Digital Diaries on American ICUs

Identifying Barriers and Solutions to Digital Diary Implementation in the US

Master Thesis Sociology: Contemporary Social Problems
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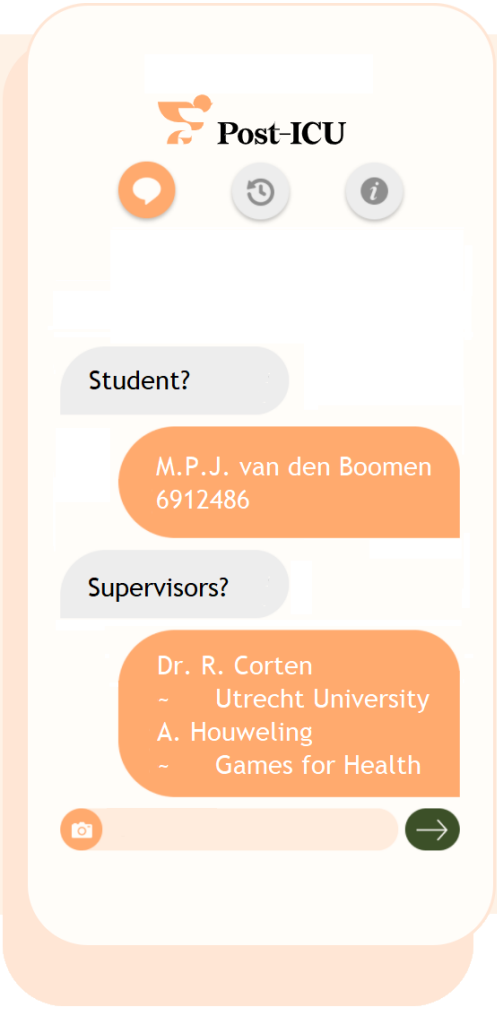

Utrecht, June 25, 2021

Abstract: To mitigate the Post-Intensive Care Syndrome among ICU survivors, Games for Health (GFH) has created a digital diary which is running in 14 hospitals in the Netherlands. GFH wants to investigate whether their invention would also work in America, where 5 million people end up on the ICU every year. American ICU staff was interviewed to identify barriers and concerns regarding innovation like a digital diary. Although their response was generally positive, many barriers were identified, such as concerns regarding inequality, the unregulated for-profit healthcare market, litigation, inconsistent stories towards families, language, the number of uninsured, and technological accessibility. Most of these can be resolved by adding new features to the digital diary and education of ICU staff and their patients.

Word-count: 10,602.

Contents

Introduction

Because of technological advances in the mid-1950s, Intensive Care Units (ICU) were introduced in hospitals (Kerlin, Costa, & Kahn, 2021). ICUs offer a last resort to the sickest of patients and are run by an inter-professional team, including nurses, intensivists, occupational therapists, and more (Donovan et al., 2018). Decades of ICU innovation have led to a steady increase of surviving patients, but with reduced quality of life for both patient and family (Cameron et al., 2016; Schmidt & Azoulay, 2012).

"Physical, cognitive, and psychologic problems are common among survivors of critical illness and are often associated with a reduced quality of life" (McPeake et al., 2019). Up to 62% of ICU survivors suffer from psychiatric impairments, more than 25% experience physical impairments, and up to 75% suffer from cognitive impairments (Rawal, Yadav, & Kumar, 2017). This collection of health disorders is known as the Post-Intensive Care Syndrome (PICS) and is also prevalent in Family members (PICS-Family), with 70% of them experiencing anxiety and 35% experiencing depression (Schmidt & Azoulay, 2012). Every year, more than 5 million people are admitted to ICUs in the United States of America (USA) (Halpern, 2021). That's a significant group of ex-patients and families who are struggling with going back to work and getting back on track in general. This is alarming in a humanistic way (for patients and families themselves), but also in an economic way (for employers, companies). The current SARS-CoV-2 pandemic takes this problem a step further, with record amounts of ICU admissions both in the US and in Europe (IHME, 2020).

To prevent PICS, medical in-ICU interventions have been proposed, like paired sedation, the ventilator weaning protocol, and goal-directed mobilization protocol (Girard et al., 2008; Schaller et al., 2016). Other recent initiatives are peer support groups (McPeake et al., 2019) and diaries. The latter has been proven to enable ICU survivors to make sense of their ICU experience, and to prevent and counteract PICS-related impairments for both patient and family (Egerod, Christensen, Schwartz-Nielsen, & Ågård, 2011; Jones et al., 2010; Perier et al., 2013; Garrouste-Orgeas et al., 2012; Bäckman, Orwelius, Sjöberg, Fredrikson, & Walther, 2010; Garrouste-Orgeas et al., 2014; Mickelson et al., 2021).

In close collaboration with the Dutch Catharina Hospital, Games For Health (GFH), a game/app development company in the Netherlands, developed a digital version of the paper diary (Post-ICU, 2021). The goal of this digital diary is similar to that of the physical one: to prevent and counteract PICS for both (ex-)patients and their families. Amongst other benefits, a digital version is especially useful during pandemics, like the current Covid-19 pandemic, in which family is not allowed in the ICUs. The intervention has already been successfully implemented in 14 Dutch hospitals and feedback has been predominantly positive.

With GFH's mission being to help 1 billion people towards happiness (Games for Health, 2021), in addition to the interest shown from the United States, the company wants to explore the possibilities and hurdles of their digital diary in the US. From GFH's own experience in the Netherlands, ICU staff turned out to be the key actors in this regard. They are the ones who have to see the added value of the intervention and the ones who introduce the diary to the patient and family. GFH wants to know the "why" underlying their behavior, e.g. why wouldn't they want to use a digital diary? Since qualitative research is most suitable to answer why-questions like this one, data collection in the US will consist of in-depth interviews with ICU staff. The first objective of this exploratory research is to answer the following descriptive research question:

What are the views of American ICU staff on digital diaries in ICUs?

It is important to mention that diary implementation comes with some difficulties. Rogan, Zielke, Drumright, and Boehm (2020), Mickelson et al. (2021), and Drumright et al. (2021) all reported professional liability and patient privacy concerns among ICU staff. All three reported complications with the actual initiation of the diary, which they believe to be easily solved by appointing a so-called

champion: "one dedicated staff member to oversee initiation and use of the diary" (Mickelson et al., 2021). A lack of support, awareness, and buy-in among ICU staff was also prevalent in all three studies. "As with the introduction of any new initiative, the greatest difficulty is with staff buy-in" (Blair, Eccleston, Binder, & McCarthy, 2017).

Some of the implications of the paper diaries are likely to disappear with a digital diary, like the necessary disinfection of physical diaries (Rogan et al., 2020), or people forgetting to bring the diary with them (Mickelson et al., 2021). However, some of these might still be prevalent with digital diaries, like liability and privacy concerns.

As mentioned before, the digital diary is developed in the Netherlands and is therefore specifically tailored to the Dutch healthcare system, to Dutch hospitals, and to the Dutch culture. Therefore, we expect that a simple translation of the digital diary won't suffice for a successful launch in the US. It is important for GFH to investigate whether this is true or not, and if so, what factors are causing the differences between the two countries. The second goal of this study is therefore to investigate whether the views of ICU staff in the US are different from those in the Netherlands, regarding a digital diary on the ICU. A holistic approach is applied to accomplish this goal, taking macro-, meso- and micro-factors into account. First of all, I will take a look at macro-factors, like inequality, the American economic structure, and the American healthcare system to see whether this impacts innovations like the digital diary. Second, the influence of American culture on digital diary implementation will be investigated, like the litigiousness (inordinate tendency to engage in lawsuits) of American society. And third, the influence of meso-factors like ICU organization on digital diary use will be investigated. There are many differences in ICU organization between Western Europe and Northern America (Sakr et al., 2015), which may partly explain differences in views. With this, the following explanatory question will be answered:

To what extent do structural, cultural, and organizational factors cause views to be different in American ICUs?

In the end, advice will be provided to GFH by answering the following question:

What can Games for Health do to overcome the discovered barriers?

Although this research is inductive in nature, deductive approaches like literature review will help with answering the research questions. Using relevant literature, sensitizing concepts will be derived. These will provide directions for the semi-structured interviews, which will ultimately answer the formulated research questions. In summary, this study aims to map the views of American ICU staff on digital diaries, explain what macro factors cause these views, and advise GFH on how to improve the Digital Diary (DD) and its implementation using these insights.

Theory

In this chapter, multiple factors will be discussed that may cause views to be different in America than in the Netherlands. Starting off with what we know from research on paper diaries and therefore expect there to be in digital diaries as well, followed by the economic structure in American healthcare, the litigiousness of American society, and the organizational structure of American ICUs.

Paper Diaries

As mentioned before, the implementation of paper diaries is proven to come with difficulties. According to multiple studies, staff was concerned about professional liability and privacy of the patient, and stumbled upon a lack of support, a lack of awareness and a lack of buy-in among staff (Rogan et al., 2020; Mickelson et al., 2021; Drumright et al., 2021; Perier et al., 2013). Drumright et al. (2021) also mention that ICU staff don't have time to take on new interventions like a DD, which is backed up by research from Kendall-Gallagher, Reeves, Alexanian, and Kitto (2017): "... ICU nurses reported to perform the unique role of providing round-the-clock care, integrating multiple demands as bedside caregiver, problem solver, care coordinator, workflow manager, advocate, and negotiator ... It's just go, go, go, go, go".

Though, the diary was also perceived to improve communication (Drumright et al., 2021; Garrouste-Orgeas et al., 2012). According to Perier et al. (2013), healthcare providers saw the human aspect of their work through the diaries and also regarded the diary as a beneficial addition to oral communication. This appreciation of an extra communication channel was shared by families of ICU patients, who said that it helped them cope with the tough emotional experience (Garrouste-Orgeas et al., 2014). All in all, I expect to find at least some of these concerns, barriers, and benefits when asking American ICU staff about their views on digital diaries.

