

The bigger picture of shared decision making

A service design perspective using the care path of locally advanced pancreatic cancer as a case

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RESEARCH ARTICLE

The bigger picture of shared decision making: A service design perspective using the care path of locally advanced pancreatic cancer as a case

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Abstract

Purpose: Solutions to improve the implementation of shared decision making (SDM) in oncology often focus on the consultation, with limited effects. In this study, we used a service design perspective on the care path of locally advanced pancreatic cancer (LAPC). We aimed to understand how experiences of patients, their significant others, and medical professionals over the entire care path accumulate to support their ability to participate in SDM.

Participants and methods: We used qualitative interviews including design research techniques with 13 patients, 13 significant others, and 11 healthcare professionals, involved in the diagnosis or treatment of LAPC. The topic list was based on the literature and an auto-ethnography of the illness trajectory by a caregiver who is also a service design researcher. We conducted a thematic content analysis to identify themes influencing the ability to participate in SDM.

Results: We found four interconnected themes: (1) Decision making is an ongoing and unpredictable process with many decision moments, often unannounced. The unpredictability of the disease course, tumor response to treatment, and consequences of choices on the quality of life complicate decision making; (2) Division of roles, tasks, and collaboration among professionals and between professionals and patients and/or their significant others is often unclear to patients and their significant others; (3) It involves “work” for patients and their significant others to obtain and understand information; (4) In “their disease journey,” patients are confronted with unexpected energy drains and energy boosts, that influence their level of empowerment to participate in SDM.

Conclusion: The service design perspective uncovered how the stage for SDM is often set outside the consultation, which might explain the limited effect currently seen of interventions focusing on consultation itself. Our findings serve as

a starting point for (re)designing care paths to improve the implementation of SDM in oncology.

KEYWORDS

oncology, pancreatic cancer, qualitative, service design, shared decision making

1 | INTRODUCTION

Shared decision making (SDM) is increasingly advocated as the preferred model to engage patients in the process of deciding about diagnosis, treatment, or follow-up when more than one medically reasonable option is available. SDM is most commonly defined as the process of integrating the best available evidence and patients' values and preferences in the decision making process.¹ Research has shown that SDM achieves benefits for patients and healthcare professionals.^{2,3} Although SDM is acknowledged to be a process, solutions to implement SDM mainly focus on the encounter in the consultation, the training of clinicians, and the provision of decision aids to patients.³⁻⁶ Despite these interventions, the effect on the implementation of SDM in oncology remains limited.⁷⁻⁹ Moreover, these solutions require extra effort from patients and oncology professionals who are already under pressure. Do we overlook the important untapped potential for improving the implementation of SDM?

We promote a new systemic perspective to expose this potential for improving SDM, that of service design. The diagnosis and treatment of patients with LAPC can be considered a service, and when co-produced by patients and professionals (which is currently not the case) it may lead to effective SDM.^{6,10} The perspective is integrative, it understands influencing factors as interconnected within the larger system of service delivery. A common approach to start a service design project is by qualitative methods to focus on the experiences with the service of those involved within a system (i.e., the patient, his or her significant other(s), and the healthcare professionals) during multiple contacts, called touch points. These touch points are interfaces between service organizations (care providers) and their clients (patients) as they occur over time, be it through material artifacts (e.g., brochures), environments, or interpersonal encounters.¹¹ Understanding the service and its touch points helps to understand what people experience, what systemic influences there are on these experiences, and how these influence the ability to participate in SDM.

In this study, we used design research methods to identify the experiences of all involved in the diagnosis and treatment of locally advanced pancreatic cancer (LAPC). We used LAPC as a case, as the diagnosis and

BOX 1 Diagnosis and treatment of LAPC in four Dutch hospitals¹²

The presumptive diagnosis of a LAPC is made by computed tomography (CT) scan or magnetic resonance imaging. In order to initiate treatment, the definitive diagnosis must be confirmed by a cytological or histological biopsy. In most cases, this is done with endoscopic ultrasound. To ensure that no metastasis has taken place that was not visible on the previous radiological examinations, a diagnostic laparoscopy is performed, during which a port-a-cath is immediately inserted for the administration of chemotherapy. Next, four cycles of FOLFIRINOX are started, followed by a CT scan for evaluation. If no progression has occurred, another four cycles of chemotherapy are administered, and further evaluation takes place. After this, it is decided whether patients are eligible for stereotactic radiotherapy (SBRT). Before the start of SBRT, radiological fiducials will be placed endoscopically. During five consecutive days, patients will then undergo radiotherapy. Six to eight weeks after finishing this treatment protocol a new radiologic evaluation takes place to decide whether patients are suitable for an explorative laparotomy and subsequent resection of their previously inoperable tumor.

