

## Identifying health and wellbeing related information management activities and needs in families with young children

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### Abstract

Understanding how families manage health and wellbeing related information in their everyday lives is important in the user-centric design of information and communication technology (ICT) supported services. Using activity theory as a conceptual framework, the aim of this exploratory research was to make visible families' everyday health and wellbeing information management activities and needs. We applied a qualitative study design using the method of longitudinal virtual focus group discussion with eight households (n=8) over four weeks of time. As a result, we identified nine information management activities and grouped them under three role categories that families with young children play in the Finnish society when seeking health and wellbeing: families as users of health and social services, families in the role of consumers in the market of goods and services, and families in the role of citizens who aspire to a sense of wellbeing in its widest meaning. Furthermore, we identified information management activities with which families felt mostly dissatisfied. The study provides a baseline understanding of everyday information management in families with young children to be applied further in ICT supported family health and wellbeing service development and innovation.

**Keywords:** family health, health service innovation, information management, activity theory

## Introduction

Models for health service delivery are changing. There is a growing interest to redesign health care processes and related communication technology tools from institution-centric to patient-centric solutions [1, 2] and, in parallel, to increase the accessibility of consumers to valid and relevant information about their health status [3, 4]. These developments have led managers and developers of health and social services to think of new service concepts that tap, for example, the potential of the internet and address better the needs of the service users [5]. At the same time, consumers are becoming the primary authorities of their own health management, and therefore have an increasing responsibility to acquire and interpret the vast amount of information available and get more engaged in activities related to healthcare [6]. Families with young children are an example of a significant group of service users that could benefit from easier access to health and wellbeing related information and improved links between service providers and communities [7]. New parents need information and support to fulfill the demands of their new role [8-12] and information plays an important role in ensuring the availability of these [10, 13-15].

There is also an increasing demand to develop and design services in collaboration with the service users [16]. One of the early steps in participatory innovation and service development is the needs analysis in order to identify user behavior and needs relevant to the innovation under development [16]. Involving users in product and service development process is not a simple task, however. It has been pointed out that users are often unable to verbalise their needs, requiring the researcher to reflect carefully on the choice of research methods. A radically novel service or product renders the situation particularly challenging [17].

In this article we present an exploratory study which aimed at modeling families' everyday practices of health and wellbeing information use. The objective of our study was to make families' everyday health and wellbeing related information management activities visible and to identify potential contradictions and problems in the current situation to arrive at a baseline description to be utilized in further service development. For the purpose of this study, we defined information management as everyday practices of the family members that relate to the six distinct, but related information management processes: identifying information needs, acquiring information, organizing and storing information, developing information products and services, distributing information, and using information [18]. However, as these processes refer originally to information management processes in organizations, some flexibility is needed in adapting them to the context of families. In order to gain an understanding of the most important activities of daily health and wellbeing related information management activities and needs in families with young children, the question we sought to answer was what kind of situations do families engage with when seeking their child's or their own health and wellbeing? What type of information management needs arise in these situations?

## Previous literature and conceptual framework

Family information management is not a phenomenon that has received much attention in the past empirical information management research. In our literature review, the closest we came across were studies on household information management [19, 20] and on personal information management (PIM) [21]. Also, a research tradition called domestication research has some relevance for family information management studies [22, 23].

Moen and Brennan [19] studied health information management in the household (HIMH) using a five-element human factors model of work based on a socio-technical approach to understand the interwoven networks of people, tools, routines, sources, and responsibilities in the household. Their key finding was the identification of

the robust and complex information storage strategies that households employ which reflect the location of the artifacts of health information and the anticipated urgency in the need to retrieve it. Kalms [20] investigated households as information systems in order to build theoretical understanding of the dynamics of why and how households process and manage information. A central conclusion of the study was that households constitute negotiated human information systems, based on the observation that household information practices emerge from continuous negotiation and interaction between householders and information, information-related devices and services, other householders and information providers. Both household related studies are relevant in family information management research. However, because the origins of this study lie in the development and design of improved health and wellbeing services for families, our decision was to use the concept of family as it is already well established in health services development and research such as the family-centered care movement [24-26].

