examiner to forget to sign the record when it was a clinic held record (17% compared with 7% for parent held records). The eight month development check showed a more marked difference. In the clinic held records there was nothing recorded for 27% of the children, despite their mothers reporting that their child had had an eight month check. This compared with only 8% in the parent held records (which is probably still too high). Furthermore, before the eight month check more items had been completed and there were more comments recorded on the parent held records. Throughout the figures relating to the recording of head circumference at key ages there was a consistent difference of about 10% between the parent held records and clinic held records, with apparently greater care being taken to measure and record head circumference for those children with a parent held record. Similarly, greater effort to

both record and plot weight seemed to have been made with parent held records, over three-quarters of which had 90% or more of the listed weights plotted. Just under half of the clinic held records were 90% complete. While very few of the parent held records had less than 10% of the weights plotted, over a fifth of the clinic held records were complete.

The parent held record included a checklist for parents to fill in concerning hearing, vision and development; 180 (70%) of the 257 parents bringing their records had the checklist available at audit, 26 (10%) said these were at home, four (2%) had lost the pages and 47 (18%) said they had never had the extra pages. Of the 180 hearing checklists available 61% were either fully or partially completed, as were 55% of the 180 vision checklists, and 69% of the 180 development checklists. Four per cent of parents said they had had concerns about hearing or development and 9% about vision.

Discussion

Parents' views on who should hold the child health record showed that those who had had experience of parent held records were more positive than those who had not, and this is similar to an earlier report of the views of general practitioners with and without experience of parent held records. ¹¹

The reasons given for wanting to hold the record fell broadly into two categories: those concerned with the information it gives parents ('I like to watch her weight and progress', 'It acts as a reminder') and those concerned with the nature of the record ('I can see what's written', 'I feel more involved, there is less secrecy'). This suggests that some parents feel more confident holding the records and see themselves as being allowed to share in information that was hitherto the sole property of the health visitors and doctors.

The comments from those who felt the clinic should hold the child health record were mostly concerned with fears of losing the record if they kept it. Only three parents felt that the record was safer with the parents compared with the 43 who said that they would not want it because they thought they would lose it. In fact only four out of 284 parent held records had been lost and replaced. Another common comment ('I prefer the clinic to keep it as long as I can see it whenever I want to') suggested that for many parents with no experience of parent held records, access rather than possession may be the key issue.

The total proportion of parent held records which were not available at audit was 10%; 2% had been left at home deliberately. Although some parents gave reasons for not having the record it may simply be that they felt more comfortable giving a reason than admitting to having forgotten it. Leaving aside this possibility the proportion of records forgotten becomes 7%, which compares favourably with the 5% of clinic held records which were not available. As the majority of these clinic held records were records stored at another clinic used by the family it is possible that if the records had been parent held they would have been available.

A very large proportion of the parent held record group were confident that they always or nearly always remembered the record, but the group with no experience of parent held records were, not surprisingly, more cautious. The fact that 90% of records were in fact available for audit suggests that the parent held record group's confidence in themselves was not misplaced.

This audit has shown that parent held records were more thoroughly completed than clinic held records in terms of information recorded by professionals. The two month developmental check was well recorded in both types of record but the eight month development check was much better recorded in parent held records than in clinic held records. Similarly, greater care was taken to record head circumferences and record

and plot weight in parent held records than in clinic held records. Immunizations were well recorded in both groups and this probably reflects the high priority given to this by health visitors and doctors in Oxfordshire.

A number of parents (10% of parents bringing their records) had left the pages for their own observations at home, suggesting that they attached less importance to this part of the record than the main child health record. About a third of parents had completed the vision, hearing and development checklists, with about half having made some entries. It would seem that health visitors were not going through the checklists with parents and were not seeing that part of the record as an active discussion document, merely something for parents to complete if they wanted to. The numbers of those who had some concern about their child's health or development were very small and it is not clear whether the information contained in the record enabled them to seek help sooner than they might have done without it.

The audit succeeded in its aim of establishing a loss/forgotten rate for parent held records although this was in a self-selected population, that is those who attended clinics and in parents who had only held the records for less than 18 months. Records were not randomly distributed in the same area and there could be a bias depending on which part of the area parents were from. Nevertheless, the audit was carried out in random clinics across a range of social class and maternal age groups and included a large number of subjects. Further work is needed to look at whether such a large number of records are still available after a longer period, for example, three to five years.

Overall, it would appear that the child health record has a better chance of being completed by health professionals if it is kept by the parents. It also enables parents to use it themselves, although this is still a very new concept for many; clearly parents need considerable encouragement and support to make more use of these records for recording their child's health.

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