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Creative Toolkits for Developing Biomedical Technology for Children with Chronic Illness

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Abstract

This paper details the development of an interview toolkit designed for research with children dealing with chronic illness, aimed at discovering information about their daily routine, and what barriers they experience as a result of their condition.

Because of the challenges of working with children, especially children with chronic illness, traditional interview methods may be ineffective in soliciting authentic information regarding their needs and desires. Alternative methods must be used to elicit their input. The methods explored for this research propose an 'interview toolkit', based on methods used in child psychology and play therapy.

The toolkit's aim is to gather information regarding the children's aspirational needs and desires. This data could then inform the development of future technologies aimed at enabling them to mitigate the stigmatization associated with chronic illness, as well as empower them with tools to monitor changes in their health.

Keywords: Medical device design, children, participatory research, design approaches, chronic illness, interviews

Introduction

Anthropologist Christine Kiefer (Kiefer, 2007, 101) suggests studying people's perceptions of their problems may lead to better design interventions to fit their needs, and that one of the best strategies in aiding patients is to help them recognize their own knowledge and abilities, and arrange for them to be able to take a leadership role in their problem solving and health management.¹

The genesis of this research project was to analyse and evaluate if there might be an opportunity for a design intervention, whereby medical monitoring systems in the form of new biomedical technology or smart garment system may be able to assist children with chronic illnesses, in facilitating wellness by empowering them with a more comprehensive understanding of the fluctuations in their health during cycles of illness or throughout their daily activities.

The research design strategy for this project includes the use of participatory design methods is to empower the user by sharing in the co-creation of products that meet their needs, preferences, and fit their contexts of use.

A specialized 'interview toolkit' has been developed for this project, for the purposes of facilitating communication in a format common to children's colouring books, along with 'context stickers'. These 'thought-starter' context stickers were developed based on a menu of potential activities that children participate in, including school scenarios, group activities or clubs, and solo play. The hope is that this toolkit will enable researchers to gain more meaningful insights into the world of children, including their needs and desires, when it comes to new products.

Theoretical: Ethnography and Arts-based Interview Methods

Ethnography allows researchers to develop empathy for users, by allowing information to flow from the user regarding their lived experience. The goal of phase one of the interview processes of this research project is to gather and report data from the field related to users' perceptions on the potential for new biotechnology, their responsiveness to pervasive health monitoring systems, and what their needs might be in terms of monitoring. For these purposes, ethnographic observations and open-ended interviews have been planned for use.

¹ (C. Kiefer, 2007)

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This paper details the development of a specialized interview toolkit designed for research with children dealing with chronic illness. The goal of this toolkit is to facilitate more in depth interviewing with sick children, and for discovering information about their daily routine, or what barriers they experience as a result of their medical condition.

The toolkit's aim is to gather information regarding the children's aspirational needs and desires. This data could then inform the development of future technologies aimed at enabling them to mitigate the stigmatization which may be associated in living with chronic illness, as well as empower them with tools to monitor changes during their cycles of health and illness.

Research Design

For a project of this scope, anthropologist LeCompte suggests in-depth, open-ended interviewing, because it allows for a topic to be explored in detail, with along with the flexibility to deepen a researcher's knowledge by allowing for all relevant responses.² The goal of using the semi-structured interview format is to collect information from a more holistic perspective, so that data can be reviewed for key details, details that can be compared across respondents. This data can then be compared for explanations of relationships among certain variables (such as: when I do X, this happens), and evaluated for emerging issues or themes.³

However, Kiefer (Kiefer, 2007, 128) notes that feelings and perceptions about one are often difficult to discuss, particularly when the respondent is a child who may be in a more subordinate role due to the nature of adult-child relationships.⁴ In typical adult/child rapport, socio-cultural dynamics are structured to create power relationships, which may force the child/patient into a role of subservience, and fear of domination. This role may pose a barrier to fluid communication between patient, caregiver, and their healthcare provider, and make the veil of research difficult to penetrate.

Here, interview techniques borrowed from child psychology and medical play therapy have been adapted to facilitate the interview process for this research project.

² (LeCompte, 1999)

³ (Metcalf, 2009)

⁴ (C. Kiefer, 2007)

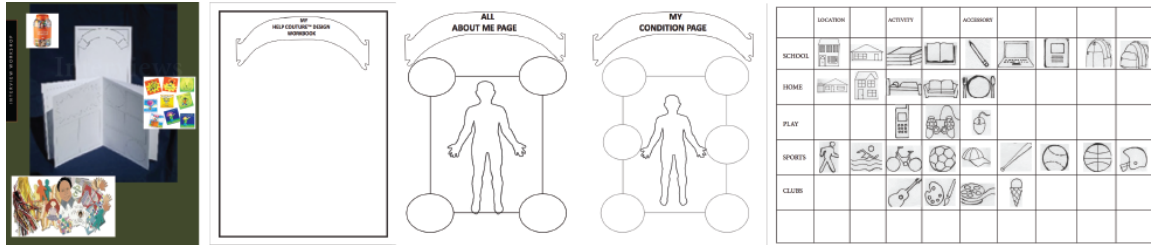


Figure 1: [From left to right: Art supplies to be used in conjunction with toolkit during interview process, Title Page and Banner of Interview Workbook, All About Me and My Condition Page Spreads from Interview Workbook, Mock up of Context Menu Sticker Icons]

Interview Toolkit and Context Stickers

One of the goals in this research is to learn about the child's daily routine, including what kinds of barriers he/she may be experiencing as a result of illness.