The theoretical approach of this study is based on activity theory. In a nutshell, activity theory understands human activity as a systemic entity directed by a motive of achieving a joint outcome, embedding a number of actors involved in mediated actions on a shared object, and having mediated relations with each other [27-30]. A central tenet is that an activity system is not a static entity. On the contrary, all the elements of an activity system, the subject, the object, the means and tools of construction, and social relations are in a continuous process of being constructed and transformed leading to the eventual expansion or contraction of its current state [27]. Taking a close look at the developmental dimension of an activity system provides the researcher and practitioners a way to understand and make visible those dimensions of the system that are not yet there, but under the process of being constructed or expanded from their present state [27].

Families' health and wellbeing related information management is collaborative by nature [31], and therefore fits well in activity theoretical thinking. Family information management can be understood as a collective human activity facilitated by technological means in which several groups of actors are bound together with the aim of achieving a joint outcome. Conceptualizing families' health and wellbeing related information management through the lens of activity theory allows describing and analyzing both its present state and the developmental dimension, providing tools for example for service innovators to visualize how the present state and array of services could possibly be modified. In the area of personal health and wellbeing systems, activity theory has been applied successfully as a tool for information analysis [32]. Our approach in the present study, however, is not to describe and analyze in detail the information that families use, but rather to describe in what kind of situations and for what purposes families use and manage information.

## Materials and methods

The research design was qualitative research [33]. The data gathering method applied in this research was virtual focus group discussion. The idea of a virtual focus group discussion is very similar to the standard focus group method. However, instead of having the group getting together physically in one place the discussion takes place over the internet [34, 35]. A total number of 8 families who were expecting a baby or who had a child of maximum 24 months old were recruited for the study. The participants were recruited in the city of Kuopio, a middle-sized city of 97,000 inhabitants in Eastern Finland, by advertising in local maternity clinics and by the snow-ball method through personal and professional contacts of the research team. All the participating families were composed of a heterosexual couple with the number of children varying from none (expecting a baby) to three children. The social and educational background of the participants was very homogeneous. The age of the parents varied from 29 to 35 years. All parents were highly educated having received minimum a college level degree, and all but one

family lived in an urban or semi-urban environment. The families described themselves as regular users of health care services and active users of the internet, all but one family using it daily.

One adult member of each family, six women and two men, took part in the virtual focus group discussion continuously over a four-week period in November-December 2008. The participants were explained the purpose of the study and their right to withdraw from it any time in a face-to-face meeting that took place prior to the internet discussion, during which they gave their informed consent to participate in the study. The internet discussion was moderated by the first author of the paper by regular presentation of the discussion themes and by active participation in the discussion that followed. A new theme and related questions were published every three or four days on the virtual platform provided by an educational institution and respondents were invited to discuss the theme and comment on other participants' answers as long and as often as they felt they had something to contribute until the end of the data collection period (Table 1).

