END-OF-LIFE: ACTION BY DESIGN

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ABSTRACT

Research on value co-creation focuses on the business-consumer (BC) relationship where businesses drive innovation processes by improving consumer products and services that match consumer experience. This paper argues that although there is value in the BC process, there is also unrealized value in the co-creation process between designers and consumers (DC). In this paper, a pre-designed toolkit activity developed by Frog Design is used to identify problems, promote knowledge share between key stakeholders (e.g., caregiver, lawyer, and physician) and help in the design process of a final product solution which adheres to the unmet needs of patients at end-of-life (EOL). After considerable (re)iterations a prototype for the "iCare for EOL" social networking site was developed. This site promotes more interaction and discussion for those working together yet separately with the same patient. This is one of the main problems, identified by participants as to why end-of-life care services need to be revaluated. Participants also believe that an iCare for EOL social networking site will facilitate time-stamped legal recordings of advance directives, reduce overall conflict between medical staff and family members, and increase preferred medical attention and healthcare outcomes.

Keywords: Co-creation, Design Thinking, Patient-centred Care, User-Centred, Design Research

1 INTRODUCTION

Current demographic trends in the West are experiencing drastic increases in senior populations that are rapidly changing the way that end-of-life care is being provided. End-of-life care is defined as an advanced, progressive, incurable illness (NCPC, 2008; 2). Because most physicians believe and are trained to keep people alive, they oftentimes use medical technologies to sustain a patient's life long after the patient is actually living. In certain situations, this can be in opposition to a patient's last wishes as indicated by his or her advance directives. This can also be extremely costly for relatives and medical providers which raises a number of concerns about changing medical practices, reducing costs and meeting patient wishes.

Due to this phenomena, state legislation and industry movements advocate for improving patient-centered care. Patient-centered care is primarily concerned with how patients would like to be cared for based on their needs, wishes, and preferences (Stanton, 2002). Which is unlike the "one size fits all" practice of prescribed medicine. It is also different due to the nature of the end-of-life context where a number of moral, ethical and even cultural issues compete for

center-stage. In some cases, belief and opinion by any one actor can supersede legality because advance directives are not being enforced.

An advance directive is a certified legal document that is filled out by the patient before he or she is at end-of-life. It is issued by the patient's lawyer and is used to give specific instructions about what kind of medical care that the patient would like at end-of-life to the patient's medical care providers. The problem rests on the fact that patients often fail to work with their legal representative on this document before it is too late, medical providers do not follow the instructions on the document at the point-of-care and family members may or may not enforce this document due to unknowns or differing opinions.

In order to disentangle the complexity of this problem, this article aims to apply design thinking and co-creation methodologies to answer the research question, how might a pre-designed, design thinking toolkit activity facilitate a value co-creation process between designer-consumer (DC) for primary stakeholders in the end-of-life context? Applying design thinking and co-creation to this particular problem as a means of sense-making should afford primary stakeholders the opportunity to leverage a well though-out product solution and help primary stakeholders identify accurate, up-to-date resources to help patients express their wishes, including a variety of ways to ensure availability of documents and a structured way to help decision-makers, patients, and physicians communicate effectively.

Design Thinking and Value Co-creation

Of recent, there has been an interest for large companies such as SAP, P&G, IDEO or GE Healthcare (Thienen et al., 2011) to want to either employ design thinking in there research agenda or to hire a company to perform design thinking workshops to help them find better solutions to 'wicked problems.' Buchanan suggests that 'wicked problems' are where the entire system is thoroughly confusing (Buchanan, 1993: 15). Design Thinking and wicked problems have long been associated with one another, implying that thinking like a designer can unwind complexity and help innovate new ideas and products.

Design thinking is discussed in a number of different realms ranging from business management (Dunn and Martin, 2006; Martin, 2009) to education (Martin, 2008; Plattner et al., 2011; Thoring and Muller, 2011). The most cited author of design thinking is Tim Brown who writes about how the world of production and industry are changing from a manufacturing economy to a knowledge work and service delivery economy. He argues that innovation takes place at the intersection of service design and a design thinker's personality (Brown, 2008: 86).

However, what is less talked about in the literature is the designer's personality and how the characteristics outlined by Brown—empathy, integrative thinking, optimism, experimentalism, and collaboration—contribute to the value and feasibility of a co-created design solution. Co-design refers to the creativity of designers and people not trained in design working together in the design development process (Sanders and Stappers, 2007). The term co-design can also be referred to as, co-creation, or participatory design however the approach is the same, "collective creativity" (Sanders and Stappers, 2007).