treatment of LAPC are complex and involve many decision making moments (see Box 1). Surgery is the only chance of surviving, and in case of LAPC, neo-adjuvant chemotherapy aims to allow for surgery. Both surgery and chemotherapy carry risks of mortality and strongly impact the quality of life. Patients are made to feel that they are one of the "winners" if they qualify for surgery,¹⁰ hindering a weighing of the pros and cons, as is needed for true SDM.

Our aim was to understand the experiences of patients, their significant others, and their healthcare professionals during the trajectory of diagnosis and treatment that enable or hinder SDM. We use a service design perspective to understand the system causing these experiences, as the

first step toward designing an improved service supporting SDM in oncology more broadly.

2 | PARTICIPANTS AND METHODS

For an overview of the methods used, see Figure 1.

2.1 | Auto-ethnography

The first author (I.P.M.G.) is a service designer and service design researcher, who was already investigating improving the implementation of SDM when confronted

with the diagnosis of LAPC of her husband. The auto-ethnographic study^{13,14} started with a log that she kept for 6 months from the start of her husband's symptoms till the end of eight courses of FOLFIRINOX and his blog. It provides both the perspective of a close significant other and that of a service designer and researcher.^{15,16} The log was open-coded by all three researchers to generate as many potential categories of codes as possible. The coding process¹⁷ focused on the experiences that might influence participation in SDM. The next step was axial coding to find relationships between codes. In mutual consultation, the three investigators grouped the axial codes into overarching themes (selective coding) that characterized the most important (groups of) barriers/facilitators.