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1. **Daily information use:** Describe in detail a situation in which you last dealt with health and/or wellbeing related information. Who were the actors, what was the information about, how was the information handled. Were there any problems present? Any particular emotions? (N.B. This theme was posted in total six times along with the other themes).
  2. **Changes as a service user in pregnancy:** Describe how your role has changed as a health and social service user since you started expecting your first baby? How did your information needs change? What kind of support would you have needed but did not get?
  3. **Health information storage at home:** Describe where and how do you store your personal or your child's health and wellbeing related information? Does your storage system work well in your everyday life? Have you ever thought about a digitalized storage system? How should it be so that you would find it useful?
  4. **Preferred communication tools:** Describe your favorite communication methods with health professionals, peer groups, friends, family members and relatives. Has the birth of your child changed this pattern somehow?
  5. **Visualizing the future:** Imagine yourself in year 2020. What has changed with the communication with health professionals? How do you store your personal health and wellbeing related information?
  6. **Elements of good life:** What elements are essential to make life enjoyable for a family with young children? What kind of health and wellbeing related support is fundamental?
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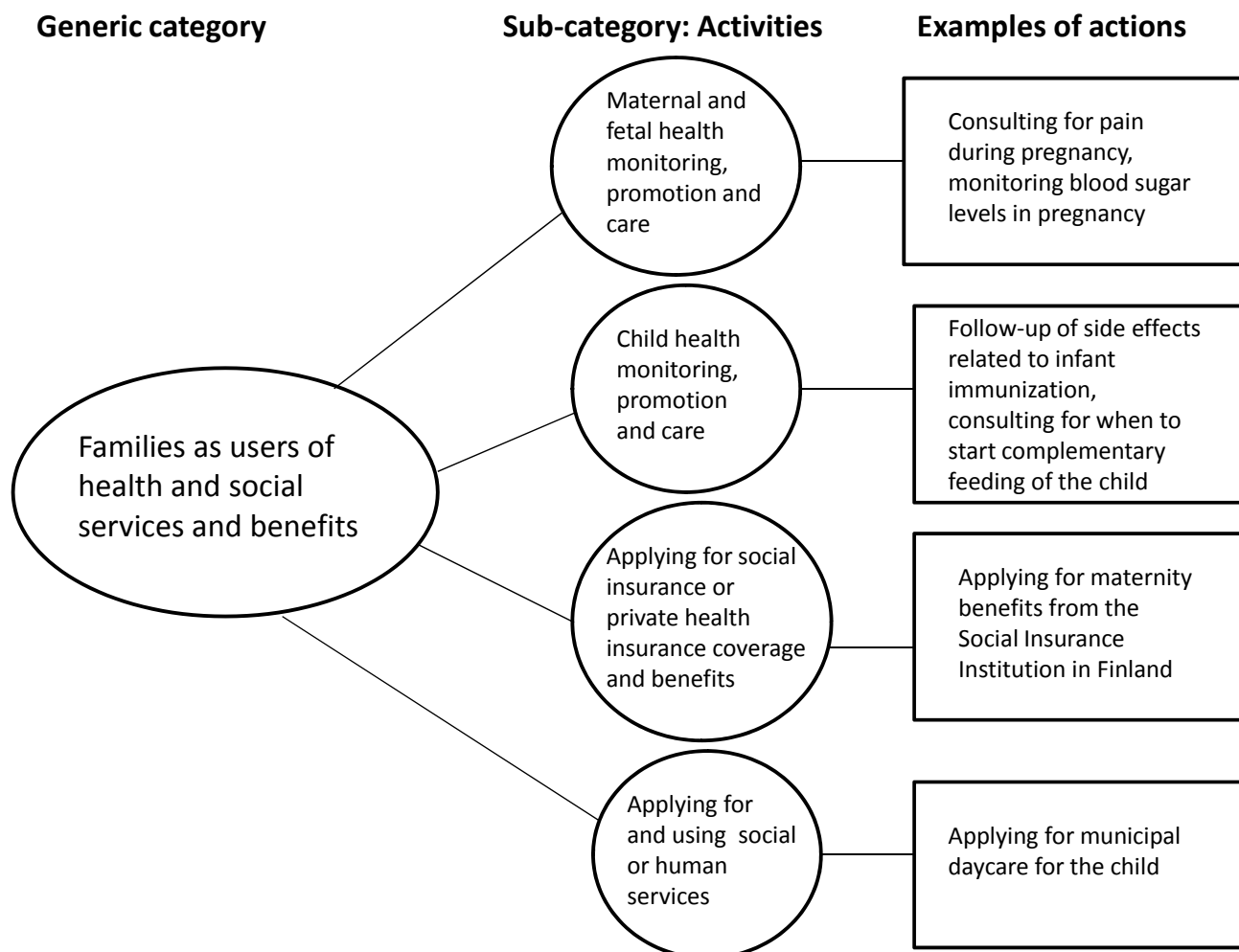
**Table 1.** Discussion themes posted on the internet platform.

After the data gathering period, a text file was prepared of the discussions on the internet platform and later analyzed by the inductive content analysis method for qualitative data. In inductive content analysis, the outcome of the analysis is a condensed description of the phenomenon under study through the process of open coding, creat-

ing categories and abstraction [36]. We applied a realist approach in the data analysis treating the data as respondents' descriptions of facts and events reflecting their external reality [37]. The data was read repeatedly to allow immersion, and the coding process started with identifying the smallest meaning units in the data, everyday actions of information use. We then continued the coding process in order to identify the emerging sub-categories, the activities of families' health and wellbeing related information management. The sub-categories were further classified into generic categories of meaning reflecting the roles that families play in society when seeking for health and wellbeing.

