

Exploring design strategies to determine information needs of caregivers

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Abstract

In this paper, the authors present information needs required by caregivers in a resource-constrained community during their health-education activities with considerations to design ethics. The role of visuals and technology in facilitating health communication, the need to design “with” users and the benefits thereof are discussed.

The study adopts a service design ethos to obtain data from research conducted with the Grabouw community in the Western Cape, South Africa. Participatory and co-design workshops were organised with caregivers in the community. Due to the complex nature of healthcare services provided by caregivers, ethical considerations were factored into co-design activities. Researchers in this case adhered to relevant ethical procedures and therefore were “enkratic”, giving due consideration to the concerns of the caregivers at all times in every design engagement. This process helped in establishing desirable trust and empathy needed to facilitate the co-design activities.

Also, the study highlights design as an evolving process of engagement and how designers are becoming increasingly eco-centric. It lays emphasis on designing “with” stakeholders at the grassroots level, which potentially fosters community participation and emancipation. Thus eco-centric design is encouraged in community engagements rather than “ego-centric” design – which is designing “for” users, without including their perspective. The authors suggest “co-design” as a process of enquiry – an alternative to determine information needs of healthcare workers in resource-constrained contexts.

Keywords: Caregiver, Co-design, Design Ethics, Information Needs, Service Design

Introduction

Information is relevant in health education activities to promote health literacy. Improving patients' health through preventive measures requires relevant information that patients can relate to in order to improve their health behaviour (Schulz & Nakamoto 2013, p.5-9). Currently, through the use of available Information and Communication Technologies (ICTs), Community Healthcare Workers (CHWs) are able to communicate with their clients and facilitate health-education in resource-constrained settings (Braun *et al.* 2013, p.1-2). However, providing equitable health information using ICTs to patients in remote settings is sometimes a challenge for health service intermediaries such as caregivers. The disparities in literacy levels among patients, limited relevant promotional materials and Internet connectivity are some of the drawbacks to health education in such communities (McConnell *et al.* 2006, p.20-21).

In this study the researchers focus on inquiring about information needs desired by caregivers to facilitate health education activities to mothers in Grabouw, South Africa. Although ICTs are available to caregivers in this community, the provision of health information via these platforms still needs to be explored. Thus, service design strategies such as co-design and participatory design methods were adopted to engage with caregivers to determine their information needs relating to Maternal and Child Healthcare (MCH). Outcomes of the design activities revealed that promotional materials for caregivers were insufficient. Consequently, educational materials are desired in critical areas in

women's health – before, during and after pregnancy. Thus, exploring the use of multimedia messaging as a means of communication can facilitate women's access to health information (McConnell *et al.* 2006, p.5).

Further, ethics and accountability do matter in service design activities. Service designers usually serve as advocates for their users and are perceived as the voice *of* and *for* the people. They rarely assume the position of their users. Instead, they empathise with them using service design tools such as personas, storyboards, and design probes to find solutions to problems. In such engagements, designers are perceived to be ethical when their solutions are geared towards sustainability although this might not be the best approach to solve problems in all cases. Designers are expected to reflect on their choice of solutions and its impact on the lives of end-users as part of ethical considerations in design activities (Carlsson 2010, p.2-4). In this study, the authors discuss how efforts were made in applying ethical norms during design engagements with participants. Fundamental ethical considerations in line with design principles were made during co-design activities due to the nature of healthcare workers involved. Efforts were made not to exhibit *akrasia* (acting on opinions rather than reason). Rather, the researchers focused on "*what*" they wanted to achieve with deep reflections on *enkritic* norms (acting reasonably) which is expected to be demonstrated by designers in co-design engagements (Young 2013, p.90-91).