Neo-liberal Policy, Inequality, and American Healthcare

Inequality is everywhere, although in the US, the gap between rich and poor is among the highest of all industrialized countries. The US has the third-highest income inequality (Gini index) and also the third-highest poverty rate of all 37 OECD countries, see Table 1 below. According to Pickett and Wilkinson (2015) higher income inequality is positively related to social and health problems, such as life expectancy, mental illness, and social mobility, causing the US to come out on top, see figure 1.

Table 1: *Inequality in the USA and the Netherlands*

Country	Gini index	Poverty rate
U.S.A.	0.39	17.8%
Mean OECD	0.31	12.0%
Netherlands	0.29	8.3%

Source: OECD (2018); Statista (2019)

According to Coburn (2000), both the high income inequality and health problems of the US are caused by the neo-liberal (market-oriented) policies of the country, which undermine any form of welfare state. This causes the US to be the only industrialized country in the world that lacks the provisions to ensure healthcare coverage for all citizens (LiPuma & Robichaud, 2020). Proposed reasons for the American resistance to universal healthcare are their negative attitudes towards the government, the need for freedom of choice, and the ingrained ethos of self-reliance, which also resonate with the conservative, neo-liberal policies in the country (Sniderman & Brody, 1977; Kulesher & Forrestal, 2014; Vladeck, 2003). The way the neo-liberal notion is applied to American healthcare is best described by Enthoven's 'Managed Competition', which is "a purchasing strategy to obtain maximum value for money for employers and consumers. It uses rules for competition, derived from rational

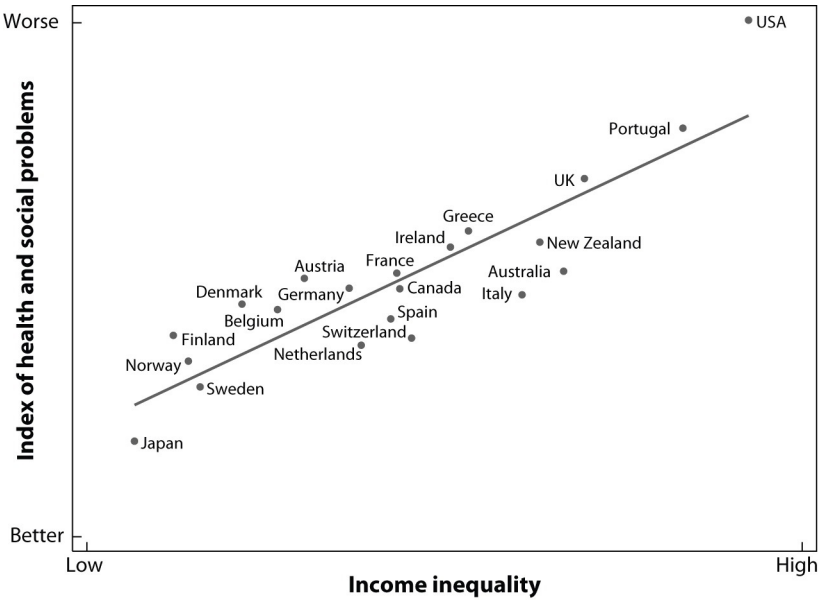

Figure 1: *Index of Health and Social Problems in relation to income inequality in rich countries. Income inequality is measured by the ratio of incomes among the richest compared with the poorest 20% in each country. The index combines data for the 10 outcomes listed in Table 2. Raw scores for each variable were converted to z-scores and each country given its average z-score. Reprinted from "Income Inequality and Social Dysfunction" by R. G. Wilkinson and K. E. Pickett, 2009, Annual review of sociology, 35, p. 597. Copyright 2009 by Annual Reviews.*

microeconomic principles, to reward with more subscribers and revenue those health plans that do the best job of improving quality, cutting cost, and satisfying patients" (Enthoven, 1993).

However, in practice, it turns out to have major drawbacks. In their renowned book 'Redefining Health Care', Porter and Teisberg (2006) state that the free, unregulated market incentivizes hospitals to reduce costs by restricting services, also causing them to resist innovation. Furthermore, the competitive free market system, amongst other things, has made the US the country with the highest expenditures per capita on healthcare, see Table 2 (Bodenheimer, 2005; Porter & Teisberg, 2006). One of the implications of these rising costs is the increasing number of uninsured people (Bodenheimer, 2005). Despite an attempt of the American government to increase healthcare coverage with the Affordable Care Act in 2010, still 27 million people remain uninsured (Dickman, Himmelstein, & Woolhandler, 2017). The US has created too many separate systems for separate classes of people, leaving many people uninsured (Kulesher & Forrestal, 2014).

Table 2: *Health expenditure per capita in 2019*

Country	USD/capita
1. U.S.A.	11,072
2. Switzerland	7,732
7. Netherlands	5,765

Source: OECD (2019)

In cross-national research, Schoen, Osborn, Squires, and Doty (2013) concluded that US adults were significantly more likely to refrain from care because of cost than adults from all other Western nations, including the Netherlands. Furthermore, US adults were also significantly more likely to have difficulty paying their care bills, even when they did have insurance. To be precise, 37% of US adults didn't go to a doctor when they felt sick or went without recommended care because of cost. So US citizens seem to be quite cost-conscious, which is inherently related to a free, unregulated market (Bodenheimer, 2005). In theory, ICU patients might feel the need to avoid the DD or ICU rehabilitation in general,

because of cost, even though it would be recommended by practitioners. Hart's (1971) inverse care law might still prevail: "The availability of good medical care tends to vary inversely with the need for it of the population served".

Language

In 2016, 65,520,000 people in the US did not speak English at home, which was about 20.3% of the population (Gambino, 2018). The most common non-English language is Spanish (40,490,000). The language barrier in American healthcare is regarded to be a major challenge to effective healthcare delivery (Pérez-Stable, Napoles-Springer, & Miramontes, 1997; Erzinger, 1991). "Lack of interpreter services or culturally/linguistically appropriate health education materials is associated with patient dissatisfaction, poor comprehension and compliance, and ineffective or lower quality care" (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016). Therefore I expect there to be references of linguistic barriers regarding the DD.

American Litigiousness

Since the 1820's there has been a steady increase in litigation rates in the US (Galanter, 1983, Figure 1), which many scholars and even judges regarded as alarming. "Few Americans ... can tolerate more than five minutes of frustration without submitting to the temptation to sue" (Auerbach, 1976). Judge Forer agrees: "There can be no doubt that ... Americans are the most litigious nation in human history" (Forer, 1975). The underlying assumption is that a higher number of lawyers and judges reflects a higher demand for their services, which in turn reflects the inbred cultural preference for suing in American culture (Galanter, 1983).

Table 3: *Litigation Rates*

Country	Cases per 1,000 population
Germany	123.2
U.S.A.	74.5
Netherlands	16.0

Source: Wollschlager (1998)

Data from Wollschlager (1998) (see Table 3 above) and Galanter (1983, Table 3)) confirm that litigation rates are higher in the US than in the Netherlands. However, Galanter (1983), Blankenburg (1994) and Van Aeken (2012) do not think this is due to differences in culture, but in institutional arrangements. In the Netherlands, there are many more alternatives for dispute resolution than in Germany and the US. Besides, in Germany and the US, the court system is very cost-efficient and therefore "attracts masses of petty claims" (Blankenburg, 1994).

Nevertheless, "Americans are ready to believe in, almost to the point of insistence, their own allegedly litigious national character, even when evidence for this characterization is absent, ambiguous, or contradictory" (Greenhouse, 1989). Therefore I expect American ICU staff to be more concerned about legal issues regarding a DD.

Organizational ICU Structure

Half a century ago, Max Harry Weil, Medical Doctor and one of the founding fathers of critical care medicine, believed that critical care should be organized around intensive care specialists coming from different backgrounds (Weil, 1973). This way of organizing the ICU is also called the *open format*, in which ICU patients are treated by the specialist that brought them into the ICU.

The Open Format has some major downsides though. First, referring specialists had thorough knowledge on the specific disease of the patient, but lacked the knowledge and skill regarding the

necessary critical care treatments. And second, because the referring specialists also had to take care of their patients outside of the ICU, ICU patients didn't get the continuous care they needed (van der Sluijs et al., 2017).

Therefore, a new format was invented: the *closed format*, in which critical care specialists, so-called intensivists, rather than the referring specialists, take care of the ICU patients without having any other medical duties. This reorganization had a major positive impact on patient outcomes, like lower ICU mortality (Pronovost et al., 2002).

In the Netherlands, this closed format is standard practice (NVA, 2006), but American hospitals continue to fail meeting this standard, mainly because of a growing shortage of intensivists (Siegal, Dressler, Dichter, Gorman, & Lipsett, 2012). "Published estimates indicate that intensivists currently provide care to only 37% of all ICU patients in the United States and that they are located primarily in large hospitals and teaching institutions" (Lois, 2014).

Apart from better patient outcomes, the presence of an intensivist is also beneficial for the ICU team. According to Pronovost et al. (2006), intensivists "coordinate *communication* and *collaboration* with the patient, family members, other ICU clinicians and medical specialists", which suggests that a lack of intensivists would result in worse communication and collaboration between staff members, and between staff and family. Because of the lack of intensivists, i.e. the lack of central leadership in the vast majority of American ICUs, family members of ICU patients often find that each healthcare practitioner provides different information about their relatives, resulting in an inconsistent story and confusion among family members (Reeves et al., 2015). Family members mentioned that this was partly due to the many different teams that visit the ICU: "You've got your liver team that comes, ... and then there are respiratory therapists who come in. Then you've got the nurses, and they all change" (Reeves et al., 2015). According to Engoren (2005), the intensivist's presence enables *rapid evaluation*, which presumably causes these diverging stories from all of those different teams to be more in line with one another, therefore causing less confusion among family members.

