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Transforming health systems with design health literacy: Presenting the 40-20-40 model for digital development

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ABSTRACT

Intro: Digital tools and services are becoming the standard for delivery of health care, especially hastened by the restrictions and needs during the COVID-19 pandemic. While early experiences with telemedicine have been a foundation for modern day digital tool development, the use of co-creation, user meta dialogue, and follow up services are often short and few. This represents a powerful potential for designing upcoming services for a multi-level platform. This requires, however, equity in digital health literacy, which is often not the case. Rather than seeing effect or impact as the outcome of the service itself, the value of including and referencing user expectations before and after the session holds an even stronger value; therefore we've explored and created a new co-design approach to digital development we call the 40-20-40 model.

Results: Using the 40-20-40 approach we focus on early user communication and input as a part of the specific session or service design, a *prologue-phase*, that gathers vital input to align expectations. After the specific *intervention-phase*, we utilise the *epilogue-phase* as an extension of the intervention itself, an echo of the prologue, and a gathering of user outcomes. We believe the pro- and epilogue phases represent a total of 80% of the overall impact of our services. We also argue that digital developers and public health service providers would benefit from a stronger use of this design model to improve the quality of care and the use and impact of care services, in particular for patients with limited digital health literacy.

Background

Although the primary aim of healthcare services is to improve the health of patients, they can also be considered to be part of an industry, revolving around logistics, ensuring a steady flow of productivity to both manage resources and needs. This has often led to the use of optimisation processes and theory, e.g. LEAN, to further boost the number of patient interactions and thus reach more people with the same or fewer resources. In many cases this has been led by the expectation of an enormous boost in productivity [1]. For some - both patients and health care professionals - this has also led to a feeling of doing mechanics more than human connections. Digitalisation of healthcare and health promotion services can be seen as boosting both these tendencies, i.e. higher productivity with less human connection or workload [20].

The COVID-19 pandemic has then accelerated efforts of digital transformation of health care services - especially due to a need to service delivery with social distancing. Some hailed this as a process long overdue, others lamented the loss of physical interaction (Committee of European Doctors, 2021) [7]. While both these perspectives have merit, our key message is that this should not be seen as an either-or situation.

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We would also argue that one of the key challenges is not choosing between pace and connectedness, but in recognising the citizen/patient as the true creator of health - and thus see the role of service delivery not as fixing, but as a part of a joint process of facilitation and motivation.

Digital services surely hold a clear potential for improved access and quality of care, but also have certain limitations. The users involved are as human today as they were yesterday; meaning that the impact of the interaction between the citizen/patient and the health care professional involves a lot of intrinsically human elements that can hinder or boost the value of any service delivery [22].

Recognising that the true value of a health care service or tool hinges on its ability to motivate and empower the patient/citizen to make certain choices - taking their health literacy into account as well, this means, that while the health care professionals are in contact with patients/citizens most of their time, the citizen/patient only uses a fraction of their time on this specific interaction; 99% of their time is them performing self-care - or not [3]. The prologue and epilogue phases before and after the specific service delivery situation are both paths to significantly boost the empowerment and the motivation of users/patients. This still means the facilitation in the actual intervention is vital, but for holistic planning of digital health and/wellbeing services and for actually implementing key advice or uptake of practices, these two additional stages must be considered key factors for service providers in the interest of delivering significant outcomes.

For many, a new realisation would be that low digital health literacy or lack of continuous strategies to improve literacy remains an obstacle and that an increased pace of digitalisation is not really helping. Digital health literacy has been defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [26]. And while health literacy in a traditional perspective would often be correlated to educational level, socioeconomic factors, age, or other sociological factors, the challenge of digital health literacy follows slightly different lines. For digital health literacy almost all traditional tiers or groups of target audiences are having difficulties in navigating a constant stream of endless (more or less user-friendly) possibilities they don't fully understand and/or use [33]. And as a case in point regarding use of digital health interventions, data shows that often many available apps are frequently downloaded, but rarely or never actually used [34].

Health literacy in digital metamorphosis and behaviour change

Behavioural change is at the core of medical and public health interventions for both preventive and curative care (Instutite of Medicine Health and behavior, 2001) [15]. Shared decision-making also plays an important role in the behavioural change process. At both the clinical level and at the patient level, patient empowerment leads to increased willingness and preparedness to fully engage in health behaviour modification.

In the ability to change one's health behaviour and to engage in shared-decision making in the clinical context, health literacy plays a critical role. And as such, it can have a great influence on the success of treatment, the cost of health services, and quality of care as perceived by the patient. Health literacy is influenced by two factors:

1) **Personal skills, experience, and knowledge** such as educational level, language and mathematical skills [5].
2) **Context** such as socio-economic and cultural circumstances. These include opportunities for schooling and education, income, and housing, among others [24].