Background and purpose

Information needs of caregivers

Information needs or "wants" by healthcare workers can be multifaceted and varied, encompassing different scopes in their field of expertise (Pakenham-Walsh & Bukachi, 2009, p.8). The roles of health workers are different and so are their information needs. Soliciting information directly from caregivers can potentially indicate the "wants" on relevant topics where information is desired in their professional practice (McConnell *et al.* 2006, p.51). This way, they are more likely to use health information materials developed in their professional practice than when they are offered materials without their contributions.

The community caregiver and health education

Community healthcare workers such as caregivers play a crucial role in the South African Public Health Sector. The authors refer to home-based carers as caregivers in this paper. They act as front-liners in providing health information to improve the health of patients in their localities (Cargo & Flores, 2014, p.8). They have contributed extensively to health outcomes in remote areas especially with MCH by providing basic information on Prenatal-Care, Antenatal-Care and Postnatal-Care to women (Medhanyie, Spigt & Kifle 2012, p.2). The authors did not elaborate on the activities of caregivers in this paper as they have been discussed extensively in earlier publications from this research case but highlighted the context of caregivers and opportunities for technology integration in their education and work practice (see Debrah *et al.* 2014, p.96-99; Van Zyl 2014, p.1-7). In this paper, some of the challenges that confront caregivers regarding their information needs desired for health education activities are discussed.

Studies have shown that there are complexities that always confront health professionals such as caregivers in communicating information to patients. Some of these challenges have been outlined by Kreps (2012, p.14) as:

- "Limited, availability and access to relevant health information,
- Lack of sensitivity in the delivery of care,
- Ineffective health education and health promotion programs,
- Poor consumer adherence with health recommendations, and
- Failure to engage in recommended behaviours to help detect and avoid health risks" .

These challenges, among others, slow down the progress of health organisations to achieve global health targets such as the *Millennium Development Goal (MDG) 5*, which aims at improving MCH (United Nations 2012, p.30-38). Evidently, the role of relevant information in minimising these challenges cannot be underestimated. For instance, the challenges with health literacy are compounded by how health information is designed. A well-designed health education and health promotion strategy, facilitated by simplified information without language barriers, could increase the interest of patients in health messages to promote health literacy (Paasche-Orlow *et al.*, 2005:182). As indicated by McConnell *et al.* (2006, p.51), engaging community partners in research processes can facilitate the design of relevant information for effective health education.

Further, the inclusion of users in the design process conveys a sense of ownership and minimises strong resistance to accepting health education interventions, tools and policies (Kreps 2012, p.17). Inclusive design strategies allow data to be obtained directly from end-users, and relinquish power to them in making suggestions which could directly provide solutions to their problems (Holmlid, 2009:2; Mager & Sung 2011, p.1). In this research, the investigators focused on community caregivers as the participants by assessing their challenges with information needs regarding MCH. Thus, the questions underlining this research are:

- How can design strategies be employed to determine information needs of caregivers in the African context?
- What ethical considerations should be factored into the design engagements?

In addressing these questions, service design strategies such as co-design and participatory design were adopted to determine the information needs from the perspective of caregivers.

The co-design methods and ethical considerations followed in this research have been deliberated upon in the subsequent subdivisions of this article.

Materials and methods

The study was conducted qualitatively using service design strategies. Service design aims at designing from the user's perspective. Service design can be described as a multidisciplinary process that incorporates functionality and the complexity of services by visualising systems "with" the "user" at the heart of the process (Trischler & Zehrer 2012, p.59). The services must be useful, usable and desirable to the user; they must be efficient and effective from the provider's point of view (Mager & Sung, 2011, p.1). Design modalities such as co-design were used to obtain data. The design process began with prior investigations through informal conversations and observations. The adaptation of these methods made it possible to gain insights into the context of caregivers and their challenges with information in their healthcare service delivery.

