

Evaluation of the Use of a Parent-Held Child Health Record by Pregnant Women and Mothers of Young Children

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Abstract

The purpose of this evaluation was to document (a) the level of patients' satisfaction with use of a personal parent-held child health record (PHCHR), (b) their frequency of using it for specific reasons, (c) behavior changes participants made due to use of this record, and (d) perceived barriers to using the PHCHR. Eighty-two mothers completed the 22-item validated evaluation instrument. Patients reported high levels of satisfaction with all applicable use of the PHCHR. Respondents believed the PHCHR was a useful tool that served as a cue to increase their action in health seeking behaviors. Healthcare providers may consider use of PHCHR for pregnant women and mothers of young children.

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Introduction

Maternal and child health providers require pregnant women and parents of young children to keep track of health and medical information about themselves and their children. Parents are asked to have information about (a) immunizations, (b) doctor visits, (c) nutrition, (d) growth and developmental progress of their children, (e) visits to other health and human service providers, and (f) medical prescriptions. Much of this information is stored on computers at the site where children and pregnant mothers receive the particular services and is not directly given to the parent in a transportable medium. Conversely, parents often are required to see providers from different institutions and locations that have separate data storage and dissemination protocols. The information provided to parents is often complex with varied medical terminology. Language and terminology barriers may prevent the parents from understanding and being able to recall the information from another healthcare provider when performing their own medical assessment.

One possible solution to the problem is the parent-held child health record (PHCHR) which

the parent/patient would present at a visit regardless of the healthcare provider's function and location. The PHCHR provides valuable information, which can be updated with each visit. The record contains dates, telephone numbers, and addresses of clinics as well as specific and personal medical information that allows the primary healthcare provider to adequately assess and care for a pregnant woman or a mother and her child/children.

Literature about the utility and the effectiveness of patient/parent held health records is limited. The majority of the research about PHCHR use resides in the United Kingdom, Norway, and Australia. The majority of the research about the acceptance and usefulness of patient held medical records was done in the 1990s. There is little research about the effectiveness of patient-held child health records in the United States. In addition, the literature indicated use of personal health records (PHR) is greater among mothers and for children's health than among patients with chronic conditions such as cancer and mental health problems.

A survey of 213 physicians, 183 dentists, and 369 patients in Scotland found that 87% of the

dentists and 68% of the doctors thought that an integrated medical-dental personal health record (PHR) would be of use sometimes. Furthermore, 70% of the patients liked having a copy of the PHR (Jones, et al., 1999). A study of 147 new mothers in New South Wales, Australia found that most of the women liked using personal health records (PHR) for their babies, used them often, and would use them again for future children (O'Flaherty, Jandera, Llewellyn, & Wall, 1987). A follow-up household study of 622 parents in New South Wales found 89% of respondents claimed they had retained the PHR for four years, and 78% were able to produce the record for inspection at the interview. Most respondents expressed satisfaction and the respondents entered important data. In addition, 64% of all healthcare providers felt the PHR was beneficial (Jeffs, Nossar, Bailey, Smith, & Chey, 1994). A similar study in South Australia showed high levels of understanding of the parent-held child health record by parents and increased use of the records by general practitioners (Volkmer, Gouldstone, & Ninnes, 1993). Another study in Fife, United Kingdom, examined the views of both parents and health care providers on personal child health records (Campbell & Halleran, 1993). Parents found these records to be useful and brought the PHR regularly to appointments. Healthcare providers were reported as less receptive to the PHR and had concerns about sensitive information, duplication of paperwork, layout of the records, parents forgetting the record, and the PHR being poorly completed by other health professionals.

Recently in Glasgow, United Kingdom, Wright and Reynolds (2006) conducted a study where they compared two types of personal health records (PHR). One type was a traditionally used record and the second type was a new one in a different format and with brighter and less formal presentation. Parents rated both types of personal health records as useful. The majority of the parents used PHR regularly, took them to baby clinics, and used them for their own information. The researchers found that PHR were popular with parents yet underused by healthcare providers except for health visitors. Health visitors are registered nurses or midwives who are trained to assess the health needs of

individuals, families, and communities. Their role is to promote mental, physical, and social well-being in the community by giving advice and support to families in all age groups, although they work closely with parents of children under the age of five.

Bjerkeli, Grimsmo, & Ivar, (2006) studied the effects of a parent-held child health record (PHCHR) in Norway. They found the PHCHR was well accepted by parents and health care providers, but produced no effects on (a) collaboration, (b) healthcare utilization, (c) parents' knowledge of their child's health, or (d) parents' satisfaction with information or communication with providers. Because of their findings, the PHCHR use was not justified for nationwide use.

A study by Walton, Bedford, & Dezateux (2006) examined the usage of personal child health record (PCHR) throughout the United Kingdom. The study included mothers of 18,503 children born between 2000 and 2002. Walton et al. found PCHR use less among those who were (a) admitted to the hospital previously, (b) resided in disadvantaged communities, and (c) had mothers with young maternal age, or (d) were in a large family. The National Service Framework for Children endorsed the PCHR. Saffin and MacFarlane (1991) found that 94% of a sample of 473 parents said they had not lost the record.

For this project, a parent-held child health record, referred to as Passport, was developed for use by pre-natal/postnatal patients and parents of infants and young children. The purpose of this paper is to present self-reported results of patient satisfaction with (a) use of Passport, (b) the frequency of Passport use for specific reasons, (c) behavior changes parents or pregnant women made due to use of Passport, and (d) perceived barriers to using a Passport.

