

## Review Article

## Digital Care Planning: A Matter of Co-Creation

Ate Dijkstra\* and Hetty Kazimier-van der Zwaag

Research Group iHuman, NHL University of Applied Sciences, Leeuwarden, The Netherlands

### Abstract

This article describes the development of an Electronic Care Plan (ECP), in which care agreements are made with patients that fit their individual needs and wishes. This article outlines the development process in more detail, particularly the importance of co-creation. Nurses and carers have taken up the challenge of redesigning their caring process (and smarter) with the help of the digital possibilities of today. A web application has been developed to actually translate the wishes and needs into a care plan together with the patient (or his legal representative) in a simple and understandable way for the patient. In doing so, the patient is given as much choice as possible to choose care activities from the range on offer that meet his or her basic needs.

**Keywords:** Co-creation; Digital transformation; Electronic care plan; Elderly care organization

### Introduction

Healthcare benefits greatly from information- and Communication Technology (ICT) solutions that are well attuned to the workplace and support the caring process. This also applies to the Electronic Care Plan (ECP). The ECP ensures that care professionals can work more effectively and purposefully and that they can really devote their valuable time to the care of the patients entrusted to them. The future of ICT in healthcare does not lie in 'more of the same', but in 'caring smarter'. The ECP thus contributes to the digital transformation of elderly care organizations and anticipates new forms of collaboration between patients and care professionals. All available time should be spent as much as possible on contact between the patient and care professionals in order to provide personalized care and wellbeing.

\*Corresponding author: Ate Dijkstra, Research Group iHuman, NHL University of Applied Sciences, Leeuwarden, The Netherlands, Tel: +31 0651330515; E-mail: ate.dijkstra@icloud.com

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Care professionals caring in a Dutch elderly care organization struggle with the question of how to make care agreements with each patient about the right amount and type of care appropriate to the situation and wishes of the patient. In the eyes of caregivers and nurses, caring with a paper care plan to give the patient what he asks for, offers no solace: too much writing on different forms, chance of ambiguity about mutual expectations, too much of a product from thinking from the perspective of care and patient-unfriendly in use.

### A Digital Care Plan Requires a Vision

Digitizing data within an elderly care organization never or rarely has the desired result. The starting point of digitization is often chosen too high in the organization. The (higher) management wants to be able to steer and wants figures to justify and substantiate choices. The original core value of an electronic care plan becomes out of sight; supporting care professionals in carrying out their work. From this abstract level analyses and designs are made. These result in architectures that offer an abstract solution to the digitization problem. The underlying layers in the elderly care organization are eventually confronted with software that is too abstract and complex for the care professionals. They do not see the added value of the new caring process that is imposed on them. For them, there is no answer to the 'why' question: "why is digital work of value to me?" This involves a lot of costs: in extra education and training in the use of complex software, which also results in more time needed for the 'digital contact moments'. These facets can be expressed in time and therefore in Euros. But there are also less obvious costs in terms of social capital: frustration, annoyance, evasive or recalcitrant behavior, the flight back to one's own paper lists, or even to another job. A reflection on digitization is therefore essential; what is needed for an organization where communication with and about the patient is central? [1].

The reason for opting for a digital care plan must therefore lie in both the care vision and the vision of digitizing an elderly care organization. As far as the care vision is concerned, elderly care organizations will have to ask themselves how they want to shape the dialogue between patients and care professionals in order to enable maximum self-reliance and self-direction. The challenge is therefore to let the patients formulate the care themselves as much as possible. So really start with the care-demand side, with the needs and wishes of the individual patient. "For despite the fact that current care is provided with great dedication and is generally of good quality ... yet it has to be done differently! (...) In the current system the care provider is not challenged to take the wishes of the patient as a starting point as much as possible. Too often the best intentions for the patient are still considered and the patient surrenders himself to the care provider" [2].