In co-design, diverse experts come together, such as researchers, designers or developers, and (potentially customers and users—who are

experts, that is, "experts of their experiences" (Sleeswijk Visser, Strappers, Van der Lugt, & Sanders, 2005) to cooperate creatively and users and customers of this design process are generally located centrally (Brown, 2014; Alam 2002). The benefits of co-creation include, a collaborated framework for shared knowledge through idea exchange and experience which result in better products taking into account customer needs and preferences (Hoyer et al. 2010; Samson and Roser, 2009). Further research suggests that there are some discrepancies to this approach. Some authors have argued that businesses are taking advantage of customer insights only to make a profit (Ritzer & Jurgenson, 2010). Perhaps breaking away from this paradigm will shed more light on the value co-creation process. In this paper, design thinking and the co-creation of value is emphasized through a pre-designed toolkit activity and the relationship of designer-consumer (DC) which exists outside of the traditional business-consumer (BC) paradigm.

Research Methods

Frog Collective Action Toolkit (CAT)

The Frog Design Collective Action Toolkit (figure 1) was employed as a foundational tool for conducting participatory workshops with three key stakeholders – primary caregiver, physician, and lawyer. Later, group activities were adapted to meet the needs of the participants in order to develop one final design solution thought to be the most feasible to implement and to create value.

The Frog Collective Action Tool Kit (CAT), designed by Frog Design, is a toolkit used by individuals, designers and focus group participants to solve specific economic, social and cultural problems. It can be applied to any particular situation where individuals are interested in using design thinking to bring people together in the community, to help individuals understand each other and accomplish goals collectively.

Participant groups (figure 2) were identified through Qsource a non-for-profit healthcare consultancy firm located in Memphis, Tennessee and the University of Memphis. The objective of these workshops were not funded by Qsource or another firm but were socially centred on community concerns and motivations to improve end-of-life care. Keeping this in mind, all participants worked collaboratively to co-design several alternative solutions for meeting patients' needs. Patients at end-of-life are identified as patients who have been determined terminally ill and who are incapable of making their own medical decisions.

Six end-of-life participatory workshops were conducted with approximately 8-10 participants, most of whom work in healthcare as lawyers, social workers, nurses, and physicians, while other participants work in non-healthcare professions but have been primary caregivers or whom have just recently experienced the loss of a loved one. The focus of the workshops were guided around five key elements; unmet patient needs at end-of-life, shared decision-making, fulfilling patient wishes and values, addressing family needs legally and addressing family needs emotionally.

For this project, I decided to use the activity, "Finding True North" (FTN). FTN is used to help participants identify their collective goals and to try to figure out how to reach them. This is an ideal activity for the current end-of-life participant group because each stakeholder has a separate primary goal. For example, based on the conducted research in this project, the physician's

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primary goal is to keep the patient alive. The lawyer's primary goal is to manage the patient's advance directives and the caregiver's primary goal is to make sure that the patient has an advance directive. Therefore the objective of this activity was to design something that matched each individuals' goals with the patient's goals. The difficult part for the designer was to help individuals see the problem from another's perspective and to help them decide how they should interact and what they should discuss to first, fulfil the needs of the patient, and second to meet their job requirements.

The activities designed in FTN are to have each participate stand in a circle and tell the group what goal they would like to accomplish. This is recorded on a large piece of paper. After each participant has spoken everyone rates the project goals from 1-3 as to which one they would like to work on. The problems that did not receive any stars are then discussed as to why no one is interested in looking at them (these may be the most important problems to solve and should be considered for a later group discussion). Key ideas were recorded and then we counted the stars given to each problem. The problem with the most stars was the first problem to work on, the problem with the second most stars was the second problem to work on and the problem with the third most stars was the last problem to work on.

Identified problems were as follows: 1) Patients do not have an advance directive and therefore patient wishes are not being met. 2) Family and professional staff working with a terminally ill patient do not communicate (about money, health and future outcomes). 3) Everyone surrounding the patient including family, legal, and medical staff has a different idea about how the patient should live before dying. The following solutions to solve these problems were developed by the group.