The design milieu

The design milieu is situated in the Grabouw community in Western Cape, South Africa. The general public living in this locale are predominantly farmers. The high population ratios in the area put pressure on healthcare and other amenities in the community. Grabouw is confronted with social issues prevalent in similar resource-constrained settings in developing parts of Africa. These include drug abuse, teenage pregnancy and crime (Mendonca & Van Zyl 2014, p.103). Other crucial challenges are in relation to women's health – where there is a lack in educational materials for health education. Caregivers in Grabouw provide additional health education to complement what is offered in major community hospitals (Van Zyl, 2014, p.5). They care for patients in their homes to achieve global health objectives for women and children as stated in *MDG 5* (United Nations, 2012:31-33). Thus, through service design approaches, the researchers explored possibilities of achieving some of these health goals by giving due consideration to design ethics.

Ethical considerations: human-centred-design perspective

The concept of ethics is defined as the philosophical study of morality (Keller 2009, p.11). Ethics in research terms refer to the moral principles such as the norms and values identified by a research

community to guide a particular research project. The word *ethics* is often used interchangeably with *morality* where morality means ethical behaviour (Keller 2009, p.11; Collins, 2010, p.82). Morality encapsulates what we think is *right or wrong* as moral agents. There are still unanswered questions about the meaning of ethics from the philosophical point of view, many of which seem to be multifaceted.

For instance, the questions about who or what should be counted in ethical deliberations is answered by philosophers from the human-centred perspective that humans are the right subject matter for ethics and rationality is the necessary state to demand ethics. Western traditions and philosophers such as Socrates and Sartre assure that humans are the core of ethical considerations (Keller 2009, p.40).

Further, design is defined as a problem solving activity that is directed at meeting societal needs or creating something new towards the goodness of society. Designers by their professional standards have good intentions in their practice and are expected to be rational in the process of solving problems for social good (Inácio & Gerardo 2006, p.1-3).

However, as design research and practices evolve, humans have become more central in the design process from the pre-design to the post-design phases in the design of products or services (Sanders & Stappers 2014, p.11). The issue about *ethics, value, rigour and accountability* cannot be discounted during the design of solutions to multifaceted problems when humans are the core beneficiaries of the designed solutions. The idea of being ethical in simple words can be said to be “*doing the right things*”, which is accepted by society. Therefore ethical reasoning in design engagements to a large extent, is essential to foster the “*making*” of “*right*” solutions based on “*rationality*” that will benefit end-users. Contrary to these norms and values, the designers’ behaviour is perceived as irrational regarding design ethics (Inácio & Gerardo 2006, p.10).

Ethical reasoning in co-design

Ethical reasoning in design is a crucial issue that needs to be tackled in creative research whether visual or textual and in contemporary research approaches to protect the actors involved in the creative process. *How then do we define ethics in design?* Porter Stewart states, “*Ethics in other words is knowing the difference between what you have the right to do and what is right to do*” –(as cited in Collins, 2010, p.82). Designers, irrespective of their specialisation in the discipline, have guidelines and codes of ethics that govern their sense of judgement in design which ought to be factored into the design process. However, in design activities where human-centredness is the core of the outcomes, design values, attitudes and beliefs regarding what design-researchers reasonably believe is *right* to do, are significant concerns which ought to be factored into the planning process and brought to decision making during co-design engagements. Some of these ethical considerations include providing informed consent and ensuring that participants are aware of how visual and textual data will be disseminated. In situations where there are observations through audio-visual documentary, images and audio data must be managed and used creditably without compromising ethical norms and values in visual related research (Collins 2010, p.84-85).

Co-design in practice: Enkratic versus Akrasia in review

The philosophy underpinning these concepts of *enkratic* and *akrasia* is that designers have to behave ethically (Young 2013, p.90-91). Inácio and Gerardo (2006, p.10) assert that “*To be enkratic, one must hold to the rational judgment he performs, i. e., he must rationally choose the good course of action and take it. This is contrary to the akratic behaviour, where the agent, in spite of knowing what the good action is, he chooses something else*”.