During the interviews, the relationship between the presence of intensivists, fragmentation of ICU staff, and diverging stories will be scrutinized in order to determine whether this has any effect on digital diaries or not.

In this chapter, I presented different macro- and meso-factors that are unique to American society. According to sociologists like McClelland (1961) and Coleman (1994), it is inevitable that these social conditions shape individual decision-making and behavior of American ICU staff, which will determine whether the DD will be a success in America or not. As mentioned before, ICU staff are regarded to be the key actors. In the next chapter, I will explain how I will reach this group and how I will test whether the above-mentioned factors affect their views or not.

Methods

This research was conducted from February through June 2021. This study aims to answer why-questions, to understand behavior, beliefs, and opinions from the perspective of the participants themselves (Weber's Verstehen). Since we are not interested in change over time, cross-sectional research will suffice. Therefore I opted to conduct in-depth interviews with participants drawn from the target population: American ICU staff. I follow earlier research on paper diaries where researchers also interviewed ICU staff (Rogan et al., 2020; Drumright et al., 2021). The only requirement was for ICU staff to have over 24 months of experience on American ICUs, because otherwise their views would be based merely on the Covid situation.

Participant Recruitment

To reach this population, different purposive sampling methods were applied. At first, participant recruitment was done by following up on multiple leads from GFH, in combination with 'American ICU staff' related Facebook groups (Ackland, 2013, p. 32), the company's LinkedIn network, and the Society of Critical Care Medicine. With this approach, one expert in the field of intensive care was recruited. American ICU staff, however, turned out to be difficult to reach, because of the global pandemic and geographical reasons. A different approach was necessary. I started targeting researchers and ambassadors of paper ICU Diaries, in combination with snowball sampling. This approach was successful, although it came with some bias, which I will cover in the limitations section. Towards the end of data collection, Facebook advertising was used to reach ICU staff without any diary experience, but with no result. In the end, I conducted twelve in-depth interviews, including one expert interview, and one in-depth interview with two participants at the same time.

Data Collection and Ethical Considerations

Before starting data collection, this study was approved by the Ethical Review Board of the Faculty of Social and Behavioral Sciences of Utrecht University. All interviewees read the information letter and signed the informed consent document before the interview. The interviews were conducted online, because of the ongoing pandemic and the target population living abroad. This was done in a synchronous manner using Google Meet and Zoom. This way of interviewing resembles traditional face-to-face interviews the most (Ackland, 2013). Disadvantages of online interviews are the fact that it's more difficult to observe the social context and body language of the interviewee, and that it's harder to achieve rapport (a trust relationship) with the interviewee (Hennink, Hutter, & Bailey, 2020).

Interviews had a semi-structured nature and took 45 to 60 minutes. Starting with short and simple questions about who they are and what their role is in the ICU. This was followed by questions to loosen up and try to gain rapport with the interviewee, and then changing direction towards ICU diaries. The topic list that was used as a guideline for the interviews can be found in Appendix A. Open, broad questions were provided, giving interviewees the chance to come up with their own answers. I gradually narrowed it down and probed with sensitizing concepts that were acquired using theory, like ICU organization and the American 'fear of litigation'. With the latter, the intensity peak of the interview was reached and was followed by lighter questions to lose momentum and let the interview come to a stop. The interview guide was iteratively adapted after each interview, by slightly changing questions or removing them when they turned out to be insignificant. Participants did not receive any monetary compensation, since this might influence the information that is provided (Hennink et al., 2020). The interviews were recorded using OBS Studio 26 and were saved on the encrypted cloud provided by the University of Utrecht.

Data Analysis

Recordings were transcribed and participant names were replaced by pseudonyms, which were used throughout the rest of the study. The anonymized transcripts were also saved on the encrypted cloud, after which the respective recordings were deleted. Coding was done using NVivo 12.6. Starting with open coding and followed by axial coding, the raw interview data was structured into codes to draw conclusions and answer the research questions.

Positionality and Reflexivity

I'm aware of the fact that my position as an intern at GFH might have influenced the interviews. Since I'm interviewing participants about a product of a company that I work for, that I represent, participants might act more socially desirable and share less of their negative ideas regarding a DD. Furthermore, everyone at GFH is very keen on the DD. Both feedback we get from Dutch hospitals and previous research confirm that (digital) diaries have desirable effects, which all resulted in bias on my side. As a researcher, I tried to be as objective as possible, but this bias might still have influenced the way I conducted the interviews and the conclusions that I drew from them.

Results

Three main themes arose while analyzing the data: expected benefits of a DD, concerns regarding a DD, and finally the organizational structure of American ICUs. Each of these themes consists of multiple topics, which are all presented in this chapter with participant quotes for extra clarification. All topics have the same names as the corresponding codes, which can be found in Appendix B. All topics are ordered from most-mentioned to least-mentioned and the amount of participants that reported a specific topic is presented in parentheses, e.g. (7/12). Concrete solutions for specific issues can be disclosed by hovering your mouse over the little GFH logos (Adobe Reader/Acrobat is necessary), which are also presented in the Advice chapter.

Table 4 presents demographics and other relevant characteristics of the twelve participants. Most participants worked in academic hospitals and in big cities with at least 700,000 citizens. The healthcare expert I interviewed has worked in both American and Dutch hospitals, making him able to provide unique insights.

To put all findings into perspective, it's important to note that almost all participants (11/12) had experience with *paper* ICU diaries, which was accompanied by a generally positive attitude towards that intervention. In addition, most participants (10/12) had a positive attitude towards *digital* ICU diaries, explicitly saying things like "I personally love it" or "That would be awesome". Most even said they'd prefer digital over paper, because of the expected benefits it would have (see next section). However, two participants were rather reserved and concerned regarding a DD, being the only participant with no diary experience and the oldest participant with an age of 67.

Table 4: *Participant Demographics and Characteristics*

	Mean (SD) or n = 12 (%)
Age	40.6 (12.1)
Years of experience	15.5 (13.1)
Female	11 (92%)
Experience with paper diaries	11 (92%)
Academic hospital	8 (67%)
Academic/Community hospital	2 (17%)
Veteran hospital	2 (17%)
Colorado	6 (50%)
New York	2 (17%)
Tennessee	2 (17%)
Virginia	2 (17%)
Senior Occupational Therapist	5 (42%)
ICU Nurse	4 (33%)
Clinical Program Coordinator	1 (8%)
Expert; Intensivist	1 (8%)
Patient Experience Partner	1 (8%)

1. Expected Benefits

All participants mentioned at least one thing that they found desirable about a DD, like the fact that they won't need to worry about their bad handwriting anymore (2/12), and more:

Families can use the DD from home (8/12). The fact that families of patients are able to work with the DD from home was also perceived as a major benefit. Especially for patients and family who come from afar, which is more common in the US, being a geographically big country. Some (2/12) mentioned that a DD would get more involvement and buy-in from families, because they can use

the DD from home and won't be bothered by overwhelming and expensive cities. Many participants (7/12) also mentioned that communication between staff and family would improve significantly:

> "Because there's a lot of family members that can't come into the hospital, you know, they live in a different area. They can't come in, and if that's the way I can communicate with them and be like, "Hey, your loved one got extubated today and he's doing great, and he smiled", like that would feel really nice, holistically, that I'm taking care of the patient and the family too." (Luna, 34)

Not losing it (8/12). Most participants mentioned that they like the idea of a diary that is not just in one place. A diary that is digitally accessible anywhere, making it nearly impossible to lose it. Especially when patients move from one unit to the other, paper diaries get lost, resulting in painful situations with family:

> "I've had at least five people that had family members die, and then have come back like, "Oh, we left the diary on the counters, is it still there?" And I'm like, "Nooo", and they just like, they're hopeless, and we've called like the cleaning company or everybody to try to find it and you can't find it. And so that's the first thing I think of ... it's just so nice that you can't lose it." (Luna, 34)

Including pictures (7/12). Many participants were enthusiastic about the fact that pictures could be easily added to the DD. They believe that it helps with filling in the blanks for the patient and also prevents them from losing sight of their progress during their stay. Some pointed out, though, that it must comply with HIPAA (Health Insurance Portability and Accountability Act) in order to get support from the legal team.

Fits in with 'American Social Media Culture' (5/12). The fourth most mentioned benefit is that a digital diary "fits in very well with American culture":

> "So this feels more similar to like social media and Americans are obsessed with that, myself included. There are a lot of people who are very comfortable recording their entire life through their social media account, through twitter, things like that. So this is almost like a twitter for the ICU bedside." (Emma, 30)

Although some (2/12) say that this mainly holds true for the younger generation.

2.1. General Concerns

Writing in a digital diary instead of a paper one (10/12). The majority of participants (8/12) thought it was fine or even expressed verbal and visual excitement to write in a digital diary. However, others (2/12), including this older participant, really preferred paper over anything else. They felt that they could write faster than they could type or they simply found that paper was a better medium for emotional content:

> "You get a card in the mail and that kind of like makes your day versus getting an e-card where, oh it's nice but ... [not really]." (Elizabeth, 67)

Litigiousness (9/12). A minority (4/12) felt that they could be easily sued over the contents that they'd write in a DD. One participant decided to only put her first name in the diary, to make sure that she stayed out of trouble. Some have been sued themselves in the past, making them feel a bit cautious to use the DD, but they also believe that it's ingrained in American society:

> "Well, anything that has to do with 'I can be sued', whatever the reason, uhhm, that immediately raises very anxious feelings here ... It is not safe [agitated], because the diary belongs to the patient, so everything you write down as a healthcare employee is available to the patient with name and surname and date and time." (Miles, 64)

However, others (7/12) believe that suing will not be a problem at all, because staff is not writing about milligrams, i.e. nothing written in the diary can be used in court. Usually, medical, technical messages are translated to layman terms (i.e. simple language), for the patient and family to comprehend what's going on. Furthermore, "the diaries are kind of sacred to the patient and family", making it even more inconceivable for them to use the diary in court. Lastly, staff working in Veteran hospitals cannot be sued directly, since they work for the government, resulting in no worries regarding litigation (1/12).