Methods

Sample

The non-probability sample consisted of 100 pre-natal/postnatal patients and mothers of infants and children up to age five, who received care at one of six public pediatric or maternal

and child health clinics in a midsize Midwestern city. Participants were given a Passport to utilize for 12 months. Passports were used by mothers who were pregnant and/or by those with children age five or younger. Nursing staff at participating clinics, who had been trained in the use of Passport and in data collection procedures, presented the instrument to 100 English and Spanish speaking pre- and post-natal patients as they came in for scheduled visits. The patients completed the questionnaires while in the waiting room. Nurses were available to answer questions about the instruments as they were completed by the patients. There were 82 instruments returned (82% response rate) of which 79% were in English and 21% in Spanish.

Measures

The survey instrument consisted of 22 items. The instrument was reviewed with respect to clarity and face validity with nurse managers and with participating patients. The final version was then translated into Spanish and pilot tested with native Spanish speakers. Nurses presented the instruments to participating ante partum and post-partum patients as they waited to see their doctor.

Results

Questions in the first section of the instrument related to satisfaction with the use of Passport. Likert-type questions were asked about the patient/parent satisfaction with the Passport regarding: (a) the ease of reading, (b) locating information, (c) understanding all the Passport words, (d) organization of the contents, and (e) sturdiness of the document. The range of answers were: 1 (not satisfied at all), 2 (somewhat satisfied), 3 (moderately satisfied), 4 (very satisfied), and 5 (extremely satisfied). The means for each section was higher than 3.8, indicating moderate to high levels of satisfaction in each dimension. Patients reported being very satisfied with Passport's sturdiness (4.05) and ease of reading (4.03); while they reported slightly less satisfaction with the organization (3.99), ease of locating information (3.85), and ease of understanding all of the Passport words (3.81).

The second set of questions on the instrument asked the patients about their use of the Passport. Participants were asked how often they brought Passport to their appointments, and if they or the provider wrote information on the Passport. Additionally, the participants were asked if they used Passport to: (a) find key phone numbers, (b) get important information, (c) ask the doctor precise questions, and (d) if they took the Passport to other clinic/doctor appointments. The mean of each section was 3.2 or higher, indicating moderate to high levels of usage; the range of responses were: 1 (never), 2 (almost never), 3 (sometimes), 4 (almost always), and 5 (always). Patients reported they always wrote information in the Passport as advised (4.19) and brought the Passport with them to each visit to the healthcare provider (4.02). Patients reported that they used Passport sometimes to get important information (3.63), find important phone numbers (3.54), take them to clinics other than their primary provider (3.43), or ask their doctor the appropriate questions (3.23).

In the third section of the survey instrument, patients were asked about any behavior changes they made because they were using a Passport. The mean for each question was 3.8 or higher, indicating high levels in all dimensions; the range of responses were: 1 (not likely at all), 2 (somewhat likely), 3 (moderately likely), 4 (very likely), and 5 (extremely likely). Patients reported they were very likely to stay informed about their children's health (4.30), visit the doctor as recommended during pregnancy (4.29), keep baby shots up to date (4.28), remember their healthcare appointments (4.16) and stay informed about her own health (4.08). Patients were somewhat less likely to call the doctor when they thought they themselves were sick (3.97).

In the final section of the survey, patients were asked to identify reasons that would be strong enough for them to not use a Passport. Barriers reported by patients that decreased their Passport use were: (a) not being asked to present it by clinic staff (24%), (b) feeling the use of Passport was not important (18%), (c) the Passport was not in the correct language (16%), (d) forgetting

to use the Passport (13%), and (e) feeling that using the Passport took too much effort (5%). Although these perceived barriers were significant to the individuals who reported them, overall, patients reported none of the reasons were strong enough to prevent them from utilizing the Passport at each healthcare professional visit.

Discussion

Patients' reported satisfaction with various aspects of Passport was consistent with results of similar studies which found that parents have high level of satisfaction with personal child health records (Bjerkeli et al., 2006; Campbell & Halleran, 1993; O'Flaherty et al., 1987; Volkmer, Gouldstone, & Ninnes, 1993; Walton et al., 2006; Wright, & Reynolds, 2006). Responses to the final question that asked for comments about improving the Passport seemed to confirm findings from the first section, as respondents indicated using the Passport for a variety of reasons and that they used it often. From the overall responses, participants found the PHCHR to be a versatile document. One of the primary purposes of the study was to determine if use of a Passport made a difference

in the behavior of the respondents. The respondents were asked about changes they made because of the use of Passport. According to the responses, participants in this sample made changes in (a) keeping appointments, (b) maintaining vaccination schedules, (c) obtaining prenatal care, (d) knowing when to call their doctor, and (e) staying informed about their own and their child's/children's health. The reason cited most often for not using the Passport was that members of the clinic staff did not ask the patient/parent about the Passport. Based on the findings of this study, the PHCHR was found to be a useful tool for these pregnant women and mothers of young children.

Limitations

The non-probability sample is not representative of all pregnant women and mothers of children age five and under at these clinics. Results are based on self-report, which includes the possibility that the respondents may not have been totally honest or they may have been mistaken in some responses. In addition, the respondents were limited to women in a midsize, Midwestern city, and all attended public clinics. It is recommended that future studies use a random sample and include women from a more diverse geographical area.

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