## Results

The data analysis revealed nine distinct health and wellbeing information management activities that covered most of the everyday actions of information use brought up by the families. From the identified activities we inferred a taxonomy of three generic categories reflecting the different roles that families with small children have in the Finnish society as health and wellbeing seekers. These generic role categories were families as users of health and social services, families in the role of consumers in the market of goods and services, and families in the role of citizens who aspire to a sense of wellbeing in its widest meaning (Figure 1).



**Figure 1.** Example of data analysis process: Generic category of activity, sub-categories of activities, examples of actions.

*Activities in the role of users of health and social services*

Many health and wellbeing related information management tasks in families with small children take place in the context of the formal, and in the Finnish context mostly public health and social service system, in which families act in the role of service users. The many daily situations as service users reported by the families enabled us to identify the following activities in this category:

- Maternal and fetal health monitoring, promotion and care
- Child health monitoring, promotion and care
- Applying for social insurance or private health insurance coverage and benefits
- Applying for and using social services

The everyday actions that required information management in this category included, for example, seeking health professionals' assistance in monitoring or curing ailments related to a pregnant mother's or child's health mainly through physical visits or by telephone consultation.

*Family 3: "My wife developed an itching on her tummy and elbows around the 28th week of pregnancy. We knew that this might be caused by hepatogestosis and that's why my wife contacted the maternity clinic straight away to ask for a referral to a liver function test, which she got immediately. The following week we received the results during a consultation visit at the clinic."*

Also, interviewees reported often actions that were related to applying for social services provided by the local government, such as daycare for the child, or to applying for welfare benefits to which they are entitled by law in this phase of life, such as maternity benefit or family allowance mostly by the internet.

#### *Activities in the role of consumers of products and services*

Expecting a baby or having young children in the family is a phase in life in Western societies during which families suddenly become active consumers in the market of child and pregnancy related goods and services. The activities in this category differ from the first category by the fact that the providers of the goods and services are a myriad of private actors, which poses a different type of challenge for the families and requires plenty of information to be able to make an informed choice. The following two information management activities were identified in this category:

- Selection and purchase of child care or pregnancy related equipment
- Consulting for safe travel during pregnancy or with young children

The interviewees reported many situations that were related to the selection or purchase of, for example, a pram or special clothing for the breast-feeding mother.

*Family 4: "This week as I was surfing on the internet I came across a support pillow that you place between your legs while sleeping to support your back, and to ease the pressure on your hips. It was on sale in a net shop, which inspired me to do some comparison between similar products on the internet."*

The information management actions in this category were mostly events of information acquisition or information exchange through the internet either directly with the service or good providers, or in informal internet based discussion groups.

#### *Activities in the role of citizens aspiring to a sense of wellbeing*

Not all situations concerned with health or wellbeing described by the families were about satisfying health or social service related needs or buying goods or services in the market as an informed consumer. Many situations, in fact, served purposes for which there was no need for specific service or product outside the family context, in

other words there was no health or social service use or product consumption involved in the activity. Activities in this category included:

- Seeking and maintaining peer and community support
- Seeking and maintaining peace of mind on health and wellbeing related issues
- Organizing and storing health and wellbeing related information at home

The actions under these categories reported by the interviewees included, for example, meeting other parents and children in a play park, looking for other parents' experiences about specific health related problems in an informal discussion group on the internet to decide whether the problem needs professional attention, and filing family members' clinical papers in folders at home.

*Family 6: "A couple of days ago I was wondering whether our 2-months-old could be having his first tooth as he was drooling a lot. [...] I discussed the issue with my sister-in-law who has 4 children already who was of the opinion that this might be the case."*

Activities in this category seemed to support the family members' overall wellbeing and sense of coherence, and seeing the world as meaningful and predictable.