Patient Privacy (11/12). Participants were concerned about confidentiality in multiple ways. Some (2/12) mentioned that family members don't necessarily get along, so it should be up to the patient who gets access to the diary. Moreover, the most common concerns were about hacking or data breaches (10/12). This would get both patient (privacy) and hospital (liability) in trouble, but it wouldn't affect DD usage of staff.

> "Would potentially be more of like a confidentiality issue for the patient. Like if that was ever to be a security issue or it would be hacked or something um, but I don't think that it would be a concern for me as a professional." (Emma, 30)

Besides, normally, paper diaries are just laying on the counter and anyone could look in them, so one participant actually believed that privacy would increase if the diary were to be digital.

Technological barrier (11/12). Most participants (11/12) claimed to have many patients with no access to technology, like an electronic device or the Internet, making it impossible for them to use a digital diary. Most (10/12) were concerned about the older population, who mainly own flip-phones, if they even own one, and who are also often technologically illiterate (4/12). Some (3/12) explicitly mentioned that it would be no problem for staff to write in a digital environment, since they're already used to writing in the electronic medical record. Participants (4/12) also commented about many patients being poor, uninsured or even homeless and therefore having no electronic devices:

> "But in, especially the burn unit (ICU specialized in skin burns) that I work on, mostly, the people that we see are very poor, often homeless, ... a lot of them don't have a smartphone. I'd say, like, most of our patients don't have a smartphone. If they have a cell phone at all, it's often not a smartphone. So that would be you know, that kind of eliminates the option." (Camila, 30)

The latter issue will be discussed in greater detail in the following section on structural concerns.

2.2. Structural Concerns

Some of the expressed concerns were related to macro circumstances of the USA, like the inequality between rich and poor, the number of uninsured people, the linguistic barrier, and the for-profit

healthcare system.

Many uninsured (12/12). All participants acknowledged that there are many uninsured people living in the US. The majority of participants (10/12) didn't see this as a problem regarding DD accessibility and usage, though. Participants said that their hospitals have strict ethical guidelines about providing the same care to everyone, no matter what their insurance status is, meaning that uninsured patients would get access to the DD too. However, this is only the case if hospitals are the ones paying for the digital diaries. Some participants (3/12) insisted on the fact that hospitals should foot the bill, because both uninsured and insured patients would most likely decline a DD if they needed to pay for it themselves:

> "I think that if you tell a patient that this would be an out of pocket expense for them. I think that 9 out of 10 patients would say "No, I'm not going to do that then"." (Chloe, 35)

My data suggests that hospitals are willing to pay for the diary if they see the value of it. But even if the hospital is paying for it, uninsured patients might still be hesitant in using the DD, because they're afraid it will cost them (2/12):

> "I could see family members, especially our poor family members, like avoiding it, thinking that they'll have to pay for it. Because the way American hospitals work is they bill you later. And so you get charged for things that you don't realize. Even though this wouldn't be of charge, I could see the perception being that there would be a price to it." (Camila, 30)

Language (7/12). Many participants said that a significant proportion of patients don't speak English, in some cases over half of all ICU patients, meaning that a significant group of patients and family will be excluded from using a (digital) diary. Some (2/12) brought up the fact that Americans in particular are not great at second languages, especially when compared with the Netherlands. In the Netherlands, most patients speak Dutch, but when that's not the case, staff is usually able to communicate in English, presumably making them able to communicate with a wider range of nationalities. To solve this problem, most American hospitals use so-called 'interpreters' which are devices that translate speech to any other language, thereby enabling staff to communicate with different nationalities. However, this device only helps with speech, causing diary exclusion to persist.

Spanish was the most prevalent among non-English speakers, but there were also references about Russian, Arabic, Cantonese, Vietnamese, Nepalese, Burmese, and Chookies. One participant pointed out that non-English speakers end up on the ICU relatively often, because of their lifestyle:

> "We found that over half of our patients with Covid, because they're the ones most likely to have service-based jobs or be without insurance or unable to follow social distance guidelines, because they live in multi-generation households, who are most likely to get sick. So in any day, I may have one English-speaking patient and eight that either speak Spanish or Cantonese or some other language, so I would say that that is a barrier to implementation." (Charlotte, 38)

N.B. Since it's a requirement to speak English to serve in the military, all patients in veteran hospitals speak English. The linguistic barrier described above will therefore not be present in veteran hospitals.

Money-Focused USA (5/12). There were some remarks (3/12) about the fact that the American healthcare system is for-profit, money-focused and productivity-driven, which makes it hard to get funding for 'extras' in healthcare, like diaries. Also, hospitals are always looking for other cheaper solutions, even though the solution presented is only pennies on the dollar (2/12):

> "I think, just our health system in general being like for-profit um is, you know, time is money versus like a universal healthcare system. I think that's a little bit of the push for us to not take on new interventions or take on new tasks is we're, we're so limited with our staffing, we're so limited with our resources that really like every minute has to be 'best bang for your buck'." (Sophia, 34)

Inequality (5/12). The topics presented in the 'structural concerns' section seem to be connected. There is a substantial group of people that isn't too wealthy (i.e. low on social determinants), including many non-English speakers, who cannot afford to be insured or own an electronic device, thereby missing the opportunity to use a DD. For this reason, some participants (3/12) believe that the diary wouldn't be successful in impoverished areas where citizens have lower socioeconomic status (SES):

> "America has a lot of like, barriers, we call it social determinants of health. You know, do they have food? Do they have housing? Do they have any financial income? So I think it's kind of like Maslow's hierarchy of needs, right? Where if you don't have shelter, and you don't have food consistently, this diary is going to be difficult to maintain. I bet there's a correlation between like when the social determinants of health are low, their ICU diary use would be low ... So, of course, like many tools in health care, what's most necessary for certain groups, it's harder to get them to adapt, because they don't have the same resources." (Evelyn, 39)

Healthcare expert Miles (64) believes that supplementary services like a DD would not only have less of a chance in impoverished areas, but also in impoverished hospitals, like public or city hospitals where 95% of patients have no insurance:

> "Well, for example [Hospital A] is a city hospital, so that means the salary of everyone who works there is lower, so you get a different kind of nursing; you go to different kinds of patients. In [Hospital A] 5% of patients has insurance. [Hospital B] is a private, academic hospital where 5% has no insurance, which means you serve a completely different population over there. ... Look, [Hospital B] is rich enough to give the 5% who are uninsured a diary, but for [Hospital A] that could well be a significant financial barrier, as the vast majority is uninsured." (Miles, 64)

According to Miles, this inequality in healthcare access is normal practice in the US, referring to ingrained American meritocratic beliefs:

> "'Then you simply should have tried harder in college' [shruggs] Yes, people believe it's your own fault." (Miles, 64)

2.3. Concerns regarding a digital diary based on perceived problems in paper diaries

Many participants ran into problems with the paper diaries which they thought were likely to occur with digital diaries as well:

Lack of time (10/12). Almost all participants made statements about staff being too busy to do that extra task of writing in a diary. Many participants (5/12) mentioned that especially the nurses are swamped, which often causes them to not use the diary at all:

> "Nurses are always the ones that are, kind of, tasked with things, like "oh let's implement this, the nurse will do it" or "oh let's do this, the nurse will do it", so it was perceived as just another thing on the long, long list of to do's, right, it was very overwhelming." (Sophia, 34)

The diary was often seen as a burden, because staff already had to write in the medical record and felt irritated about the fact that they needed to 'document twice' (5/12). However, some (2/12) believed that a DD might mitigate this problem:

> "Probably the biggest issue for the clinicians in particular was "I'm documenting twice", ... We have a total electronic medical record so I think that would be a plus, because you're already there, but I think the minus would be, I already wrote "blah blah blah" and now I have to write it in, you know, simpler terms um for the patient." (Elizabeth, 67)

Lack of buy-in (8/12). One of the main problems that participants encountered with the paper diaries is a lack of staff buy-in, which is partly caused by the previous point of them being too busy. One participant said that it could have something to do with physicians not being the 'touchy-feely type'. Others (2/12) said that Americans don't want to be told what to do, and that staff needs to see the benefit of it in order to use it:

> "They [staff] kind of have to discover like "Okay this really does benefit my patient, so therefore I choose to do it" versus somebody telling me um so I think um that is something that's unique about American healthcare, all right in American culture is um people don't like being told what to do, which is very hard [chuckles]". (Charlotte, 38)

However, some (3/12) thought that a DD actually would increase staff buy-in, because writing digitally is way faster than using pen and paper:

> "And so having it be online, I can type so much faster than I can write, and you can type and delete, and it's not so stressful. And so yeah, see, I think that that would be helpful and that people would be more encouraged." (Eve, 36)

Lack of awareness (3/12). Another concern was about the fact that a lot of staff members aren't really aware of the presence of diaries and therefore did not use them. Participants (2/12) imagined that this would be an even bigger problem with digital diaries, because these are not physically in front of them, whereas a physical diary would serve as a visible reminder:

> "But I would put the diary next to my notebook, so that I would remember to write in at the end of the day. If again, if it's *out of sight, out of mind*, what would make me go to it, it might be harder to get people to do that." (Madison, 37)

A physical diary was not only regarded as a reminder for oneself, but also to give to other staff, thereby reminding them to write in it (1/12).

