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A CASE STUDY OF INTERACTIVE COMMUNICATION BY VIDEOPHONE BETWEEN PARENTS WITH HANDICAPPED CHILDREN

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This paper reports cases in which families having a handicapped child used a digital videophone system as a means of interactive communication. The subjects were two mothers, each having a child with cystic fibrosis (CF). They utilized the videophones to introduce their children to each other and to demonstrate a new pulmonary physiotherapy. Implications for the usage of the videophone to promote social support networks among these parents are discussed.

Key words: videophones, handicapped children, cystic fibrosis, mothers, social support, networks, telemedicine.

INTRODUCTION

Social support networks among families with handicapped children have several unique functions to promote their psychological adaptation (Adachi, 1996; Beckman et al., 1993; Dunst, Trivette, & Cross, 1986; Kazak & Wilcox, 1984; Speechley & Noh, 1992). For example, one of these functions is the exchange of medical or other helpful information concerning their children. It is the parents who are in the best position to know their own needs. Even if they do not ask professionals, they may get the information to satisfy their needs through other parents. Additionally, in the process of sharing information, they are able to discuss their feelings and to develop a sense of being "in the same boat" (Beckman et al., 1993). Such experiences contribute to their psychological well-being.

In recent years, professionals in intervention services have increasingly acknowledged the unique role of social support among parents with handicapped children for the reasons given above. However, there have been relatively few concrete proposals to facilitate their exchanging social support. This paper reports the cases in which the mothers of children with cystic fibrosis used the videophone as a means of interactive communication. The implications for the usage of the videophone to promote social support networks among these parents are discussed.

METHOD

Subjects: Two mothers of children with cystic fibrosis (CF) served as subjects. The

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informed consent to the study was obtained from each mother. One mother lives in the Tokyo metropolitan area (abbreviated as Mother A), and the other mother lives in the northern part of Japan (abbreviated as Mother B). The distance between their homes is about 400 km. Both of them participated in an earlier study (Miyasaka et al., 1997) of interactive communication in high technology home care.

Apparatus: Subjects used stand-alone color digital videophones with a built-in fixed focus camera (Fig. 1; Picsend R, NTT-Hitachi, Tokyo, Japan). This videophone uses a public



Fig. 1. The videophone used in this study.
(reproduced with permission from NTT).



Fig. 2. The usage of a videophone at a patient's home.
(reproduced with permission from NTT).

digital telephone network ISDN (Integrated Services Digital Network with a capacity of 64kbps), and it is not based on PC (personal computer) operation or internet technology; thus no keyboard operation or computer software knowledge is required. It can transmit near TV quality (320 × 200 resolution) pictures at 5 to 10 frames per second. The motion is still jagged, but facial expressions and body movements can be observed. The quality of sound transmission is excellent, but there is a delay of approximately 0.5 seconds from the picture. The conference function of this videophone enables meetings among up to 4 different locations.

Procedure: One of the authors recorded the videophone communications at Mother B's home in June and July of 1995. After they finished the videophone call, each mother was asked about her impressions and feelings during the videophone communication.

RESULTS AND DISCUSSION

Case 1 : Introducing Each Other's Children

Mother A and Mother B learned of each other through their mutual doctor in January of 1995. However, they had not met each other and had communicated by regular telephone about twice a month before this study. Since a videophone was set up in Mother A's home in June of 1995, Mother A could begin to communicate with Mother B by videophone. Mother B had used the videophone to communicate with the doctor before then.

In the first communication, they took up their position with their children in front of the videophone (Fig.2), then introduced their children to each other. After that, both mothers discussed the physical appearance of each other's children. They made comments like, "Your child seems to be tall! How tall is he?" and "Oh, your child seems to be plump!" The reason for the concern with physical appearance is that one of the major symptoms of CF is physical abnormalities resulting from nutritional disorders (Cunningham & Taussings, 1991). Parents of CF children always worry about the physical growth of their children.

These parents had frequently exchanged information about how to solve the nutritional problems of their children since the first videophone communication. They reported that they had not exchanged such information when they used regular telephones. It seems reasonable to infer that "the information richness" (Daft & Lengel, 1984) of videophone communications enabled them to exchange information about problems that would not have emerged during a conversation on a regular telephone.

In addition, after the first meeting by videophone, Mother A gave her impression of Mother B as follows:

I had the impression that she was a sensitive mother from her voice when we spoke on regular telephones, so I thought it was difficult for us to frankly talk about CF. But I was relieved to see her smiling on the videophone. I think I will consult with her about the matter of my son without reserve.

It would appear that such a change in perceptions also promoted information exchange between them after the first videophone call.

Case 2 : Teaching the Usage of the Flutter

In July of 1995, Mother A taught Mother B how to use the Flutter, which is a new portable device for pulmonary physiotherapy (Pryor & Webbber, 1992).

Respiratory problems are the most serious aspect of CF (Cunningham & Taussings, 1991).

Almost all of the patients with CF will develop lung disease, because, in CF, the thick and sticky mucus in the small airways interferes with normal gas exchange and makes removing particles and germs from the airways difficult. Therefore, to prevent these problems, CF patients must receive pulmonary physiotherapy such as percussion and postural drainage. But, in recent years, the Flutter has been substituted for the traditional physiotherapy.

The Flutter is a small pipe-shaped device through which the patient exhales. It helps the patients remove thick mucus from the lungs as well as percussion and postural drainage, and it has the advantage of allowing them to perform their own physiotherapy. In contrast, to receive traditional physiotherapy the patients must request an assistant.

The CF child of Mother A had formerly used the Flutter. Mother B heard about the efficacy of the Flutter from Mother A and she asked her to teach its usage by videophone.

At first, the CF child of Mother A exhaled through the Flutter in front of a videophone. Then the CF child of Mother B imitated him in the same way. Mother A also taught Mother B the angle at which the Flutter should fit in his mouth. These interactive communications became possible through videophones for the first time. We suggest that this case will be a typical example of the videophone usage by parents with handicapped children.

CONCLUSION

Although the available cases are limited, several conclusions can be drawn:

(1) Parents having a child with a rare disease cannot meet each other in many areas except in large cities. But the videophone permits a "technological visit" beyond time and space. The significance of the fact that the parents can "meet" each other and discuss their feelings is apparent.

(2) The videophone allows for demonstrations which are of great value to families who want to learn physiotherapy or nursing procedures.

(3) The videophone enables the parents to exchange "emotional information" accompanied by facial expressions and body language to some extent (Farmer & Hyatt, 1994). These social cues help them to cope with emotional problems (for example, Mother B said, "Smiles of a mother of a child with the same disease are more encouraging than any words").

Therefore, if parents with handicapped children are able to utilize the advantages of videophones given above, they can enhance communication and strengthen their social support networks.

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