For instance, in creative research that employs methods such as service design, designers are likely to use visual data, which include photographs, drawings, audio recording and so on. The right thing to do in such situations is to obtain permission from participants by seeking their “*informed consent*” in order to use visual and textual data in research outcomes (Collins 2010, p.84). When a designer undertakes this ethical process it is perceived as being *enkratic*. On the contrary when a designer knows the right thing to do and acts otherwise, then the designer may be considered as exhibiting

akrasia. Further, within the discourse of co-design ethics, designers are seen to be ethical when they design based on what they deem to be *morally right* and not otherwise. Inácio and Gerardo (2006, p.16) have indicated that even though designers are able to be *enkratic* in their actions, not all their actions are perceived to be rational and therefore *in general* they are *akratic* in almost every action (Young 2013, p.90-91).

However, if designers integrate their morals into what they intend to do, then in that case they are considered as *enkratic*-designers. In contrast, in situations where designers do not base their judgment and considerations on the same ethical philosophies in line with *enkratic* norms, they are considered to be exhibiting *akrasia*. *Akrasia* is said to be the state when people act against their personal sense of judgment (Coates, 2011, p.329-330). This conflict often occurs in circumstances when designers make decisions based on their personal *opinions* and not *reason*. In such instances, designers are considered as acting against social good – thus being unethical (Young 2013, p.90-91).

The inference is that ethics and accountability must be integral in co-design practice and in particular, design education as a whole. Designers are encouraged to take responsibility for their actions and encouraged to be rational agents. Krippendorf (1998, p.179) notes that even though designers may suffer from *akrasia*, they do not suffer from *amnesia* and are encouraged to decide to be rational in their judgment and decision making regarding ethics (as cited in Inácio & Gerardo 2006, p.16).

Co-design engagement: reflecting on design ethics

In this study, researchers made attempts to be *enkratic* during design deliberations for the co-design engagement. Adhering to *enkratic* norms, efforts were made to extend ethical considerations into co-design activities *with* the participants. For instance, to be rational agents of design, time had to be effectively managed because the participants in this case were caregivers who have patients to care for daily. In view of this, co-design sessions were spread over a period of two days per session in a manner that would permit them to attend to their patients. Additionally, caregivers signed consent forms during the initial stages of the co-design activities, providing permission for the researchers to engage with them. Explanations regarding the end use of visual and textual data were made known to caregivers involved in the design activities. Participants were not restrained from withdrawing from workshop activities should they find it not comfortable at any point in time. However, most caregivers co-operated very well and actively participated in all the design sessions.

Designing with caregivers

Design has evolved from *ego-centric* design where solutions are only designed “*for*” customers to socially responsive design which focuses on designing *with* users. Eco-centric design focuses on designing from the perspective of users rather than only designing “*for*” users (Young 2013, p.91). Socially responsive design in a developing context requires expert facilitation. However, designers usually act as facilitators using service design protocols in such contextual explorations to achieve desired goals.

Design could be defined as a process of planning to arrive at outcomes, which may either be a service or a product (Simonsen *et al.* 2014, p.1-2). Previously, designers only focused on product related outcomes with minimal inclusion of the *users* in the design process. Designs were mostly done “*for*” users and not “*with*” users. In recent times, design has become multidisciplinary as a way of tapping into a broad range of expertise to find solutions to *wicked* problems “*with*” or “*for*” users (Trischler & Zehrer, 2012, p.59). Thus, design can be described as a process to solve problems that meets human needs, by empathising with users in order to obtain the necessary user value for the desired solutions (Friedman & Stolterman 2014, p.7-9). As Mager (2006, p.7) indicates, “*good design is connected to good strategy*” and this also applies to products and services.