Long-term care of value is care that matches as much as possible what the patient wants and is therefore determined by the individual perception of the patient himself. Of course a dialogue about this is always necessary and important. Not the care provider and not

an organization with a standard care plan, but the patient himself determines what he needs and chooses the appropriate care and support (whether or not together with the family). In short, from supply-oriented to demand-oriented thinking and caring. Nurses experience demand-oriented thinking and caring as a fundamentally different starting point in looking at and approaching patients. No longer supply oriented caring: 'I know what is good for you', but demand-oriented caring: 'what do you find important and meaningful?' The introduction of demand-oriented thinking and caring requires new expertise from care professionals in order to answer the patient's wishes in a dialogue.

With regard to the paradigm switch from supply-oriented to demand-oriented thinking and caring, a parallel development is taking place with regard to the application of ICT in healthcare. This is referred to as the transition from eHealth 1.0 to eHealth 2.0: from 'supply' to 'demand driven based technology'. At eHealth 1.0, care providers work supply oriented. Care provision can be interpreted as a reasonable one-way traffic in terms of information sharing and degree of involvement in the decision making regarding care and treatment. The digitization of care plans is also characterized by the literal translation of the paper care file into a digital file. Slowly we have entered a phase in which more interaction is developing (eHealth 2.0). Information goes back and forth more often and there is a growing interaction between care provider and patient. With eHealth 2.0, care providers start from personalized care in which the needs of the patient are truly central, so that he or she can be an active and responsible partner in his or her own health [3]. An electronic care plan, in which dialogue is central, fits into the eHealth 2.0 design. It supports the view that 'nursing care is needed for both restoration and renewal of the craft; whereby ICT must be embedded in care' [4]. Another feature of eHealth 2.0 is that caregivers and nurses co-create to help shape the care ICT of the primary process, redesigning the caring processes based on the needs of the patient and the opportunities that ICT offers [5].

*Quote: 'Show that care ICT is about connections with the patient. If a nurse does not take part in it, the patient will remember the possibility of self-management and a finer life' [4].*

It will be clear that in an electronic care plan the caring processes of the carers/nurses are central, in contrast to the current generation of paper care plans, where the emphasis is on recording administrative process data. Furthermore, these paper care plans are strongly related to the supply-oriented thinking of 'we know what is good for you' (eHealth 1.0). An electronic care plan has a fundamentally different point of departure in looking at and approaching patients: fitting in with the demand-oriented thinking of 'what do you find important and meaningful? (eHealth 2.0)'.

## From Design to Realization by Co-Creation

On the initiative of a small group of care professionals, caring in an elderly care organization of care and nursing homes in the northern part of the Netherlands, thought was given to bringing together the patient perspective (demand-oriented care) and the professional perspective (providing care in dialogue with the patient) in a digitalized caring process. Each of these themes requires a practical translation, coherence and embedment in the care relationship: for the care professional recognizable and manageable in her caring processes and to the full satisfaction of the patient. A conscious choice

was to use a validated nursing measurement instrument: the Care Dependency Scale.

## Care Dependency Scale

The Care Dependency Scale (CDS) is a 15-item tool to determine the degree of care dependency of patients' most common care needs - in home care and in clinical care such as hospitals, mental health care, nursing homes and care homes. The CDS is based on the 'basic human need theory' with representatives Abdellah, Henderson, Maslow and Orem. These 'needs' are considered to be fundamental, universal, independent of age and type of care institution. For decades, these basic needs have also been a continuous factor and starting point in the self or by others to give substance to what each individual understands by quality of life. Various (inter) national studies have examined the reliability and validity of the CDS [6,7]. Again and again the good psychometric properties of the CDS have been demonstrated. The 15 items measure a one-dimensional structure of care dependence and in clinical practice the CDS can be used to compare both groups and individuals. The usefulness - instruction, use, filling in time - is also assessed as good [8]. The CDS has been translated into 20 languages and is used in the National Prevalence Measurement of Care Problems (LPZ-measurement) in Germany, the Netherlands, UK, Austria and Switzerland.