Design solution 1: "Trivia Pursuit"

Finding an opportunity to promote the advance directive and advanced care planning to improve quality care.

This solution is box of game cards that give information on advance directives and talk about end-of-life wishes. You use the box of cards as an interactive tool kit to be used with patients who would like to learn about how to create advance directive. You then address the important questions that need to be answered around end-of-life issues. In the box there are three types of cards: Questions, Wishes, and Activities. Each card gives a tip about how to discuss the specified topic with your family, friends, and/or doctor. A diary is kept inside the box where users record their answers to the questions provided, thus creating advance directives during the process.

Design solution 2: "Sensor Networking: Bundled Care"

Preferences stated within advance directives are poorly developed and are often at odds with clinical circumstances or can even effective decision-making. Usually, advance care planning and advance directives have been ineffective.

The solution is to create a home health monitoring application that helps patients with advanced care planning, their advanced directives and how to connect with key stakeholders. It can also suggest ways for patients to stay at home instead of going to the hospital. The home health monitoring sensor

network connects patients to healthcare provides by monitoring an individual's behaviour. If a patient does not seem to be on schedule, his or her community, team of providers and primary caregivers are notified. This helps patient engagement in medical decisions. Other things could be included like retirement living information, legal services and financial planning.

Design solution 3: "Color-Coded Medical Teams"

The focus on preferences concerning life-sustaining treatments commonly proves to be too simplistic, instructions are difficult to apply, often adding little to the way that families and clinicians approach care decisions.

The solution is to create a specialized team of clinical staff that are specific to the patient or surrogate decision maker. This would be done immediately upon admission to the hospital and preferable when they fill out an advance directive if they do not have one. In this solution hospital teams are color coded according to the patient's wishes. For example, all patients that choose NO to do not resuscitate (DNR) will be assigned to the "RED" medical team and patient's that wish to receive cardiopulmonary resuscitation (CPR) will be coded to the "Green" medical team. This solution prevents miss treatment and adheres to meeting the patient's wishes.

The co-creative workshop sessions helped uncover core problems associated to end of life. They also spurred idea generation and problem solving between and within different communities. Each solution is practical, viable and possible however, each solution had some of its inherent faults. For instance, the "Trivia Pursuit" model is really good for making a fun event out of discussing tough issues but it is questionable as to whether or not individuals would want to spend the time playing a physical card game and individual wishes might get lost in the process and would never reach other primary stakeholders.

The second and final solution, "Sensor Networking," is a trending solution that address patient wishes to stay at home more and to reduce healthcare costs, however, this solution does not, account for the specific end-of-life scenarios where a patient is incapable of making decisions for him or herself and the decision-making process that takes place at the time of care actually utilizing the advance directive.

The third co-design solution "Coded Medical Teams" is a really good idea for meeting patient wishes, but it does not seem as viable from a hospital administrative perspective. In order to create and implement this solution further research would need to be done that included HR hospital worker rules and regulations.

Workshop Findings

The following conclusions were made in an open and collaborative environment with all participants concerning end-of-life. 1) Medical care must be patient focused and family centred. 2) Patients should be provided with quality care, which includes physical and emotional comfort. 3) Promote shared decision-making among family members and medical staff. 4) Treat each person with autonomy. 5) Attend to the financial and emotional needs of the family members (e.g., Medicaid and Medicare options).

Final Design Solution

For the final design solution, participants created the iCare for EOL website and application (figure 3). This website facilitates conversations around long-term planning, conflict resolution, and documented decision-making. The

final goal of the design artifact is to fulfil the four main unmet user-needs in the current end-of-life decision-making dilemma - to promote the value of the advance directive, create a system that makes the advance directive readily available, educate and inform users with a process by which healthcare providers recognize, respect, and apply the advance directives to a patient's healthcare preferences.

In addition, this concept aims to provide timely assistance by bringing together different stakeholders through readily accessible advance directives. Service providers would be non-for-profit organizations, hospitals, and/or hospices. This is not a complete system offering but it fits well into an already established integrated end-of-life healthcare system that uses paper models, toolkits, and face-to-face consultations for advance directive assistance. The following design opportunities applied to the website—promote value, availability, education, and respect.

Promote value

The iCare for EOL social network creates value for users though three primary features: the video capture, health vault, and the interplay of the stakeholder network. At the core of this design concept is the creation of the advance directive by a user who video records his or her wishes through the website's video feature thereby creating a personalized time stamped record of his or her end-of-life preferences.