Service design methods were adopted to engage caregivers through participatory and co-design sessions in this research. In line with this, it was essential for researchers to consider core design concepts such as eco-centric design, to facilitate the probing process with caregivers. Through visual

modalities, caregivers expressed their ideas in the design setting. Using coloured sticky notes and visual probing tools, caregivers shared their experiences with researchers in order to identify topical areas where more information was required for women's health. These were conducted in a suitable *design milieu* with the caregivers at Elgin Learning Foundation – the training centre for caregivers in Grabouw.

The design milieu and participants

There were approximately 60 caregivers who participated in the co-design sessions. Some of the design activities were conducted directly in the communities where the caregivers lived and worked, whereas subsequent sessions were undertaken at Elgin Learning Foundation. This was done at different intervals in different working groups ranging from 20-25 participants per session. Within each design milieu, there were 4-5 participants in each working team (Figure 1). This way, participants freely shared their thoughts on the various tasks under review (Debrah *et al.* 2014, p.99-100).



Figure 1: Caregivers at work in the design milieu

Materials used for the design sessions

Basic stationery and consumables such as pens, paper, colour pencils, markers, staplers, adhesives and paper clips were the main materials used during design engagements. Projectors were used to facilitate the presentation of the various tasks in the design milieu whereas cameras were used to document activities in the design sessions for record purposes and further interpretation of data obtained (Debrah *et al.* 2014, p.100).

Design modes

In line with fundamental design procedures, initial research was conducted. This was mainly done through informal conversations and observations. The outcomes provided an understanding of the work activities of the caregivers and served to ascertain where challenges exist with information for health education (Debrah *et al.* 2014, p.99-105). This formed the basis and the starting point of the study. Also, service design processes follow concrete modalities to arrive at outcomes. As identified by the Design Council in the double diamond process, service design process is made up of four phases – Discover, Define, Develop and Deliver (Davies & Wilson 2013, p.6). The study explored through the first half of the double diamond (discovery and defining) iterative process to identify information needs of caregivers (Figure 2).

During these design sessions, caregivers came up with challenges regarding their information needs. After a collective agreement by team members, they indicated some of the topical areas on women's health where information will be required. A vivid description of the content of the messages desired on women's health were noted by caregivers. In some instances, suggestions for accompanying visuals on some of the relevant topics were communicated (see compilation in Table 1). The descriptions mainly covered preventive measures, signs, symptoms and treatment procedures to facilitate communication during health education activities.