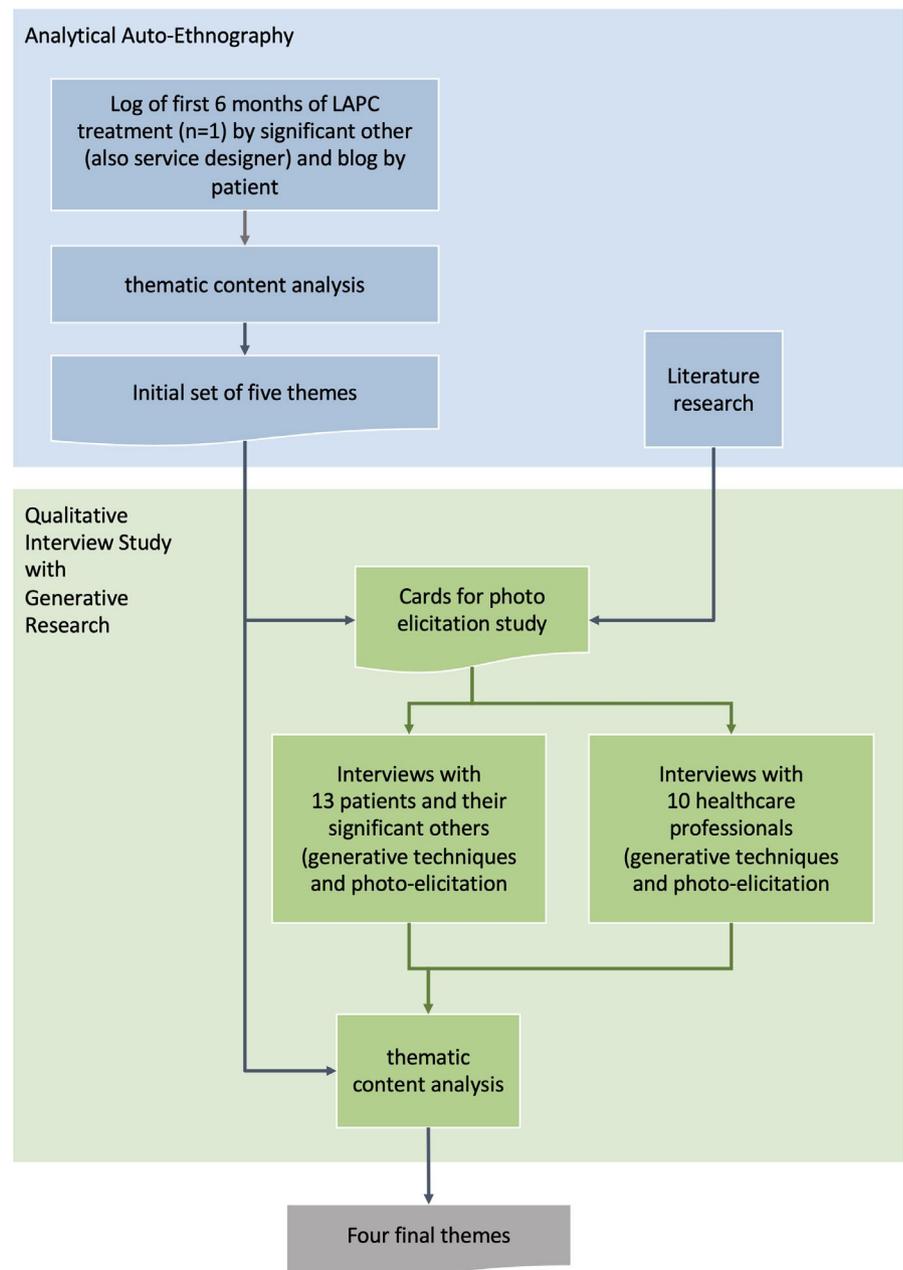


FIGURE 1 Research process

2.2 | Qualitative interview study with patients and their significant others

Subsequently, we interviewed Dutch- or English-speaking patients who were treated for LAPC at Erasmus Medical Center Rotterdam, in the Netherlands, and their significant others, between February and April 2019. We continued interviewing patients until we reached the saturation of data. If possible, the patients were interviewed together with a significant other who had been present at least half of the appointments in the hospital. The majority of the interviews (11 of 13) were conducted at home, because this enabled participants to show the investigator photo's, medical devices, information, or other products that helped them to build their story.¹⁸ Two of the 13 patients preferred an interview in the hospital.

The content of the interviews built on the themes that resulted from the auto-ethnography. We used design research techniques¹⁸: timelines^{17,19} and photo-elicitation.²⁰ First, participants were asked to map their trajectory and experiences over time along a line drawn by the researcher on a roll of paper. Next, they were shown 16 cards with concepts and images and were asked whether these brought back memories of the treatment trajectory. These techniques provide instruments of thought and tools for communication to bring to the surface intuitive responses and tacit knowledge concerning the experiences with the touch points. Participants may find it difficult to express their experiences verbally for different reasons. Sometimes they are very emotional and have not deliberated the decisions, or they have rarely talked about their experiences.¹⁰ Noting down their experiences on a timeline and responding to images concerning touch points supported them in structuring their narrative and in highlighting their own important experiences.

The card set was based on three sources: literature,²¹ the logbook, and common service design touch points to help the participants to remember their experiences with the physical and social context (places in the hospital and at home). Participants were explicitly asked what decisions they made, what considerations played a role, and how they experienced these decision moments.

2.3 | Qualitative interview study with professionals

We held semi-structured interviews with healthcare professionals who have an important role in the diagnostic and treatment trajectory of patients with LAPC at the Erasmus Medical Center. The interviews also included generative techniques. We used a medical metro line (i.e., visualization of the treatment path based on the treatment

protocol), as a tool for constructing the story of experiences^{19,22} (Figure 2). They were also asked to respond to a set of 12 cards based on the same sources.

2.4 | Thematic content analysis

All interviews were transcribed and anonymized. We performed a thematic content analysis.¹⁷ We started by open coding the first three interviews, searching for codes in line with the themes of the auto-ethnography, framed non-judgmentally, to avoid seeking the confirmation of the experiences described in the log. The next step was coding all interviews and axial coding to find relationships between codes. In the last step (selective coding) the three investigators defined the axial codes in mutual consideration and grouped them into overarching themes. The themes were shared for confirmation with the interviewed healthcare professionals. We did not share them with the patients and their significant others, because we tried to avoid confronting them with negative experiences of others (they were still in the treatment trajectory of LAPC).

All participants were informed about this study and asked for written consent. The Medical Ethics Committee of the Erasmus Medical Center provided a waiver of full ethical consent according to the Dutch Law on Medical Research with Humans.