During the last decade, digitalisation has rapidly transformed different domains of human life, including health. This phenomenon has been accelerated by the COVID-19 global pandemic, which has increased the demand for digital health literacy [32].

As an extension of health literacy into the digital domain, digital health literacy can leverage health behaviour, improve health output, and promote informed choice by access or processing well-timed information sharing using digital tools [25]. However, it also bypasses traditional health literacy challenges such as distance and time constraints and the continuity of patient engagement [31]. The nature of the pandemic has necessitated the timely and accurate provision of disease-related health information and virtual patient-physician counselling.

Therefore, there are also multiple public health challenges related to digital health literacy. Disparities in capacity and access to technology are influenced by educational level, income, and age group, among other factors. These disparities not only have an impact upon the appropriateness and effectiveness of digital health information, but also play a critical role in amplifying existing inequalities, especially as evaluating the quality of information can be a key challenge leading to better conditions for misinformation [23].

Furthermore, digital health counselling may not accurately convey the patient's health status, as the efficacy of virtual communication between patient and physician is reduced [18]. Important to note here is that one-to-one communication is established through words (7%), tone and speed of speech (38%), and facial expressions (66%), all of which are considerably compromised in virtual consultations [2].

Given these limitations, digital health literacy must also be addressed through a "health for all" approach and also by integrating general digital literacy in health equity policies and strategies. It should also be considered as an essential part of the responsibility of health-related agencies and personnel. Equity in digital health literacy can be achieved by targeting the following:

1) Capacity to process information.
2) Capacity to share relevant information and experiences.
3) Level of engagement in personal health.
4) Ability (physical, psychological, financial etc.) and motivation to actively engage with digital services.
5) Sense of control and safety in the use of digital tools.
6) Accessibility of information systems tailored to individual needs [4].

Approaches to digital health solutions must also prioritise innovation of digital literacy, particularly for those who lack sufficient digital knowledge and skills taking into consideration the special needs of diverse and complex target groups. For example, special programs focused on the digital training of older adults can better address the perceptual and cognitive changes accompanied by ageing [16].

The principle of 40-20-40

The basic idea behind the principle of 40-20-40 is, that whatever activity you are considering, you should always remember to include the expectations, hopes and visions of the participants while also thinking of the next step for the participants into the design process and project-timeline.

The principle urges the importance of planning the before-phase and the after-phase, instead of only focusing on the activity in itself. According to the principle, the prologue-phase - in which expectations of the participants are identified and processed - represents 40% of the activity, while the epilogue-phase - that follows-up and enables true action - also represents 40% of the total activity, leaving the specific intervention to represent 20% of the efforts spent.

When you are considering digital solutions, if you use the expectations and knowledge of your target audience, and you support them in defining the next steps, then you have a better chance of reaching the target performance indicators for your activities, as you are co-creating the activities with your audience. In practice, the prologue phase helps establish a clear vision for the users of what to expect from the coming session, and once they experience that these expectations were also met, then the epilogue-phase has a much better chance of producing change.

See Fig. 1:

Based on and inspired by the Design Double Diamond Model (Groeger & Schweitzer, 2014) [10] , we have focused on a design theory-based approach to digital development. However, where the Design Double Diamond sees the product as the end goal, we realised that while the eventual intervention outcome might be seen as a product, the circumstances before and after the actual intervention were crucial parts in providing this outcome. Hence, we adapted the process and structure to not just work to develop a particular solution or product, but as a process model for designing a three-staged plan for co-creative group based interventions.

The model is also applicable 1:1 to other types of interventions (individual/couple); the Danish Committee for Health Education (DCHE) are eg. using the principle in a couple-based intervention for stronger support of breastfeeding, which suggests an inherent versatility in the model.

In the 40-20-40 process, the organiser plays a vital role in framing and facilitating the processes of co-creation; whether the event or project being a research process, a public health project, a peer-to-peer support initiative, or the establishment of an event in a local community. The organiser can be any stakeholder in the context (eg. a scientist, a citizen, a patient, an NGO). To reach co-creation processes in projects, there is an urge for education of the organiser to ensure a culture where citizens are not solely accepted or allowed into the projects, but valued and sought after, if they are not initiating the projects themselves.

The term co-creation traces back to an article published in 2000 in Harvard Business Review by Prahalad and Ramaswamy [29]. They later characterise co-creation as "[t]he joint value by the company and the customer, allowing the customer to co-construct the service experience to suit their context" [30]. Co-production and service user involvement are increasingly encouraged in research [11] where new buzzwords are "collaboration", "co-creation/co-production" and "dialogue" [28]. Co-created processes can enable a need driven approach to innovation and elevate mutual educational processes for all of the people involved. The 40-20-40 Model has a prologue-intervention-epilogue-structure in which each stage allows both a gathering, adaptation, sharing, and adoption of needed reflections from the group, within the group, and from the planners to the group.