To meet this goal, psychologist Rawley Silver's concepts of stimulus drawings were adapted into 'context stickers'. The 'context stickers' were based on a menu of simplified icons associated with potential activities, locations, and artefacts that a child might encounter in a typical day (Silver, 2001).

Toolkit design: workbook and context stickers

In conjunction with the utilization of the 'context stickers' as stimulus drawings, a design 'workbook' has been developed as part of this project's interview toolkit – a colouring book that could be used by the child respondent during the interview to spark conversation. In addition, 'stimulus drawings'⁵ images are utilized as thought-starters, to aid respondents in further interacting with the interview toolkit.

The workbook involves two parts, to be used in phases over the course of two to four interviews. The first two pages are described as the 'All About Me' and 'My Condition' pages. The pages encompass layouts with sections for the child to identify contexts in which they interact, and express what they value most in those situations.

The form of the questions for such an interview centres on beginning with open-ended questions, and narrowing down into more specific inquiries. Questions are phrased as:

- "Let's talk about your daily activities."
- "What do you like to do when you are at home?" "When you are at school?"

⁵ (Silver, 2001: Chapter two: Stimulus Drawing Assessments)

- “What kinds of things do you enjoy doing by yourself?”
- “Are you involved in any groups? What types of games do you play when you are with your friends?”
- “How does your illness prevent you from doing the things you like to do?”

Starting with standard locations, such as home and school, the ‘context stickers’ also call out other situations the child might be involved in, such as ‘solo play’, ‘group play’, and ‘clubs’, either sports clubs or social clubs.

The menu format of these context stickers items would then aid in the phases of the interview discussion, to flesh out information regarding the child’s typical daily routine, or, more specifically, what they aspired to or enjoyed most in their daily routine, on a sketchbook designed specifically for this research on the page labelled the ‘All About Me’.

Context Stickers Design

The sticker menu itself is also a designed system, to be used as a communication tool. The organization or design of the interview tools themselves may prompt what Don Norman (Norman, 2005) refers to as a ‘visceral’⁶ reaction or emotional response from the informant, based on how their brains have been exposed to the signs and the items they signify. Based on these previous experiences, the viewer’s sense of ‘pattern matching’ or interpretation of the icons will prompt either a positive association or a negative one. Meredith Davis (Davis, 2012) highlights that choosing appropriate signs for communication systems can be a complicated task in and of itself, so the sticker menu has been designed to be flexible and adaptive as users identify new metaphors that may need to be incorporated.⁷

‘Context’ stickers, based on simple ISOTYPE⁸ styled iconographic designs, will be used to prompt conversation, similar to Krampen’s and Silver’s “stimulus drawings”⁹ utilized in child psychology (Krampen, 1991; Silver, 2001). The ISOTYPES are ‘iconic shortcuts’ for meanings when used as images as part of this interview toolkit; they represent simplified expressions of common items, places, or things. The goal in using this menu of icons in conjunction with the interview workbook is to provide the child being interviewed with a ‘thought menu’ through

⁶ (Norman, 2007) (Davis, 2011: The cognitive context for design: how we are alike and different) Davis details Don Norman’s three levels of emotional response to products and sign systems. The “visceral” level of emotion relies on appearance.

⁷ (Davis, 2012) Davis suggests that iconic metaphors allow for opportunities to make the strange more familiar, by revealing aspects of a known thing through comparison with something else.

⁸ (Hartmann, 2007) Hartmann reports that Otto Neurath developed the ISOTYPE system as a universal pictographic system which was meant to clarify ideas by delimited concepts down to the simplest forms of expression. His main objectives in developing this system were to create a “helping language”, using pictures to “make connections”.

⁹ (Krampen, 1991) (Silver, 2001) Both Krampen and Silver suggest using projective tools, or concept drawings, to launch conversation and inspire discussion when working with children in interview contexts. These “thought starter” or “stimulus” drawings can ease some of the tension that informants feel when being asked to “perform” certain tasks, such as drawing during an interview.

which to express them, without the need for complex or potentially emotionally traumatizing conversation.¹⁰

The 'Context' sticker menu is organized so that pictorial elements are shown in relationship to one another. Down one axis, the menu items represent contexts of use. Across the other axis, the icons depict items that are meant to be associated with each of those contexts, based on generalities or assumptions. For example, the home ISOTYPE is a simple single-story triangle-shape roofed house. For the context of play, there are two channels: the solo play category offers items one might associate with computer gaming, while group play shows an array of sports club equipment.

The follow up in phase two of the interview would then look for 'pain points', or barriers, which the child may be experiencing as a result of their illness, in achieving the quality of life to which they aspire. This section of the interview was designed to use the 'context stickers' on the sketchbook page labelled 'My Condition'. On this page, a compare-contrast process would take place, either with the child indicating how they were personally affected, or, depending on their comfort level, through the use of an avatar: that of a metaphoric 'friend'.































	LOCATION		ACTIVITY		ACCESSORY				
SCHOOL									
HOME									
PLAY									
SPORTS									
CLUBS									

Figure 2: [Detailed View: Context Sticker Menu Mock-Up]

¹⁰ (Hartmann, 2007) Hartmann references the work of philosopher John Locke, stating, "As the main objective of language in communication is to be understood, words are not suitable for this purpose." The idea expressed suggests icons can be a more effective medium than the "arbitrary" use of words to express and communicate across cultures.

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