3 | RESULTS

3.1 | Auto-ethnography

From the log, the investigators identified four initial themes that characterized the main bottlenecks experienced and one that was supportive: decision making took place at several moments in the diagnosis and treatment process, both announced and unannounced, and with different care providers; the disease and its treatment were experienced as complex; there were many moments of confusion and the improvisational skills of patient and partner were demanded; collaboration with and among healthcare professionals was not always experienced as effective; there were times when both felt supported and empowered by the healthcare professionals.

3.2 | Qualitative interview study

We invited 15 patients and their significant others. Two patients refused participation, 13 were willing to participate, with their significant others. We invited 10 healthcare professionals: three surgeons, a surgical resident,

Locally Advanced Pancreatic Cancer Process

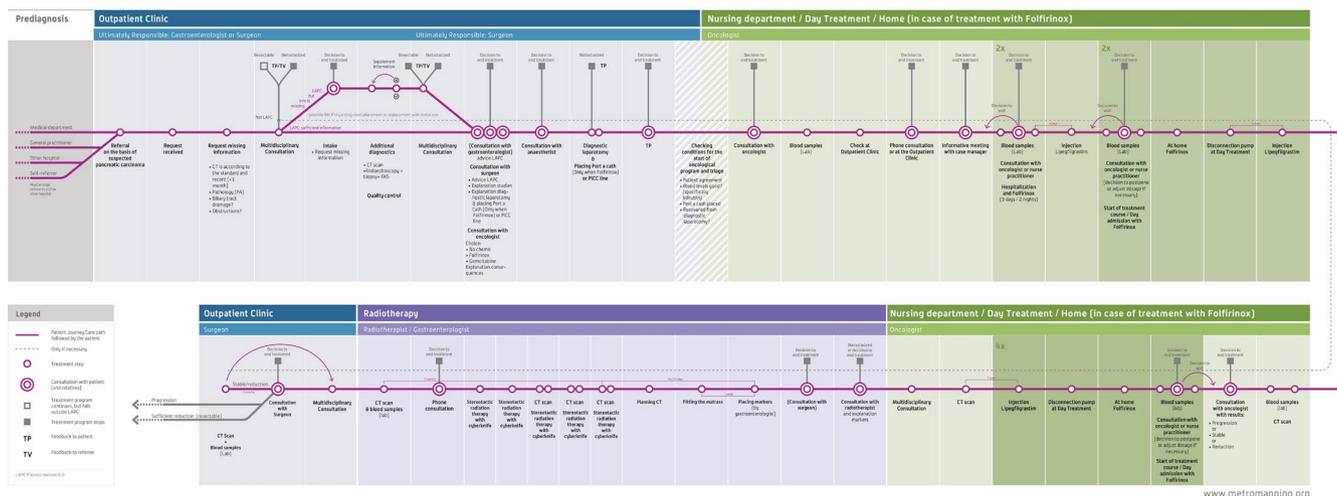


FIGURE 2 Medical metro line



FIGURE 3 Examples of the cards (“tijd” = “time,” “thuis” = “home,” “eten en drinken” = “food and drink”)

a gastroenterologist, a medical oncologist, a radiation oncologist, a planning coordinator, and two specialized oncology nurses from the same academic hospital. None refused. The topics for the cards used in the interviews with patients and for the cards used in the interviews with professionals are listed in Table S1. Figure 3 shows examples of the cards.

Coding (see Box S1) and analysis of the interviews resulted in four final themes that describe positive and negative experiences that influence SDM. Figure 4 contains some quotes of patients or their significant others related to each theme.

1. *Decision making as an ongoing and unpredictable process:* Patients experienced that they had to make many decisions. Those are treatment decisions but also about participating in trials, practical matters (changes in nutrition, managing visitors, transportation), and existential issues (such as arrangements in case they do not survive). Decision making occurred at several moments in the trajectory, not always in formal consultations, and was often unannounced. Test results were perceived by

some patients as exams to “pass” rather than as a pre-condition for remaining options, including “doing nothing.” Healthcare professionals mentioned that sometimes it is better to delay decision making to see how cancer progresses, despite the pressure that patients sometimes feel to move forward as fast as possible in the trajectory. Unpredictability of the (side) effects of treatment, and lack of sufficient evidence, particularly for tailoring to the individual patient, made it difficult for healthcare professionals to provide a clear recommendation. They indicated they did not always sufficiently discuss this with patients. Some mentioned that they tended to present the effect or side-effects of therapy too optimistically because they want to give hope. Some mentioned experiencing large variation in preferences for participation in decision making among patients, and between patients and their significant others.