From a fully face-to-face intervention to an online-blended-learning-group-intervention: using the 40-20-40 model

A commonly found challenge for bowel cancer patients is that many need a stoma for some period during or after their treatment [6]- and while this of course is a very fundamental necessity, it also affects their quality of life. In a study done by Beaubrun en famille Diant, Laury et al., they explore on the one hand, the psychological impact of colostomy on colorectal cancer patients' quality of life and, on the other hand, it analyses the correlational links between body image, self-esteem and anxiety during the stoma. The study found during a variety of surveys that body image, self-esteem and anxiety negatively affect the quality of life regardless of the type of stoma [6]. To help alleviate this situation,

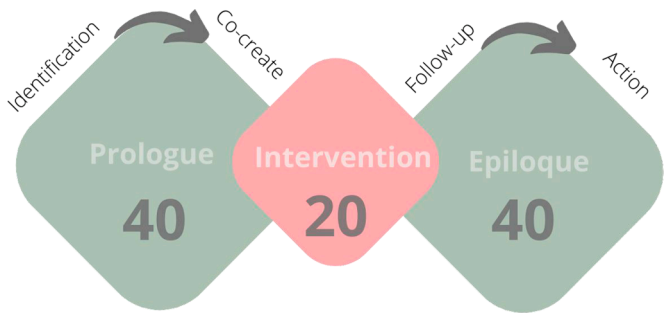

Fig. 1. The 40-20-40 model.

the DCHE planned a face-to-face intervention with the purpose of training people on how to live with stomia in which nine topics regarding life with stomia were identified, inspired by a pilot study by Hubbard G, Taylor C, Beeken B, et al. where the patients ranked nine stoma-related quality of life topics in order of research priority [13].

Instead of planning the lectures for each topic as a textbook or similar, the intervention was planned to first allow the participants to initially reflect and comment on each topic - before the lecture - regarding what they felt was most important within the particular topic. Based on this feedback and reflections, the relevant professionals (e.g., dietician, sexologist, physiotherapist, nurse, patient organisation representative, doctor) would subsequently deliver their lecture.

This structure of an initial inclusion of the pre-lecture reflections of the participants served several purposes:

- First, it made sure the lecture addressed the particular issues that the participants found most relevant - and for exactly that particular group of participants too.
- Second, it also ensured the instructor would focus the lecture to respond directly to the gathered reflections.
- And third, it was much easier and more motivating for the participants to implement their learnings from the lecture in their everyday life, as the course had addressed the exact issues, they had needed solutions for.

This was one of our initial trials of an intervention using the 40-20-40 model. The reflection was then the first 40% of the work, the lectures itself the core 20% and subsequent actions and implementation in everyday life are the final 40%. And since the participants also knew that they would be asked to reflect further in the next of the nine sessions, they started these reflections well before attending each session.

A structural challenge for the planner, when using this approach, however, is that more vocal participants can risk overrule reflections of other participants that may need more time to reflect or voice concerns. This is a continued observation point in the Danish Committee for Health Education (DCHE) group interventions.

In constructing the 40-20-40 model, we asserted, that no matter how you gather a group, you will have some level of diversity in self-efficacy or verbosity, that risk to slightly distinguish participants on a scale from strong to more fragile; often giving the stronger patients a position of more influence or power in the group, risking part of the potential of the co-creation process becomes biased and not relevant for the entire group. Indeed, less vocal participants could often have inputs that would otherwise be relevant for the entire group but doesn't quite reach the agenda. We argue that gathering these reflections before the actual group sessions helps offset this traditional challenge for group-based interventions.

Online empowerment for people living with anxiety and/or depression

Since 2012 the Danish Committee for Health Education (DCHE) has operated a face-to-face intervention for people with anxiety/depression, a derived version of the Chronic Disease Self-Management program (CDSMP) [14] that in Denmark is called Learn to Live [19] . The core element of CDSMP is a group intervention for 12–16 participants, operated by two volunteers, who themselves have experience with long term conditions. The group meets 2½ h once a week for seven weeks, with the focus of introducing and testing coping strategies for dealing with anxiety and/or depression in everyday life [9]. After each session, a goal-setting action plan - sometimes referred to as a to-do-plan - is produced to help participants revisit the key points of the session and to aid in the follow-up and practical actions.

To reach more people this intervention was in 2020 transformed into an online group intervention, with a mixture of e-learning, live webinars and explorative actions in your everyday life that allowed participants to

add their reflections and experiences into the sessions. A core change from the physical intervention to the online intervention is that an online module consists of individual work via e-learning, a live webinar and the testing of coping techniques in everyday life. During e-learning, the participants are asked to respond to questions. These responses are then collected and used in the live webinars.