Availability

iCare for EOL digital platform is for shared healthcare communications between patients, primary caregivers, physicians, and lawyers to connect virtually. This platform allows for 24/7 access to all of its shared networks including special access to a health vault which harbours a user's advance directives, wills, decisions pertaining to end of life, his or her electronic healthcare records, and all other important communications between stakeholders. This access facilitates point-of-care decision-making in times of emergency or extreme (e.g. does a patient prefer a DNR order or a CPR medical provision when under distress?).

Education

Educational and instructional diagraming is featured in the iCare for EOL social networking site which includes information about what an advance directive is, how to create a video, vault, and capture, and "pop-up" windows that tell you what is missing from your profile (e.g. "You do not currently have a primary legal representative. Click here to connect with one.") The video, record and capture feature allows patients to openly express their end-of life-wishes, firstly, through a prompt of questions pertaining to the important aspects of making an advance directive and then further "pop-up" windows direct the user to ensure that he or she is answering all of the questions that need to be addressed in order for his or her lawyer to create the legal documents (e.g. advance directives) and store them.

Respect

Although an electronic healthcare vault can capture and record an individual's wishes and the digital platform is both readily accessible and educational, it does not mean that people will respect and apply the contents available to them. iCare for EOL is not 100% guaranteed. However, through

social networking there is a greater likelihood that participants who have shared personal information about themselves and who share a common goal within a community will want to honour their agreements.

Conclusion

The concept behind the iCare for EOL web application is to have a network based, patient-centred, healthcare information community key stakeholders: primary caregiver, lawyer, and physician. The core of this service is the 24/7 accessibility of the advance directive. The supplemental benefits and features of this application help families resolve conflict, help lawyers build a responsible practice, and help doctors share and advertise new technologies as they engage in joint decision-making with family members. In addition, the DC paradigm does not put any pressure on participates to solve profit-seeking business problems. The DC relationship is motivated by the skills of the designers and the motivation of the community to design solutions to real world problems through cross-pollinating creativity.

Contribution

In recent years, value co-creation has piqued the interest of design scholars and managerial strategist to help firms innovate new products and create novel services. The idea behind this process is that customers have latent and unmet needs that companies would like to access and that innovation will be created at the intersection of business capabilities and consumer input. However, in spite of the emerging literature on this topic, little research has been done on the DC process of value co-creation at end-of-life.

Therefore, this article attempts to contribute to the literature by providing a new perspective on DC value co-creation. It highlights how in certain contexts, BB and BC value co-creation projects may be inefficient for full participant participation, heterogeneity and motivation and how a DC dynamic can improve process innovation and value co-creation. In addition, this article shows how a pre-designed toolkit activity chosen by the designer can contribute to three innovative and feasible design solutions and one final product design that meets stakeholder criteria.

Future Research

The main goal of this research is to show how primary stakeholders working with end-of-life patients can participate together to co-create a final design solution that meets their goals and objectives and provides patients with products and services that they need for quality care at end-of-life. It attempts to empower the relationship between the designer and the pre-designed toolkit activity methodology which facilitates a co-designed value solution through design thinking. This research is limited however, to a single case study and could be complemented by replicating the study with different working professionals in the field or in different sectors. Additional considerations of how to implement a final DC design solution into businesses could also be beneficial. It could spur more research in the role of the designer bringing innovations to market either alone, with other industry providers, or with the participants and how this process unfolds, including selling the idea to top management, fully developing the product, and consumer engagement. Consequently, because there is no particular firm involved in the DC co-creation process future research could attempt to bridge the gap between the DC final product and firm adoption.

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Figure 1 – Frog Collective Action Toolkit.

Figure 2– Group Workshop Participants.