2. *Division of roles, tasks, and collaboration:* The treatment of LAPC and many other cancer types involve a whole team of professionals including surgeon, medical oncologist, radiotherapist, specialized nurses. It was often unclear to patients and their significant others who has which responsibility and who they should contact in emergency situations. They also experienced that GPs are not sufficiently involved or kept informed. Healthcare professionals confirmed that many different professionals are involved in the treatment, some of whom rarely see the patient. Patients often did not have a complete picture of the treatment process and its location. Patients experienced that these professionals do not always agree with each other about patient life expectancy and treatment. When other hospitals were also taking care of the patients,

1 Decision-making as an ongoing and unpredictable process

They do ask if you dare. But you don't know at all what you say yes to.

Female patient 7

My choir had... it had a performance on the tenth. I had to get chemo the week before, but because of that cystitis and those antibiotics they postponed it for a week. Then I could still be at the performance of my choir. Well it really was a miracle. Was a real miracle.

Female patient 7

2 Division of roles, tasks and collaboration

My husband says: "But if I don't get that chemotherapy until a week later, what should I come for? I don't need a blood test, because the last test has just happened." "Yes, but you must come anyway." You know, people have no idea how you are lived because of hospital appointments and appointments with doctors and then there is a doctor who comes by at home and then you have to go back to the pharmacy. There is so much time that is filled with all that the disease entails.

Wife of patient 1

A 10-day treatment [of CreonForte]. Then we had contact with the dietician. "Ten days?!?" she says, "Are you kidding? You should have had it from the start!"

Male patient 1

3 "Work" for the patient and/or significant other in obtaining and understanding information

That urine gets "dark" and the stool "light" and stuff and I think yes, maybe I have that or maybe I don't.

Male patient 10

[Name of doctor] called immediately the next day, but I didn't know he would call. So I had no questionnaire prepared and [name of husband] was not there to help.

Female patient 12

4 In "their disease journey", patients are confronted with unexpected energy drains and energy boosts, that influence their empowerment to participate in SDM

It was freezing cold. I was lying alone in an operation gown on that rock hard couch [waiting for the anesthetist] and it lasted and it lasted and it lasted. I haven't seen anyone there like that for half an hour. I almost went crazy there. I had to pee, terrible..

Male patient 1

....and just then I had to cry a lot in that waiting room and then one of those nurses came and he came to chat with me and he says: are you okay? He says: would it help you if you could see what we're going to do? I said, oh, yes I'd like that. Then he took me into that [radiation] room

Wife of patient 13

FIGURE 4 Coded quotes by patients or their significant others

for example, secondary care hospitals, patients, and their significant others sometimes experienced poor coordination between hospitals. As a result, they sometimes tried to organize the coordination themselves. Furthermore, the significant others experienced a considerable burden due to extra tasks and stress, and often their social network required attention. Some patients were reluctant to express doubts about the provision of care or to give suggestions for the care path for fear of a negative influence on their relationships with professionals. Some patients felt powerless in their disease and treatment and had wanted to contribute more to the trajectory themselves. Some healthcare providers were concerned whether the patient received the required support from their significant others and whether they could handle the intense situation of the illness.

3. "Work" for the patient and/or significant other in obtaining and understanding information: Patients and their significant others expressed a need for more information concerning the disease, anatomy, treatment options, disease course, interpretation of results, nutrition,

and self-management. Much information was provided, but it did not always meet participants' needs for self-management or (participation in) decision making. The discrepancy was caused by information format, language, the amount of information, the moment it was provided (e.g., after negative results). Sometimes the information disturbed the delicate balance between patients' hope and realism. Many patients searched for additional information. Patients and their significant others valued pictures, calm explanations, written reports, and the offer to come and take a look (e.g., at the department of radiotherapy). In particular, more adequate information was needed for medication and pain management. Jargon was sometimes difficult for patients and their significant others to understand, for example, the difference between a diagnostic laparotomy, explorative laparotomy, and pancreatoduodenectomy. Healthcare professionals encountered a range of information needs: some patients had already acquired information before the consultation, some wanted to know all details of the disease, others only wanted practical information. The majority of the information provided

was oral as healthcare professionals often considered the flyers, booklets or websites unsuitable. They were unsure if their information to patients was always consistent with information from other healthcare professionals. They feared that some patients do not understand when it is important to contact them, for example, in case of fever or pain.