Together with a software developer, the web application Lable Care<sup>1</sup> was developed as part of a digitalized caring process in which the care professional, together with the patient or his representative, (re)translates his care needs and wishes into a care plan during admission and subsequently at agreed evaluation moments. The software developer uses the philosophy of co-creation in building web applications: innovate together with end users in coming up with and elaborating ideas. In this way, together with care professionals, a web application has been built with which they can translate the patient's care request into a care plan on one web page without scrolling or clicking to another screen or tab. In this way the future users themselves have become co-owners of the solution. In order to get to know and understand the caring process of care professionals, Lable's designers and software developers stood on the work floor themselves. A key question for Lable is "what makes you happy?" Lable has used all experiences, information and models together with her own vision on communication to create a beautiful solution. The way in which the electronic care plan has been created, proves that it is possible to shape a suitable solution and new work patterns from co-creation.

## Proposed Caring Method

The core of the proposed caring method is to develop a digitalized caring process in order to consult with the patient or his representative, as a carer or nurse, about his care plan. The patient is offered a digital list, based on the Care Dependency Scale, through which he can express his opinion about his life as he was accustomed to it. What have his daily activities been and to what extent has he become dependent on others? This input is then translated into a choice menu of activities, which the carer or nurse can offer the patient in order to be able to continue living life the way he was used to. The menu of choices responds to the patient's own wishes, preferences and habits. In this way it is achieved that the care plan is established in

- 1 The digital care plan Lable Care was chosen as winner of the Dutch Best Practice Award 2010.

consultation with the patient or his legal representative and fits within the indicated care profile<sup>2</sup>. In the same way, after an agreed upon time (legally, at least twice a year) in a dialogue to re-evaluate and adjust the electronic care plan.

The CDS in digitized form creates the possibility for care professionals to visualize both the demand for care and the extent to which the patient is dependent on others. This is then translated into a choice menu of activities that the care professional can offer the patient in order to be able to continue living their life as they used to. Also, based on the CDS, the web application makes some-score cut-offs; it is possible to indicate for each patient the risk of one or more of the following care problems: decubitus, malnutrition, falling [9-11]. A care pathway is automatically activated for these three problems. The starting points of the care pathways are early identification of risks, correct application of preventive measures and correct treatment in the presence of the care problem.

The digital care pathway development is experienced as a professionalization within the field of nursing and care for the elderly and is therefore seen as an improvement in quality. By offering the right information at the right time to the right person in the care for decubitus, falls and malnutrition in the elderly, together we improve the quality of care. The digital care pathways developed within this project also proved to be a good replacement for the large, extensive paper protocols that generally accompany the caring process [12].

## Conclusion

An initiative has been developed by and for care professionals to improve direct patient care. The challenge was to take advantage of the many changes in legislation and regulations and to redesign the caring process (and smarter) using today's digital possibilities. During the redesign, the patient perspective was explicitly chosen as the starting point and the choice for a validated nursing aid, the Care Dependency Scale (CDS). The care needs of the patient and the degree of dependence on others are taken as the starting point for the nursing procedure. At the same time, the possibilities that the CDS has in the form of risk predictors of care problems have been used to (further) link digital care pathways to the digital care plan. The most important conclusion (and compliment to the initiators) is that care professionals indicate: 'now to understand what the care needs are for the patient and to be able to translate them into their own professional actions'. Healthcare organizations should therefore be critical of the information systems they bring in. After all, only if their requirements are clear and the suppliers make an effort to meet them can the user-friendliness of the electronic patient file be raised to a higher level. This will benefit not only the staff, but also the patient [13].

Finally, caring with a digital care plan is an example of further digitization of caring processes. This increasing role of technology in healthcare emphasizes the importance of continuously learning to work with new forms of eHealth technology: home automation, robotics, apps and serious games. That is why healthcare institutions need to invest in training and computer skills [13]. Learning to work with technology means retraining when digital knowledge and experience lags behind, co-users can advise on the use of technology and are aware of the risks associated with the use of new technologies in the field of privacy and data storage [14]. Not only within healthcare

organizations, but also within the initial and post-initial nursing training programs, this is indispensable for caring with technology.

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2 A care profile contains a description of the nature and content of the need for care and the necessary care, which forms the basis of the financial compensation.



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