Ease of access (6/12). This topic touches upon all three previous topics. Participants claimed that if the DD was easily accessible for staff, both awareness and buy-in would increase, partly because it would take less time to get to the diary. The often proposed solution was to create a link in the electronic medical record to the DD:

> "You can't have it take too much time. So if there's a little way that you can easily click on to it and just write a little note, ... more people will be able to do it." (Luna, 36)

However, healthcare expert Miles (64) says that a link to an external website inside of the medical record is regarded as a "big no-no" by the hospital's IT department, because it will jeopardize the "security, confidentiality of data". Ironically, some participants (3/12) believe that a DD would make access easier "because you're already there" for the medical record.

3. ICU Organization

All participants (12/12) said that they have intensivists on their ICUs, but this didn't necessarily improve communication (5/12). Some said that it depends on the intensivist whether communication improved or not. According to healthcare expert Miles (64), American ICUs are "a mess" compared with Dutch ICUs, regardless of the presence of intensivists. Miles says that American ICU staff believe that they apply the closed format with intensivists being in charge, but in reality, the unit is still very much open, resulting in 'too many cooks in the kitchen' (7/12):

> "So we have a primary team that kind of manages everything, but then we have all these consulting teams so orthopedics, neurology, plastic surgery, whoever, and communication can be challenging because you have so many specialists working on one case that sometimes family doesn't always get the um the full message, because there's just so many kind of 'cooks in the kitchen'" (Sophia, 34)

They all (12/12) agree on the fact that this, among other things, results in diverging stories being told to family members. However, while Miles believes that this would also lead to "chaos" in the DD, actual users of paper diaries (4/12) claim that this wouldn't be a problem in the digital one. Usually, family members are confused because of diverging stories about the *future* of the patient, presented orally. They are confused about what's going to happen to their loved one. Whereas the contents of a diary are mostly about things that already happened:

> "I also think that a lot of times, we tend to write about what already happened, as opposed to what the plan is. And I think a lot of times the confusion comes in the planning piece of like, here's all the things to expect today." (Camila, 30)

Ironically, some participants (2/12) noted that the diary actually helped the family to make sense of the diverging stories:

> "I don't feel like it was causing problems with conflicting information. I think the diaries were helping them to understand what they were being told, because you're writing everything down in the diaries in simplified non-medical terms." (Chloe, 35)

Also, one nurse even believed that written text is less subject to change than spoken words, resulting in less diverging stories.

> "But I think, also when we have multiple family members calling and you tell them the same story, but in their heads, they came up with two different things. So when it's in writing, and they both read the same thing, I think it will be more clear. And I think as you move forward in your journey, your story kind of evolves. And by having something written down two years from now, it's the same story as it was a year from now." (Eve, 36)

Discussion and Conclusion

The purpose of this study was to map the views of American ICU staff on digital diaries, explain what macro factors explain these views, and advise GFH on how to improve the DD accordingly. As was noted in the results chapter, most participants were rather positive about both paper and digital ICU diaries. However, if even the most optimistic ICU staff come up with several concerns and barriers regarding a DD, they should be taken very seriously. In this chapter, I will discuss all of these findings combined with relevant theory.

Macro. Both data and theory agree on certain national, macro-scale problems, like (healthcare) inequality between rich and poor, and many uninsured US citizens (Pickett & Wilkinson, 2015; LiPuma & Robichaud, 2020). People that score low on social determinants, including many non-English speakers, cannot afford to be insured and miss out on good healthcare services like a DD, which is supposedly their own fault. What's more, this disadvantaged group of people is also more likely to have no electronic device, making it even harder for them to use a DD. Hart's (1971) inverse care law therefore also seems to apply to the DD: "The availability of good medical care tends to vary inversely with the need for it of the population served".

The for-profit nature of American healthcare was also underlined by the participants. People reported that even when the DD is only pennies on the dollar for hospitals and results in major benefits for patients and families, hospitals might still resist to implement it. According to Porter and Teisberg (2006), this can be traced back to the neo-liberal policies of American healthcare, whereupon hospitals want to stay competitive by cutting costs on extras like diaries. My data shows that especially public hospitals, city hospitals, and hospitals in impoverished areas might refrain from purchasing digital diaries, because they have too many uninsured patients and/or simply don't have the financial resources to invest in supplementary services. However, this shouldn't keep GFH from entering the American healthcare market. There are many hospitals that are very much open for innovation, see the Advice chapter.

It is debatable whether it is ethically sound for a country to maintain such inequalities, to let healthcare costs rocket skies, and leave many people without health insurance. According to most participants, though, uninsured people will get to use the DD just like anyone else, because of strict ethical guidelines in hospitals. However, this only applies if the hospital is the one paying for the DD. The unregulated market has made Americans more cost-conscious (Bodenheimer, 2005), which especially makes the poor, uninsured population hesitant in using 'unnecessary services' which they believe they'll have to pay for. This is something that we also saw in Schoen's (2013) research, where 37% of the American population didn't follow up on recommended care because of cost. One could say that the DD costs nothing compared to the rest of the ICU stay, and it will probably be paid for by the hospital anyway, but still, in order to get buy-in from patients and families, it's important to be clear about cost.

Another USA-specific barrier for the DD is the linguistic barrier. Many participants mentioned that up to half of their patients didn't speak the English language, excluding them from using a DD. This is supported by findings of other studies, where non-English-speaking patients also experienced many barriers to access quality healthcare (Pérez-Stable et al., 1997; Erzinger, 1991). This too is no gamechanger for GFH, but there are some things they can do to make the DD accessible to all patients, see Advice chapter.

Regarding the litigiousness of American society, I found that this only partly applies to (digital) diaries. Some people were concerned, because they had been sued in the past or felt that Americans are simply sue-heavy by nature. The latter is in line with the phenomenon reported by Greenhouse (1989), which states that Americans believe in their own litigiousness, even though evidence for this is absent. However, many of the people I interviewed are diary experts by experience who believe that litigation will not happen, mainly because the things that people write in the diary cannot be used in court. Practitioners mostly write in layman terms and don't write about medical values. It's

important to communicate this to potential users in order to get them all on board.

Meso. The data doesn't show a clear connection between the presence of intensivists, communication between staff, and the extent to which diverging stories are conveyed to family members. So the fact that there are fewer intensivists on American ICUs than in Dutch ICUs will most likely not impact the use of the DD. Because practitioners only write about events that already happened, there will be no inconsistent story and therefore no confusion among family members. By some, the DD was even expected to help with diverging oral stories, because it serves as an extra communication channel. This aligns with findings of Perier et al. (2013), where ICU staff also found diaries to be a beneficial addition to oral communication.

Micro. Finally, many topics that came up during the interviews about digital diaries align with prior research on paper diaries, like the lack of staff buy-in, lack of awareness, and lack of time, especially with nurses. The lack of awareness seemed to be an even bigger issue, because the DD is 'out of sight' and therefore allegedly also 'out of mind'. Also, paper diaries were already perceived as a contributor to staff/patient/family communication, but the DD adds the extra advantage of communication at distance. This is especially beneficial in big, spacious countries like the US, where the family often lives far away from the hospital and doesn't always have the resources to travel or grab a hotel.

Conclusion

In closing, the views of the ICU staff involved in this study were rather positive regarding a digital diary. Still, many barriers came up that find their roots in macro-factors, like their fear of being sued, which comes from the American litigiousness. National inequality keeps some hospitals and areas from using innovation like the digital diary, but once a hospital owns it, patients with any kind of insurance status should be able to use it. That is, if they speak English and can afford an electronic device. Most of the discovered barriers can be resolved by adding new features and educating ICU staff and their patients in a different way, which will be covered in detail in the Advice chapter. If GFH succeeds to take on this advice, the digital diary is likely to slowly gain ground in the US and might ultimately be as successful in the US as it is in the Netherlands.

Limitations

Because of recruitment difficulties at the beginning of the thesis, I decided to invite ICU staff of whom I knew that they were already invested in paper ICU diaries. This turned out to be highly successful and helped me gain momentum with participant recruitment, resulting in 12 interviews with American ICU staff. Because no new issues were identified during the last two interviews, I believe that I was close to saturation (Hennink et al., 2020). It should be noted, though, that ICU staff that is already invested in ICU diaries is likely to respond differently to a digital ICU diary than ICU staff that might have never worked with such an intervention, might not believe in it, or might simply have never heard of it. Although, achieving rapport was easier with the ICU-diary-invested participants, because they were very eager to learn more about this new technology from the very start of the interview. This helped with gaining deep insights that otherwise might not have come up. Besides, it was as if they wanted ICU diaries, both paper and digital, to gain ground in the US, because they believed in the power of ICU diaries and wanted more ICU patients in the US to benefit from it.

During the online interviews, I stumbled upon some difficulties, such as connection issues and delay, resulting in simultaneous talking of both myself and the participant. As mentioned earlier, it is also harder to reach rapport with participants when doing online interviews. In an attempt to increase chances of reaching rapport, the video footage of the interviewee was displayed on the upper half of the screen. This caused me to look more towards the camera which is placed at the top of the screen, inducing an increased sense of connection and presumably higher chances of rapport.