#### *Contradictions in current activities*

The second objective of the study was to identify those health and wellbeing information management related activities, in which the participant families felt they had problems that could be understood as contradictions in the system. Based on the theoretical framework of activity theory, the identification of systemic contradictions is particularly important in order to get an idea of which direction the system may be evolving through its developmental dimension and emerging new activities.

It was especially information seeking situations falling under the activities in the third category, seeking and maintaining peace of mind on health and wellbeing related issues, and organizing and storing health and wellbeing related information at home, which had left families sometimes dissatisfied. Seeking and maintaining peace of mind was an umbrella term for situations in which the families searched for information and support on the internet or from peers in situations where professionals had already been contacted, but the professional information received did not satisfy the family or was contradictory in some cases where several professionals had been consulted. The primary purpose or objective for information seeking was not so much to get an answer to a specific health or wellbeing related problem, but rather to be reassured and comforted in a deeply worrying situation. However, this was not always successful.

*Family 6: "After our visit to the maternity care clinic [where maternity nurse suspected that the baby's position was distorted while lying on his tummy] I got really worried and started calling friends, some of whom are medical doctors, to ask for more advice. I also looked for information on the internet both from medical sites and informal discussion groups. Knowing more about the problem made me even more worried because I understood that a distorted position can even be an indication of a brain injury, after which my imagination started running wild and the following two nights I was unable to sleep properly..."*



Another area in which the interviewed families expressed dissatisfaction was their system of storing and archiving health and wellbeing related personal information at home. Being active users of services, families collect a considerable amount of paper based information such as drug prescriptions and child health monitoring reports, which in most families seem to end up in disorganized paper piles in a bookshelf or on the kitchen table. More active families had a system of plastic folders and files. In many families the problem for a better organization of these papers seemed to be lack of time and lack of interest.

*Family 7: "We have saved all our papers and things carefully, I just don't know where. [...] Our filing system really does not work, but at the moment it's the only one we use. I have been planning for the past four years to sort all the papers in folders in the bookshelf, but I always found something more important to do."*

It seems that still today households lack simple and usable personal information storage systems.

## Discussion

The results of the study reflect the different, although sometimes overlapping roles that families with small children play in the Finnish society when dealing with health and wellbeing related issues: the role of users of mostly publicly provided health and social services, the role of consumers in the private market of goods and services, and the role of citizens seeking a sense of coherence and emotional wellbeing. Somewhat contrary to our expectations, the families included in the study seemed relatively satisfied with the amount and availability of health and wellbeing related information and support in their everyday lives with the existing service system and market structure. Information needs and sources seemed to be easy to identify, and information could be acquired and exchanged smoothly within the existing service systems and technology. The major problems and concerns that the families seemed to have were in areas that fall outside the current professional and/or commercial interest and care. For example, families found themselves in situations of extreme uncertainty, after having received controversial information from both health service providers and internet sources. Families also expressed concerns regarding how to organize and store at home household members' personal health and wellbeing related information to find it easily when needed.

This study focused on a single stakeholder's point of view, that of families with young children. Activity theoretical frameworks have been traditionally used in organizational settings to depict and analyze work activities from the point of view of different professional groups. Our study is an attempt to apply activity theoretical thinking in activities of everyday life. Our starting point was to describe what happens in family life from the point of view of information use. Networks connecting the different actors were not the primary focus of this study. The next step in the research process could be to make visible the inner dynamics of the activities, understood as networks that connect families with service providers, private companies, and family and peer groups interacting with technological tools to manage information. On the other hand, focusing on the end users of a potential new service has value as such. It has been pointed out that the most capable actors to expand their perspectives in relation to the object of activity are the ones concretely interacting with it, while other practitioner groups may remain reluctant to change their perspectives [38]. However, a change in perspectives is required if the aim is to come up with an expanded view of the activity and therefore to contribute to an innovative way of looking at the present situation [38]. In developing user-centric ICT-supported family health and wellbeing services, the first step is to make visible families' everyday use of health and wellbeing related information in the context of complex technology and ser-

vice environment. This research serves as an exploratory study and as such opens up new directions for future research and, as well, we believe, for future service and technology design.

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