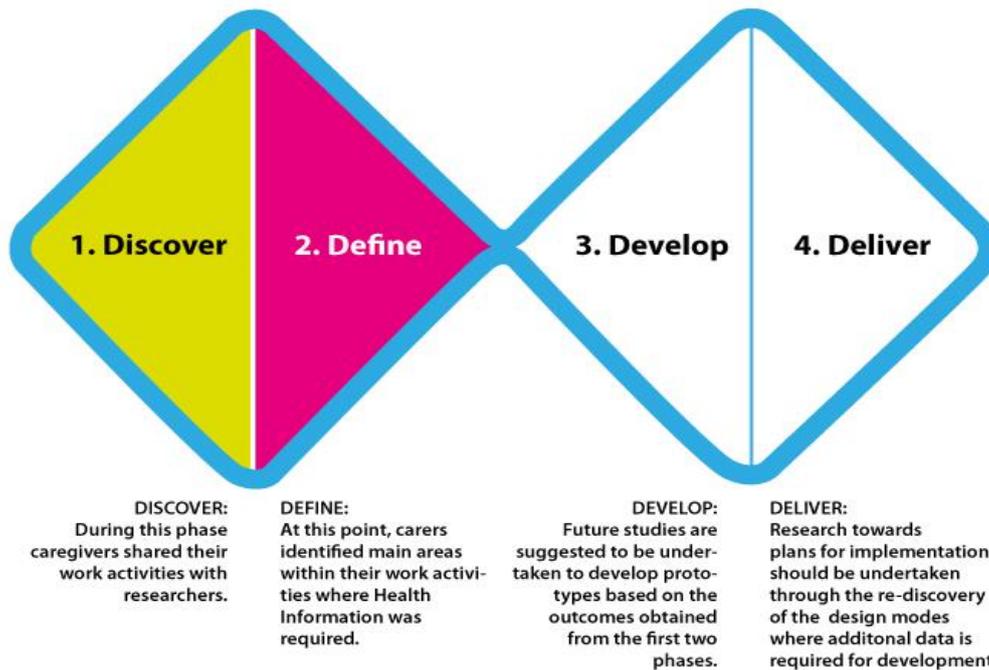


Figure 2: The double diamond design process (Davies & Wilson, 2013:6), showing phases where data were obtained by researchers in this study.

Results

Outcomes presented here are mainly based on the data obtained from the discovery and define stages of the design process during co-design activities (Figure 2). Additional data was obtained through informal conversations and observations in the community in line with ethical principles. The results obtained from design sessions revealed many instances where information was required by caregivers, a few of which are presented for discussion in this article.

The topics were mainly based on the major areas in women’s health as expressed by caregivers during the design sessions. These covered common illnesses, their signs and symptoms, as well as their preventive measures. The topics were then grouped thematically by identifying the various categories, with the classification based on the most recurring topics and suggestions as communicated from the caregivers’ perspective (Figure 3).

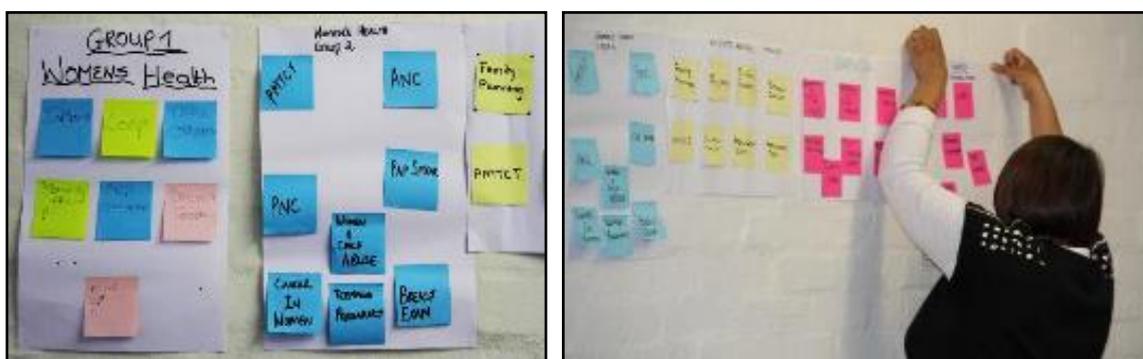


Figure 3 – Thematic clustering of healthcare topics as obtained from Caregivers’ perspective in the design milieu

Information needs identified

Most of the desired information for health education indicated by caregivers (Table 1) covered relevant health topics with their relevant description of preventive measures and treatment

procedures. The caregivers explained that due to the limited availability of promotional materials on the said topics, information communication is sometimes challenging during health education. Also, due to the presentation formats of some of the health education materials it becomes uninteresting for patients to appreciate and relate to healthcare instructions. In order to constantly achieve desirable health outcomes, caregivers require relevant information to communicate effectively with their patients. Through health education activities and empowered by technology such as mobile Health (mHealth) initiatives, CHWs could have equitable access to relevant health information to facilitate health education in developing contexts (De la Harpe, Kabaso & Debrah 2014, p.139). It is anticipated that through the availability of relevant information there will be improvement in health behaviour of women to minimise maternal morbidity and mortality in resource-constrained settings. Improved health behaviour, according to Butler (2014, p.42-43), could be realised by acting on and adhering to health information offered through planned, consistent and integrated learning to circumvent health risks.