Finally, as it is with all qualitative research, it's impossible to generalize findings to the bigger population, which also is not the goal of this type of research. To be concrete, the conclusions drawn above will not apply to all American hospitals, but more importantly, they will especially not apply to American hospitals that have no experience with paper diaries. Also, since I mostly interviewed people working in academic hospitals, the findings will mostly represent that part of American hospitals. Follow-up research would be necessary to determine what other kinds of hospitals, like public, city, or children's hospitals, would think of digital diaries. Moreover, in order to really say something about the system-level, it would be better to interview people that are a bit higher up in American hospitals, like clinical program coordinators and directors. Although it helps if ICU staff is enthusiastic about the intervention, in the end, the people higher up in the organization are the ones who decide if innovation like a DD is worth implementing or not.

Advice

First of all, in order for all American citizens to be able to benefit from digital ICU diaries, structural change is necessary. My advice for the US government would be to tackle income and wealth inequality, for instance by applying more progressive taxation (Oishi, Schimmack, & Diener, 2012). Research has shown again and again that narrowing the gap between rich and poor will improve health and well-being (Pickett & Wilkinson, 2015). I would also propose to implement any form of universal healthcare like other industrialized countries, causing all citizens to have insurance, to have equal access to good healthcare, and take away worries regarding costs (LiPuma & Robichaud, 2020; Vladeck, 2003). That being said, the rest of this chapter consists of advice for Games for Health.

Multiple important considerations for ICU diary implementation in America were identified. In this chapter, I will only present the advice that corresponds with previously discussed concerns and barriers. In Appendix C, these and supplementary findings will be presented in a concise table.

Making the digital diary accessible to everyone

As said before, there's a relatively big gap between rich and poor in the US, which causes many disadvantaged citizens to have no electronic devices. Participants (5/12) proposed that hospitals should get iPads or Chrome Books in the ICUs in order for everyone to be able to use the DD. Second, a print option (5/12) would solve the problem of underprivileged people who do not own an electronic device and would also solve the problem of the older generation preferring paper over anything else, according to Elizabeth (67). And third, hospitals can still initiate a paper diary if, for whatever reason, a digital diary doesn't work for the patient or family.

In addition, uninsured patients tend to be afraid of hospital costs and might not want to use the DD for that reason. Therefore, it should be clear to patients and family that they will not be the ones paying for the DD.

In order to overcome the linguistic barrier, many hospitals have interpreters, which are devices that translate spoken words to English and vice versa. There might be a unique opportunity for GFH to build a similar translation feature into the DD, which not only makes sure that the diary is accessible to everyone, but also improves communication between staff and non-English-speaking patients and families, thereby increasing patient satisfaction (Betancourt et al., 2016).

How should staff write?

In order to mitigate litigation concerns among staff, it should be clear to them that they will not write about medical values, i.e. nothing to be sued over. They will mainly write about events that happened that day, in simple language for family and patient to comprehend. Additionally, some participants (4/12) mentioned that they let the patient sign a consent form before initiating a diary, which is a solution to litigation concerns also used by Rogan et al. (2020). Rogan et al. (2020) used a shorter version of a consent form, called a 'Participant Agreement', because a long, all-encompassing consent form made diary initiation neither straightforward nor easy. In the case that a patient is unconscious at ICU admission, the family could sign the form instead. Since the diary is digital, you might even think of a (short) 'terms of use', which the user must agree to in order to use the diary.

Staff should be educated on how to write: write about things that already happened in order to prevent inconsistencies between entries of different staff members. Also, look at entries from other staff members before writing in order to get all entries aligned. Write in simple language and do not write about medical values in order to depict a comprehensible story for patient and family and to deprive staff of litigation worries. Prompts might help steer staff in the right direction. One tip from Elizabeth (67) is to write as if you're talking to a 10-year-old.

Overcoming the lack of buy-in/awareness/time among staff

Writing in a diary was often regarded to be a burden, because it takes too much time and staff (especially nurses) is already very busy. During data collection, I came up with the idea of incorporating audio recording into the DD, which sparked enthusiasm with many participants (5/12). It would be faster for them to leave a quick message and they also found it to be really valuable for the patient, because there's more feel to it: "I think being able to hear recording, or to see a video, like, that would be amazing. Because they might be sedated, and they might be sleeping, but to hear their loved ones' voices. I mean, like, I think that makes a huge impact" (Emily, 41).

In addition, staff would be able to use the interpreters to say something in English and then the translated message from the interpreter can be recorded into the DD, mitigating the language barrier without putting resources in a translation feature in the DD. One participant pointed out, though, that it might be unpractical due to fairly loud noises on the unit.

To solve the 'Out of sight, out of mind' problem, it could be helpful to put signs somewhere around the patient's bed, which would serve as a reminder for staff to write in the DD. A QR-code could be printed on this same sign in order to make the DD more easily accessible. Some participants (2/12) said that this would enable staff to quickly write a little note in the diary by scanning the QR-code with their phones. Another solution that was backed up by many participants (6/12) was a link in the medical record that directs staff to the DD immediately.

Lack of buy-in among staff: according to participants (3/12), staff buy-in mostly increased when there is (at least) one 'champion' who is a real believer in and ambassador of the diary and therefore keeps reminding others to write in it. Occupational therapists would fit this role best, according to participants. Buy-in also increased after staff saw with their own eyes how much a diary could mean for the patient and family (5/12). An easy and cheap way of increasing staff buy-in is by creating a prompt for patients and families, after treatment, that says something like: "Would you like to tell nurse Amber how much the digital diary helped you? Do you appreciate the effort she put into it?" When this message gets to Amber, this might increase her buy-in and enthusiasm. Also, GFH might use inspirational stories of ICU staff to get buy-in from new hospitals and staff. I put some examples of stories in Appendix D.

Who should introduce the digital diary and when/how/where?

The introduction of a DD to patient and family should be done by nurses (6/12), because they are with the patient 24/7, while all other practitioners rotate. Emily (41) adds that nurses develop a great deal of trust with the patient, so if their personal nurse recommends them a DD, they're more likely to participate. Although, others (3/12) do believe that the occupational therapist would be most likely to take on the champion role, since their focus is on cognitive rehabilitation already. Besides, nurses are already swamped with many other tasks (Kendall-Gallagher et al., 2017), causing them to see little priority in diaries. One other interesting candidate for DD introduction is the so-called "chaplain", which is a spiritual caretaker of patients and has the "emotional background and emotional training, social training to provide support". My advice would be to let the nurse introduce the diary, because they are there from the very start of the ICU stay and know best what patients are suitable for the diary and will benefit from it. Afterwards, occupational therapists and chaplains, even social workers (2/12), should get involved to keep the momentum going.

The nurse should introduce the diary as soon as possible. To make introduction as fast and easy as possible, a pamphlet with basic information and QR-code should be handed to the patient and family at ICU admission (2/12), similar to what GFH provides to patients in the Netherlands.

Most participants (9/12) thought that a DD would be most successful in big, urban, academic hospitals, because of their openness to new, evidence-based interventions (8/12), and their wish to be the front-runners of all hospitals, whatever the cost (1/12). Some (4/12) thought that it would also work in smaller, community hospitals, because there are more nurses per patient and more time for

extras. However, others (3/12) pointed out that there are simply not many ICU beds in community hospitals and very few really sick patients who stay long enough to need a diary. Staff of community hospitals is also more conservative and less likely to try new interventions.

Presentation of the DD to new hospitals

Finally, participants also provided insights that can be used to present the DD to hospital boards in a better, more convincing way:

- In the US, hospitals make decisions based on quality indicators, such as depression among patients and readmission rates. If you can convince hospitals and staff that digital diaries help to score better on those quality indicators, that would be a great way to get buy-in: "Hey this could be a great benefit for your patients, because they will address mental health and their ability to be more likely to return to work and be more functional, so they are therefore healthier and less likely to be re-admitted to the hospital" (Charlotte, 38).
- The DD results in better communication between staff and family, resulting in higher patient satisfaction (Perier et al., 2013; Betancourt et al., 2016). This is especially beneficial in big, spacious countries like the US, where families often live far away from the hospital and don't always have the resources to travel or grab a hotel. The DD might even function as a substitute for lengthy phone calls with family members, causing staff to save time and decrease work pressure.
- Many participants mentioned that the paper diary was neglected during Covid-19. The DD can be presented as a solution to this and future pandemics.
- The name "Post-ICU" suggests that the diary is mainly meant for aftercare. One participant, however, found this to be inaccurate, because the diary very much also helps *in* ICU: "I think just mentally I have tried to help people shift from a post-ICU mentality to an in-ICU mentality, like, what can we do for this person right now while we're saving their life. Not just after we saved their life and keep them engaged in their care, keep their family engaged and prevent this huge cognitive decline that can happen" (Emma, 30).
- The DD is not in one place, making it accessible for both staff and family at the same time. And equally important, the DD cannot be lost.
- Pictures of patients' ICU stay can be easily added, which helps with filling in the gaps of the whole ICU experience, therefore making them able to get back on track faster.
- It could be presented as part of the **ABCDEF** bundle, which is gaining ground in the US: "**A**ssess, prevent, and manage pain; **B**oth spontaneous awakening and breathing trials: **C**hoice of Analgesia and Sedation; **D**elirium assess, prevent, and manage; **E**arly Mobility and Exercise; **F**amily engagement/empowerment" (Pun et al., 2019)).
- Almost all participants (10/12) used the word 'diary' or 'ICU diary' when they referred to their own initiated paper diaries, instead of the by GFH advocated word 'journal'. Furthermore, almost all research I read about the intervention also used the word 'diary' (Mickelson et al., 2021; Jones et al., 2010; Rogan et al., 2020; Drumright et al., 2021; Blair et al., 2017; Garrouste-Orgeas et al., 2012; Barreto, Luz, de Oliveira Rios, Lopes, & Gusmao-Flores, 2019; Perier et al., 2013). This makes me believe that the alliterative 'Digital Diary' might land better in American ears than 'Digital Journal'.