In this way the participants are being nudged to reflect upon the topics in the webinars and thus become co-creators of the content of the webinars. Since the e-learning part is individual, it also creates an equal opportunity for every participant - strong or fragile - to contribute and frame the intervention and ensure even more relevant webinar sessions.

In the DCHE, our experience from the development of new digital solutions is that these e-learning ecosystems have the potential to motivate participants to a higher level of not just activity and interaction, but also actual learning than traditional information sharing eg. In the shape of chapters in a book or even an informative, but non-interactive website [21]. It is our experience that using these adapted digital solutions works better, as it supports the first 40% of the 40-20-40 model even more than we experienced from physical interventions. It creates a coherent process for the participants where personal reflections are met and shared in a group and the solutions found are directly applicable to your life situation.

Co-creation with citizens is meeting obstacles within academia, due to the lack of funding, lack of recognition in institutional promotion and recognition processes and the high rejection rate of proposals due to claims about low data quality. This is despite the reported benefits of the methodology Citizen Science (CS) [8] , where citizen engagement is viewed as producing more "socially robust knowledge" [27] with a high level of acceptance and trustworthiness to the general public. CS isn't only good for the science itself but has also been described by Haywood 2014 [12] and [17], to have a long list of participant benefits including enhanced science knowledge and literacy, empowering participants and increasing self-efficacy, increases in community-building, social capital, social learning and trust, just to name a few [17,12]. And indeed, it seems CS is already becoming a basic principle for research as in the Horizon Europe programme using the EC Pact for Research & Innovation in Europe 2022 as the framework.

Conclusion

In developing and improving situations for learning, a clear and typical misconception is that you can create an isolated space for a particular action or intervention. In reality, what happens in these learning spaces is always affected by the life situation of each and all the participants in the physical or digital room, including their dreams, hopes and goals for the future. Traditionally, homework and suggested readings have then been common answers to help align participants in a preparation phase. While this method has been proved to have a considerable positive effect, it does little to address underlying challenges of health literacy among the participants. The more vocal participants had a better chance of understanding the material and thus generated more relevant activity in the joint learning sessions, where the less vocal participants may have needed the allotted time to formulate their inputs to the learning sessions.

If we use the stages of the 40-20-40 model as reference, then previously the epilogue-phase has often been used for e.g., report or diary writing. However, the best outcome of the epilogue-phase comes from not just activating participants produce or reflect, but to establish a clear vision of what new competencies you will be able to gain by participation, and also later a clear vision of what new goals you have now been able to make for your own progress - a true leveraging of the existing health literacy of the target audience and an integration of the participants in the creation of the intervention. This particular process can of course also start in the intervention-phase - where the concept of goal setting gets introduced in our CDSMPs - but the quality and the activity very much benefit from the alignment of expectations in the prologue-phase.

In addition, in our recent experiences with digital health solutions we find that the transformation of traditional face-to-face delivery into a digital solution can also help activate participants even more than the traditional delivery method. The digital solution seems better able to release and deliver on the expectations and relevant comments from the participants to directly ensure co-creation processes with all participants, which helps level out the previous strong/weak participant issue. In practice we can then use the input to further improve this digital delivery to make sure that the intervention is relevant for the participants and thus has stronger outcomes. More work is needed to establish if this observed increase in activity level following this digital transformation has a temporary nature, has a one-to-one relative impact on the outcome as it had on the observed activity, and also whether it has either group or individual impact on outcome.

Digital delivery methods are also much more useful for follow up sessions since you can track both the experiences, the actual data regarding effects, and also much easier connect without travel or appointment - and thus expand existing networks and relations while the participants can experience the comfort of their trusted home environments. And while one should always be conscious of a need for support and guidance, the challenges of digital health literacy are in this setting simply outweighed by the benefits to the users with low digital health literacy as well, and at the same time it also enables a stronger self-efficacy and bolsters all the participants' digital health literacy, so that they can all see a direct interactive outcome of these interventions.

In this post-corona setting we should stop talking about whether future interventions should be digital or physical but work to create blended learning solutions. The digital elements should be applied to stimulate the pro- and epilogue-phases and - when and where possible - the eventual meeting physical or digital, is simply where interaction, problem solving, and action planning can take place. Obviously, digital learning solutions also risk confounding any issues of digital health literacy, so to counter this challenge, developers should also ensure extra easy access to support and help - and the solutions need to be tested for usability, lix, imagery etc.

We encourage the use of the 40-20-40 model to create targeted, effective learning, by widening the scope and understanding of the wider learning situation and by recognising how a stronger co-created path into digital health literacy in this case can lead to a boost of the traditional health literacy too.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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