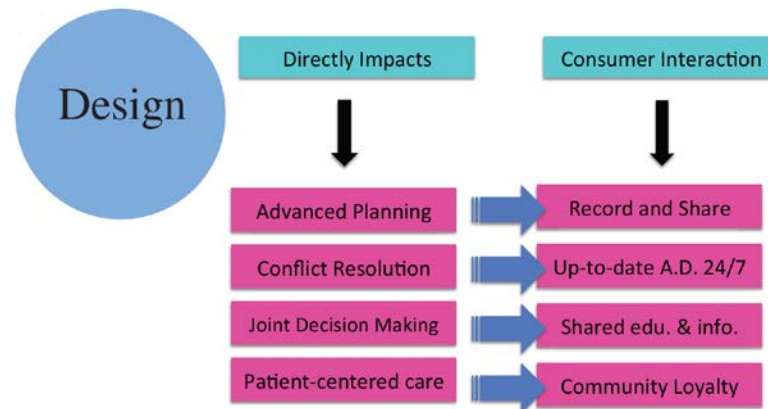*Figure 3 – iCare for EOL Co-design: Website/Mobile Application*

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Figure 4 – Design Impacts

2 REFERENCES

Alam, I. (2002). 'An exploratory investigation of user involvement in new service development''. *Journal of the Academy of Marketing Science,* 30(3). 250-261.

Brown, Tim. (2008). 'Design thinking'. *Harvard Business Review,* 86(6): 84-92.

Brown, Tim. (2014). *Change by Design.* Harper Business, Harper Collins Publishers, 272.

Buchanan, Richard. (1992). 'Wicked Problems in Design Thinking.' *Design Issues,* 8(2): 5-21.

Cantlupe, J 2013, 'A Fresh Look at End-of-Life', *Health Leaders* Media 16 September. Available from: <http://www.healthleadersmedia.com>. [25 November 2013].

Dartmouth Atlas of Health Care. (2014). *End-of-Life Care.* Available from: <http://www.dartmouthatlas.org/keyissues/issue.aspx?con=2944>. [09 December 2013].

Department of Health (2008) End of Life Care Strategy. DH: London.

Dunne, David and Martin, Roger. (2006) 'Design Thinking and How It Will Change Management Education: An Interview and Discussion'. *Academy of Management Learning & Education*, 5(4): 512-523.

Hoyer, W. D., Chandy, R., Dorotic, M., Krafft, M., & Singh, S. S. (2010). 'Consumer cocreation in new product development'. *Journal of Service Research, 13*(3), 283-296.

Jones, Peter. (2013). *Design for Care: Innovating Healthcare Experience.* New York: Louis Rosenfield.

Martin, Roger and Mihnea C. Moldoveanu. (2008). *The Future of the MBA.* Oxford University Press, USA.

Martin, Roger. (2009). *The Design of business: why design thinking is the next competitive advantage.* Boston Mass.: Harvard Business Press.

National Council for Palliative Care. (2008). '10 Questions to ask if you are scrutinising end of life care for adults'. Available at: http://www.ncpc.org.uk/sites/defautl/files/EndOfLifeCare_TenQuestions.pdf [accessed March 2014].

Plattner, H., Meinel, C., Leifer, L. (2011). *Design Thinking*. Berlin: Springer.

Ritzer, G., & Jurgenson, N. (2010). Production, Consumption, Prosumption The nature of capitalism in the age of the digital 'prosumer'. Journal of consumer culture, 10(1), 13-36.

Roser, T., & Samson, A. (2009). *Co-creation: New paths to value*. London: Promise / LSE Enterprise.

Sanders, Elizabeth B. N. and Stappers, Pieter Jan. (2008). 'Co-creation and the new landscapes of design.' *CoDesign: International Journal of CoCreation in Design and the Arts*, 4(1): 5-18.

Sleeswijk Visser, F., Stappers, P. J., Van der Lugt, R., & Sanders, E. B. N. (2005). 'Contextmapping: Experiences from practice'. *CoDesign, 1*(2): 119-149.

Stanton, M. W. 2002, 'Expanding Patient-centred Care to Empower Patients and Assist Providers'. *Agency of Healthcare Research and Quality: Advancing Excellence in Health Care*. Available from: <http://www.ahrq.gov>. [13 October 2013].

Thienen, Julia von, Noweski, Christine, and Rauth, Indo. (2011). 'The Co-evolution of Theory and Practice in Design Thinking –or—Mind the Oddness Trap.' Design Thinking: *Understand – Improve – Apply,* Spinger, 238.

Thoring, K. and Muller, Roland M. (2011). 'Creating Knowledge in Design Thinking: the Relationship of Process Steps and Knowledge'. *Diversity and Unity, the 4th World Conference on Design Research, 31 October.*

Teno, J. et al. (1997). 'Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-determination Act and the Support Intervention'. *Journal of the American Geriatrics Society*, 45(4): 500-7.