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Appendices

A. Topic list

Table 5: *Topic list*

Core concept	Dimension	Topic
Experience	◇ Paper diaries	◇ Before Covid-19
		◇ During Covid-19
	◇ General attitude towards diaries	◇ Paper diaries
		◇ Digital diaries
Benefits	◇ Not losing it	◇ It's not in one place
	◇ Works from a distance	◇ Improving communication
	◇ Include pictures	◇ Helps with recovery
Concerns based on cultural barriers	◇ Litigiousness	◇ Fear of suing among staff
		◇ Legal department
	◇ Patient privacy	◇ Hacking
		◇ HIPAA
	◇ Writing digitally	◇ Digital is better
		◇ Paper is better
Concerns based on structural barriers	◇ Inequality	◇ Low SES
		◇ Meritocracy
		◇ Social determinants
	◇ Uninsured	◇ Equal access for all?
		◇ Fear for cost
	◇ Language	◇ Second languages
		◇ Non-English-speaking patients
Concerns based on paper diaries	◇ Lack of awareness	◇ Out of sight, out of mind
		◇ Harder to spot
	◇ Lack of buy-in	◇ Defiance among staff
		◇ Americans don't want to be told what to do
	◇ Lack of time	◇ Burden
		◇ Double documentation
		◇ Swamped nurses
	◇ Ease of access	◇ It's digital instead of laying in plain sight
ICU organization	◇ Presence intensivist	◇ Open/Closed format
		◇ Communication
	◇ Division of professions	◇ 'Too many cooks in the kitchen'
		◇ Diverging stories from different practitioners
		◇ Impact on DD
GFH	◇ What should be included in the DD	◇ Features
		◇ Education
	◇ Who should introduce the DD and when?	◇ Nurses
		◇ Occupational therapists
		◇ Physical therapist
	◇ Where is the DD most likely to be either a success or a failure?	◇ Academic/nonacademic
		◇ Urban/rural
		◇ Private/Public

B. Codebook

Table 6 shows all codes, subcodes, etc. that emerged from the 12 interviews with American ICU staff. As you can see, there is a hierarchical structure to it, in which the bold headcodes correspond with the respective themes in the Results chapter. For each code, the P-value represents how many participants mentioned it and the R-value represents how often it was reported by these participants.

Table 6: *Codebook*

Code	P	R
0. Experience	0	0
▷ Experience with ICU diaries	11	12
▷ ICU Diary was less successful during covid	6	6
▷ ICU Diary was successful during covid	3	4
▷ General attitude towards icu diaries	0	0
▷ Negative attitude towards digital icu diaries	2	3
▷ Positive attitude towards digital icu diaries	9	14
▷ Positive attitude towards paper icu diaries	11	13
1. Benefits	0	0
▷ Not losing it	6	7
▷ Fits in with American Social Media Culture	5	6
▷ DD is mostly for the young	2	3
▷ Include pictures (if stored in compliance with HIPAA)	7	9
▷ Staff is already on the PC for the medical record	3	3
▷ Families can use the DD from home	0	0
▷ Big cities can be overwhelming and expensive for family to stay	1	1
▷ Easier buy-in from families because they can do it from home	1	1
▷ Family members can take over the writing if staff's busy	1	1
▷ Great for communication with family who comes from afar, limiting phonecalls	7	12
▷ Some staff would like if family is more at home	1	2
▷ No bad handwriting issues	2	2
▷ Easier to access because it's not in one place	3	3
▷ It works better during pandemics	2	3
2.1 General Concerns	0	0
▷ Customer is king; little trust + respect for experts	1	4
▷ Litigiousness	4	8
▷ Legal department of hospitals will resist	1	1
▷ No fear of suing	5	6
▷ FBA nurses can't be sued	1	2
▷ No fear because the diary is sacred to patient and family	1	1
▷ Patient Privacy; Hacking	10	13
▷ DD should be HIPAA complient	2	2
▷ Patient Privacy regarding other familymembers	2	2
▷ Privacy is less of an issue with DD	1	1
▷ Technological barrier	6	9
▷ No worries regarding staff, but regarding family	3	3
▷ Flipphone; Because of age	10	11
▷ Technological illiteracy	4	5
▷ No phone; Because of money	4	5
▷ Writing in a DD instead of a paper one	0	0
▷ Positive	8	13
▷ Negative; writing on paper is better	2	6
▷ Writing on paper is faster (especially for older staff)	2	4
2.2 Structural Concerns	0	0
▷ Language	0	0
▷ Americans are not good in second languages	2	3
▷ Language is not a problem at veteran hospitals	2	2
▷ People from different ethnic backgrounds live in similar areas of the country	1	1

▷ Significant proportion of patients doesn't speak English	6	8
▷ Non-English speakers are on ICU more because of lifestye	1	1
▷ Money-Focused USA	2	2
▷ For-profit results in not taking on new interventions	2	3
▷ Funding for 'extras' in healthcare is hard	3	4
▷ Many Uninsured (will also get to use the DD)	10	13
▷ Insured or Uninsured, the hospital should be the one paying for the DD	3	3
▷ Patients might be hesitant because they think it'll cost them	2	4
▷ Inequality	0	0
▷ DD will not work in low SES areas + hospitals with many uninsured	3	4
▷ Homeless people often don't get a diary because of psychiatric problems	1	1
▷ Meritocracy	1	1
▷ Social determinants of health determine if DD is used	1	2
2.3 Concerns regarding a DD based on perceived problems in paper diaries	0	0
▷ Lack of awareness	1	2
▷ Handing the diary over to other staff (as reminder) is hard	1	1
▷ Out of sight, out of mind	2	4
▷ Ease of access	6	13
▷ DD linked to the electronic medical record (usually epic)	6	11
▷ DD linked to electronic medical record is not gonna happen	1	1
▷ Americans are not good at expressing emotions	3	4
▷ Lack of time; it's a burden	9	11
▷ 'Double documentation in layman terms'	5	8
▷ It should be 'Fast and Easy'	2	2
▷ Nurses; 'oh let's implement this ... the nurse will do it'	5	9
▷ Lack of staff buy-in	7	11
▷ Americans don't want to told what to do	2	2
▷ Defiance; Unwillingness to change among staff	1	1
▷ Typing is faster than writing which increases buy-in	3	3
3. ICU Organisation	0	0
▷ Cummunication between ICU staff	0	0
▷ It depends on the intensivist if communication is better	1	1
▷ Communication is not great, but has nothing to do with the intensivist	5	6
▷ Intensivist does improve communication	2	2
▷ Diverging stories from different ICU staff	12	15
▷ Division of professions; 'too many cooks in the kitchen'	7	9
▷ Compared to NL, American ICUs are an organisational mess	1	1
▷ American hospitals claim to have closed ICUs, but they are not	1	3
▷ Intensivist	0	0
▷ Relevance intensivist for cohesive story	2	2
▷ Nursing staff is the heart of stability; consistency on a unit	1	1
▷ Everyone will have their own lens anyway	2	2
▷ There isn't a lot of interaction between intensivists and staff	2	2
▷ Intensivist present	10	12
▷ Intensivists rotating across units	4	4
▷ Will diverging stories be problematic	0	0
▷ No diverging stories, because we write not too detailed and retrospectively	4	4
▷ Divirging stories will be problematic	2	3
▷ The diary actually solves the diverging stories	2	5
4. GFH Advice	0	0
▷ Implementation	0	0
▷ Buy-in from hospital administration/system is key	2	3
▷ Education of ICU Staff	6	10
▷ Education on how to write	5	7
▷ Education on privacy	1	1
▷ It's not 1 app, located on 1 phone	3	5
▷ Most effective way to roll out the DD is via the insurance companies	1	1

▷ Improvements	0	0
▷ (Convincing hospitals by) presenting it in a different way	0	0
▷ Present it as part of the F(amily) in ABCDEF	2	2
▷ Prevents delirium	1	1
▷ Prevents further hospitalization	1	1
▷ Show evidence that it works	2	2
▷ Too much focus on AFTER-ICU, too little on IN-ICU	1	2
▷ Use 'Quality indicators'	2	3
▷ You don't have to call family, you can just communicate using the DD	7	12
▷ DD should be build into the daily rounds	1	1
▷ DD should be different for coasts than for midwest	1	2
▷ Solutions for diverging stories	0	0
▷ Include familiemembers in daily rounds	2	4
▷ Looking at other entries before writing in it	1	1
▷ Staff should write retrospectively	4	5
▷ Solutions to awareness; ease of access issues	0	0
▷ Sign at bedside + QR code for staff to access the diary using their phones	2	3
▷ Electronic devices on units for Staff	1	2
▷ Link from the medical record to the DD (See 2.3 Concerns)	6	11
▷ Link to DD for staff to remind one another to write in it	1	1
▷ Reminder; notifiation	1	1
▷ Solutions to lack of buy-in	0	0
▷ Convince 1 (or2) person, like a champion, then buy-in will trickle down	3	5
▷ Show evidence to staff that it doesn't take much time and that it works	1	1
▷ Staff buy-in increased after bedside nurses bought into it	1	2
▷ Staff buy-in increased after they saw the benefits from their own experience	5	5
▷ Solutions to litigiousness	0	0
▷ Consent form; agree to the 'terms of use'	4	5
▷ Patient cannot give consent to the DD when unconcious	3	3
▷ Solutions to technological barrier	0	0
▷ Electronic devices on units for patient + family	5	6
▷ Using the paper diaries alongside the DD	1	1
▷ There should be a way to transfer diaries from one floor to the other	1	1
▷ Interesting stories	0	0
▷ Staff was actually about to create a digital diary themselves	1	1
▷ The ex-soldier who still believed to be at war	1	1
▷ Young girl going from almost dead to walking out of the hospital	1	1
▷ Young guy going from being hit by a car to married, two kids	1	1
▷ Introduction to patient and family	0	0
▷ Initiation by using a pamphlet	2	5
▷ Staff tells them the basics, QR code takes them to additional info	1	2
▷ When	0	0
▷ Diaries are provided to patients who are here for a long time	3	4
▷ Diaries are provided to patients who are very delirious	4	4
▷ Initiation as soon as possible	4	4
▷ Introduction happens the first time the practitioner sees the family	1	1
▷ Keep reminding family of the diary when they were reluctant to use it at first	1	1
▷ Who	0	0
▷ Anybody can do the initiation	1	1
▷ Initiation by chaplains	2	3
▷ Initiation by nurses	6	7
▷ Initiation by social work	2	4
▷ Initiation by some sort of secretary or admin	1	1
▷ Initiation by 'Therapy' (e.g. OT)	4	5
▷ New areas	0	0
▷ Children's hospitals	1	1
▷ Post-ICU clinics	1	1