4. In *“their disease journey,” patients are confronted with unexpected energy drains and energy boosts, that influence their empowerment to participate in SDM*: Patients and their significant others cited various instants when reality did not match their expectations, causing tension or frustration. This included the timing of the treatment or contact moments, instructions, treatment results or side effects, disease course, and the operation of medical devices or equipment (e.g., the port-a-cath). They suspected that miscommunication with or between healthcare providers was usually the main cause. The environment in which the treatment takes place, or the medical devices, sometimes reinforced their feelings of vulnerability and disempowerment (e.g., full parking lots at the hospital, view on corridor while getting chemotherapy, the hospital gowns, lack of private space). Their private lives changed more than they had expected. In contrast, patients and their significant others felt empowered when turnaround times were shorter than expected. They also felt empowered when there was a calmness in the encounters with healthcare professionals, when these were friendly, or unexpectedly did something personal, for example, present a gift for their birthday. Patients and their significant others also felt empowered when they had the impression that a professional treated them as a person instead of a medical case: the professional knew their name, had read the file before the consultation, called back when promised, and took the patient's personal situation into account. Energy drains for healthcare professionals were logistic problems (such as waiting time for examinations, for information from other hospitals or healthcare providers, or for the chemotherapy), lack of overview of the logistics of the trajectory, the unpredictability of the effects and side-effects of the treatment, and unpractical or unpleasant hospital facilities. Healthcare professionals called the nice new hospital building an energy boost. The interviews all showed great motivation of the healthcare professionals to do their best for the patients and their significant others, which was acknowledged by the latter.

4 | DISCUSSION

In this study, we used a service design perspective to understand how a series of experiences of patients, their

significant others, and professionals accumulate to the patients' ability to participate in SDM in the diagnosis and treatment of LAPC. The design tools allowed us to elicit far more factors that (dis)empower patients and their significant others than generally observed in SDM research.

In our study, patients and their significant others provided intense descriptions of stress, fear, disempowerment, and unwanted dependence on healthcare professionals. Professionals described logistic problems, lack of overview for all involved, inconsistency in information provision to patients, and a concern about the required support in the social network of some patients. These experiences can make it hard for patients and/or significant others to participate in SDM. Some of these experiences were caused by encounters (touch points) somewhere in the service other than at a consultation. It seems that the stage for SDM is often set before the moment of consultation, which might explain the limited effect currently seen of interventions on the implementation of SDM focusing on the consultation.

Various researchers promote a wider systems approach to improve the implementation of SDM. Clayman et al.,²³ for example, promote to include roles for and actions of family members in the decision making. They advise to focus not solely on the medical encounter but on the longitudinal nature of decisions that require ongoing adherence. Each consultation should not be considered independent but as a chapter in the entire story of a person's illness. In their systematic review of patient-reported barriers and facilitators to SDM, Joseph-Williams et al.²⁴ conclude that patients not only lack knowledge but also the power to participate in SDM. With power they mean the perceived influence in decision making encounters, such as feeling permission to participate, confidence in own knowledge, and self-efficacy in using SDM skills. They also indicate that some barriers to SDM are not related to what happens during the consultation, but can be traced back to how the entire healthcare system is organized. It includes time available for SDM in the consultation, continuity of care, and workflow of the healthcare setting. The larger system of influencing elements leading to either effective or ineffective SDM is left largely untouched in implementation efforts.

Although the four themes we found each highlight a different aspect of the context in which SDM takes place, these aspects do not stand alone. The first three (decision making as an ongoing and unpredictable process, roles/tasks/coordination, and work for the patient) relate to organizational aspects of the care path which sometimes influenced each other: the collaboration between and with professionals sometimes led to information that was or was not shared with patients. In turn, this led to a lack of overview of the care path, including the decision

moments. Various energy boost and drains mentioned within the fourth theme were often caused by the expectation of a patient, significant other, or professional regarding the first three themes that deviated from reality, in a positive or negative sense. The four themes are not separate barriers or facilitators, but care system elements that are interconnected (Figure 5).

The logfile was written by the first author, a caregiver, who is also a service designer. She also did all the interviews. This double perspective might be a limitation of the study as well as a strength. Service designers have an eye for improvement: they are trained to find potentially problematic situations as starting points for (re)design to improve a service. As a result, it could be a limitation that the first author potentially had a strong focus on the current problematic aspects of the service of LAPC which might have had an impact on both the logfile and the interviews. A potential strength is a fact that the interviewees were informed of the fact that the researcher was a fellow sufferer. It might have encouraged them to share their experiences more openly.