Health topic	Information in visuals
Antenatal care	Early booking so that mothers can know their HIV test results; How the mother and her unborn baby need to be taken care of; Prepare mother for birth process; Early booking and caring for mother and baby during pregnancy.
Family planning	It is better to plan a family; Different family planning methods, e.g. pill and injection; 2 months injection, 3 months injection, implants for 3 years; How to do the implant, etc.
Breast feeding	Exclusive breastfeeding is very important; How to position the baby during breastfeeding; Such as keeping the baby in a position which is comfortable for the mother.
Road to child health	The need for children to all have cards for immunisation; Vitamin A immunisation, deworming, etc.; Mothers to take children to clinic regularly for examination.
Cervical cancer	The need for women to undertake Pap Smear; To encourage women to go for treatment i.e. between 21-30 years and every 10 years to avoid cervical cancer.
Breast cancer	How to examine the breast; The need for frequent breast examination.
HIV testing	To promote test as it is very important to know your status; Prevention of HIV from mother to child; And preventive methods such as using condoms, etc.
Drug and alcohol abuse	Effect on health and preventive measures.

Table 1: Health topics that caregivers desire information for patient education

Discussion

Health education activities always require information to facilitate the communication process for effective patient education. The engagements with the caregivers revealed areas where information is needed in women's health. The results, as compiled in Table 1, show some of the relevant areas where information is desired by caregivers to facilitate health education. Primarily, the topics obtained from caregivers were mainly related to women's health. These covered crucial areas – before, during and after pregnancy. The carers presented a vivid description of the type of images they desired for each of the topics identified in Table 1. These were mainly basic instructions required for the signs and symptoms in topical areas in MCH. Additional information was based on preventive measures on chronic diseases such as cervical and breast *cancer*.

Furthermore, caregivers presented a vivid description of these information needs and described how it could be developed as visual aids to facilitate communication during health education activities. Results obtained confirmed some of the assertions by Kreps (2012, p.13) that inequalities still persist in health information for communication between privileged and less privileged societies. Other

studies indicate that access to communication and relevant information is one of the several components which are crucial to improving the quality of maternal health education, especially in resource-constrained settings (Noordam *et al.* 2011, p.622). However, constant research to identify information required by community caregivers through design methods – participatory and co-design– are encouraged (McConnell *et al.* 2006, p.51).

Future studies are needed to explore design modalities to discover more sub-categories of the health topics identified in this case study where content is anticipated. The co-creation of sustainable relevant content (visual media) *with* caregivers in each of the desired health topics is suggested as a way to align with design ethics (Carlsson 2010:2-4). Also, the use of mass media messages seem to be eye-catching in areas where there is sufficient coverage. Potentially, it facilitates the communication of healthcare messages to viewers (Althabe *et al.* 2008, p.56). Therefore, the health topics described by caregivers in this research, enabled by ICTs with face-to-face communication, can facilitate health education process between MCH stakeholders for equity in healthcare service delivery.

Conclusion

Service design processes, such as co-design, are user-centric. The process can create an enabling environment for key stakeholders to be involved in finding solutions to emerging problems. Caregivers were the main participants for this study. Engaging with them using design strategies allowed information needs to be shared with researchers in a very conducive design milieu. Through open participation, some of the fundamental areas where information is required were documented. The use of technology to enable access to information cannot be underestimated. This is because contextualised visually engaging messages in print and electronic media, can facilitate health communication between caregivers and women. Therefore, technology can potentially facilitate access to health information. Besides, relevant instructional materials integrated into participative health education activities could increase health outcomes. Future design research needs to focus on how health education materials should be sustainably designed *with* stakeholders in order to appreciate and act on healthcare instructions. This could lead to improved health behaviour to minimise health perils. This way, caregivers can obtain desired results in their health education activities and help to improve women's health in resource-constrained settings. Regarding design ethics, the authors encourage designers to be *enkritic* in their design activities by reflecting on their essence as moral agents of design and to take action based on *reason* and not only depend on *opinions* during service design engagements and practice.

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