▷ Rehab	1	1
▷ Transplants	1	1
▷ Other ideas that came up	0	0
▷ Caringbridge.com	2	2
▷ Example document of paper diary	1	1
▷ Successfulness	0	0
▷ DD will work better at the (liberal) coasts, because of better emotional expression	1	1
▷ DD will work better in (big, urban) academic hospitals	9	12
▷ Oppenness to new, evidence based interventions	8	10
▷ High turnover rate; new people come in, new things come in	1	1
▷ Wanting to be the best, no matter the cost	1	1
▷ DD might not be as succesfull in veteran hospitals	1	1
▷ The language issue will not occur in Veteran hospitals	1	1
▷ DD might not work in hospitals that are not doing well	1	1
▷ DD will not work in low SES areas or hospitals with many uninsured people	3	4
▷ DD will work better in community (smaller, rural) hospitals	4	5
▷ DD wil do exeptionally well in community hospitals	2	3
▷ DD will work better in smaller hospitals because there's less people to educate	1	1
▷ Less patients, more time to implement, but also little need for diaries	1	1
▷ DD would work less well in community (smaller, rural) hospitals	5	8
▷ Community hospitals have fewer (really sick) patients	3	3
▷ Conservative staff	1	2
▷ Slow at picking up new tech	1	1
▷ Especially those that provide care for underserved	1	1
▷ They have less money	1	1
▷ Hospitals to start implementation	2	2
▷ Interesting conferences + organisations	1	1
▷ Things that should be included in the diary	0	0
▷ (Ideas for) prompts	7	9
▷ Ability to adjust size or contrast, because of bad vision during ICU stay	1	1
▷ Calander should play a prominent role (for delirium prevention)	5	9
▷ Goal setting; makes patients do their excercises better	1	1
▷ Location should play a role too	1	1
▷ Digital clock	1	1
▷ Drawing feature	1	2
▷ Education on different ICU staff professions	1	1
▷ Education on ICU devices	1	1
▷ Education on PICS or Delirium	1	1
▷ Include audio recording, if stored in compliance with HIPAA	5	6
▷ Cool, but unpractical due to loudness and privacy	1	1
▷ Voice to text software	1	1
▷ Names and pictures of ICU Staff	2	2
▷ Print option	5	7
▷ The option for family to invite others to the diary	1	1
▷ Translation function (at least Spanish)	4	6
▷ Video feature	1	1
▷ 'What do I want other people to know about me'	2	3

C. Advice in a nutshell

Table 7: *Recommendations and supplementary ideas for DD initiation in the US*

Topic	Recommendation
Technological barrier	◇ Electronic devices on ICUs
	◇ Print option
	◇ Keep option for paper diary open
Worries regarding costs	◇ Hospitals should pay for the DD
	◇ Communicate towards patients that it won't cost them anything
Linguistic barrier	◇ Translation feature
	◇ Interpreters in combination with audio recording feature
Litigation concerns among staff	◇ Let patients (or family) sign informed consent or agree to terms of use
	◇ Staff education: Don't write about medical values, use simple language
Introduction of DD to patient	◇ Nurse should introduce it; OTs, chaplains and social workers follow along afterwards
	◇ Pamphlet with QR-code
DD success	◇ Start with DD implementation in big, urban, academic hospitals
Lack of staff buy-in	◇ Assign a champion who reminds others to write in the DD
	◇ Make sure that positive feedback from patients and families is forwarded to staff
	◇ Use inspirational stories from staff of other hospitals to get buy-in from new hospitals
Lack of awareness	◇ Sign next to the bedside with QR-codes on it for staff to get easy access
	◇ Direct link to the DD in the medical record
Lack of time	◇ Audio recording
Presentation of the DD to hospitals	◇ Use quality indicators to prove the added value of the DD
	◇ DD results in better communication between staff and family and therefore in higher patient satisfaction
	◇ Substitute for lengthy phone calls with family
	◇ Better solution during pandemics
	◇ Put focus not only on post-ICU care, but also on in-ICU care
	◇ Accessibility for multiple users at the same time
	◇ Option of adding pictures
	◇ Might be presented as a part of the ABCDEF bundle
	◇ Possibly using the word 'diary' instead of 'journal'
Things that should be included in the diary	◇ An 'All about me' section, where the family writes about what the patient likes and dislikes, how they like to be called, music taste, etc; things for staff to talk about with patient (2/12)
	◇ The calendar should play a prominent role, because of delirium prevention (5/12)
	◇ Calendar can be used to set goals, making patients do their exercises better (1/12)
	◇ Because of occasional bad vision during the ICU stay, it would be good to be able to adjust size or contrast of the DD (1/12)
	◇ A digital clock in order for delirious people to get a grip on time (1/12)
	◇ Information on different ICU practitioners and their roles (1/12)
	◇ Information about ICU devices (1/12)
	◇ Education on PICS or Delirium (1/12)
	◇ Names and pictures of ICU staff (2/12)
	◇ The option for family to invite other close ones to the diary, because they get tired of everyone asking about it (1/12)
	◇ Drawing feature (1/12)
	◇ Prompts (see below)
Prompt suggestions	◇ Prompts that cause any expectations for patient and family, like prompts about the future, should be avoided.
	◇ Daily events
	◇ Words of encouragement
	◇ Did they progress/regress today?

	◇	Make a picture of a postcard or artwork that a grandkid made
	◇	Is family present?
Service similar to DD	◇	CaringBridge.org
New areas for DD	◇	Children's hospitals
	◇	Post-ICU clinics
	◇	Rehabilitation clinics
	◇	Transplantation department.
Recommended hospitals for DD implementation	◇	Johns Hopkins
	◇	New York Presbyterian (both Columbia and Cornell)
	◇	New York University (NYU)
	◇	University of Chicago
	◇	Northwestern Memorial
	◇	Tampa General
	◇	University of Southern Florida
	◇	Duke Health
	◇	Emory Atlanta
	◇	Cleveland Clinic
	◇	Mayo Clinic
Interesting organizations	◇	World Federation of Occupational Therapy (WFOT)
	◇	American Occupational Therapy Association (AOTA)

D. Inspirational stories to increase buy-in

According to social psychologist Cialdini (2001), people follow the lead of similar others, especially if they know them personally. In other words, "influence is often best exerted horizontally rather than vertically". Stories like the ones presented here might help with increasing buy-in among staff.

> "In MICU (Medical Intensive Care Unit) there was this one patient. And she was, I don't remember what her diagnosis was. But she was there for like three and a half months in the intensive care unit. And she had a horrendously difficult medical course. And because of that, her mom was there a lot. But there was nothing that her mother could do for her. And as a mom, that is the most helpless feeling you have. So therefore, then she's on the call all the time. And, you know, picking up little stuff, because that's the only thing she can do. And when we gave her the diary, she then had a reason to sit there and do something. And it really changed the interactions between her and the staff, because she could write down what was going on. So her daughter would know how she was feeling as a mom, and well we never read it, because it's really the patient and family's diary. When we weren't, when we got to the point where she actually asked the nurses to write down their thoughts. I mean, this young girl went from being really on death's door to walking out of [the hospital]. But as the nurses saw her progress, then they could also add their stories to it. And it just changed the whole dynamic between the family and the staff. And once the nurses saw that, then they began to buy-in more, you know, like, this really is worth the five minutes that it takes to do at the end of the shift, or during the shift. When you have something that really like sticks with the staff, then they're much more willing to buy in." (Elizabeth, 67).

> "Like, one patient in particular was a 25-year-old, was hit by a car on his bicycle. Very bad brain injury. Only a year later, from reading his diary, he recovered fully, went back, master's program, married, two kids, did great. But it was only after a year, he was reading the diary and looking at it, some photos, reading the diary, that he realized what happened to him, like a full year, he had no sense of the whole year, first year of recovery, he was just kind of like, oh, and then he was reading. He's like, wait a minute, this happened to me." (Evelyn, 39)

> "[chuckles] It really is important, it does make a big difference. I just think it's important for patients to understand their story. And I mean, you're so sick, you don't understand it. You know, and what they remember and what really happened are two different things. Particularly with delirium, like one gentleman, he was afraid. And we didn't start his diary till actually after he left the ICU, because he was kind of right at the beginning of the pilot, and nobody thought to do it, to be honest. But he had been in Afghanistan. And so when he woke, at different periods in the ICU, we had the TV on and there were stories about... he thought he was still in the war. You know, and there were all these machines, beeping and all that stuff. Well, not uncommon to have those kinds of similar sounds in a warzone. And when we were giving him blood, he thought he was bleeding. But when he learned what his past was, it all went together. You know, but if we hadn't have like, sat down and talked about that stuff, and he was afraid to tell anyone that that story, because he thought everyone would think he was crazy." (Elizabeth, 67)