The service design perspective had additional benefits. First, it ensured that not only a single moment (a consultation) was considered, but it drew attention to the entire process, the service that is provided. During this service, a series of experiences is built up through touch points and this accumulated experience can lead to certain behavior. In case of limited consistency in that series of touch

points, patients, their significant others, and professionals need to improvise and cope. Coping drains energy. In our research, we discovered several such experiences prior to consultations, some of which may prevent good participation in SDM.

Second, the service design perspective also sheds light on the effect of experiences with the larger context of care, such as the disempowering effect of the physical context (full parking lots at the hospital or lack of private space) and “work” in the social context (such as informing the social network of a patient and organizing visits at home).

To improve the implementation of SDM in clinical practice we recommend (re)designing the care path addressing these themes simultaneously. It would require providing a better overview of the care path and its decision making moments, a better understanding of the unpredictability of the care path, better information provision, and a clearer division of roles and tasks and improved collaboration. Stepped wedge randomized controlled trials²⁵ could be the next step for researching the subsequent effects of the redesigned care paths on the implementation of SDM in clinical practice. We recommend a mixed-methods approach, including qualitative research methods such as participatory action research²⁶ to fully capture and consider the complexities of the implementation process, including dealing with differences in healthcare systems. We also recommend to further investigate, understand, and deal with the causes of the patients’ and significant others’ energy drains and energy boosts.

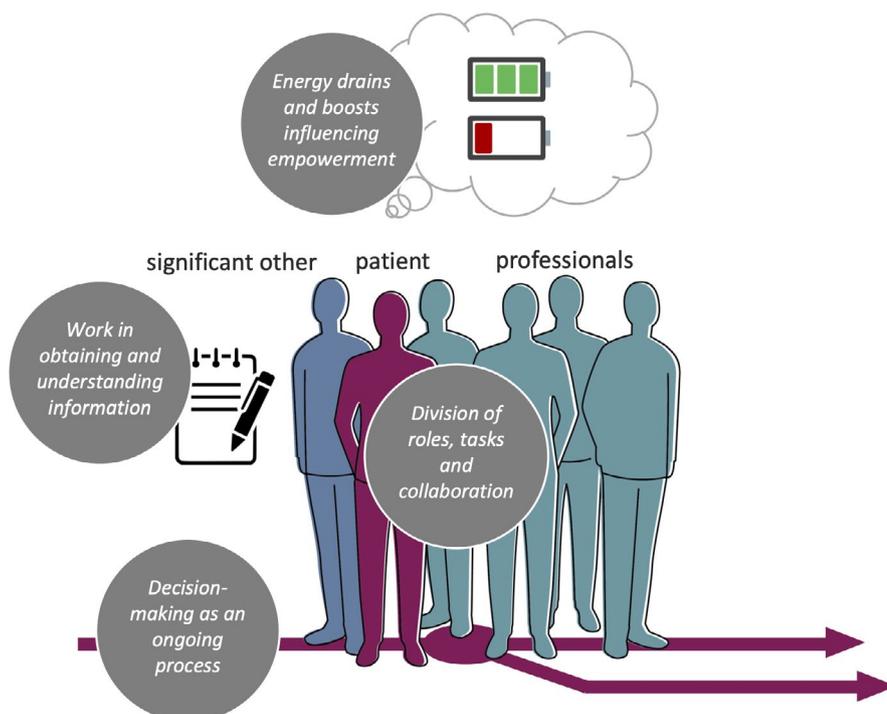


FIGURE 5 Four interconnected themes

We believe the four final interconnected themes are not unique to LAPC or our hospital, but further research is needed to discover if these are also important in improving the implementation of SDM in the diagnosis and treatment of other cancers besides LAPC, and in other hospitals.

In conclusion, a service design perspective could be included to optimize participation in SDM for patients, their significant others, and medical professionals in the diagnosis and treatment of LAPC.

MEDICAL ETHICS STATEMENT

All participants were informed about this study and asked for written consent. The Medical Ethics Committee of the Erasmus Medical Center provided a waiver of full ethical consent according to the Dutch Law on Medical Research with Humans.

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CONFLICT OF INTEREST

The authors indicated no potential conflicts of interest.

DATA AVAILABILITY STATEMENT

Transcripts of the interviews can be received from the corresponding author, upon request, after our study has finished.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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