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# Participant Use of Digital Diaries in Qualitative Research: A Strong Structuration Analysis

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## Abstract

Lived experiences of chronic conditions are marked by fluidity and change, which should be considered if care is to be truly patient-centered. Seeking to capture this fluidity, we used digital diaries via mobile phones to communicate with hypertensive patients in the Philippines over approximately 12 months. This paper draws on Strong Structuration Theory to conceptualize the complex array of factors shaping participants' usage (and non-usage) of the diaries, thereby offering a comprehensive understanding of how the diaries were perceived and used. We draw on qualitative data from 42 participants (73 baseline/follow-up interviews and 37 digital diaries), purposively selected from a larger pool of quantitative participants, as well as existing literature and our own study documents. The Philippines 'digital divide' presented barriers to the usage of the diaries, stemming from a lack of access and mobile signal especially in socioeconomically marginalized rural areas. Within this context, the sharing of mobile phones both enabled and constricted diary participation. Guided by Strong Structuration Theory, we observed three cycles of structuration evident in participants' usage of diaries. The first pertained to the frequency and mode of engagement. A low level of engagement was observed, stemming from negative or ambivalent attitudes toward texting and other factors. Conversely, mobile phone 'top-ups' enabled participation. Participant usage of the diaries as tools for monitoring hypertension and to request health advice comprise the second and third structuration cycles. These usages contrast with researchers' intended usage of the diaries and with the original brief given to participants. The conflict between participants' and researchers' understanding of the appropriate uses of the diaries represents the dynamic field of position-practice relations, wherein agents are situated and interact, either perpetuating or challenging existing societal structures. Our findings underline the importance of considering macro- and meso-level factors when considering or conducting research using digital diaries.

## Keywords

critical realism, ethnography, methods in qualitative inquiry, observational research, qualitative evaluation

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## Background

Lived experiences with chronic conditions are characterised by fluidity and change as patients proceed through different stages in the illness and treatment journey (Bernays et al., 2014; Bokhour et al., 2012; Paturzo et al., 2016; Russell & Seeley, 2010; Siegal & Lekas, 2002). Seeking to capture this nuance, we used digital diaries enabled via mobile phones to communicate with hypertensive patients in the Philippines over approximately 12 months. Such participant diaries offer an alternative method to capture longitudinal data (Chen, 2011) and have been used in research focused on chronic conditions such as diabetes (Broekhuis et al., 2020), dementia (Herron et al., 2019) and HIV (Bernays et al., 2014, 2019). They can accommodate different response modes (i.e. hand written, audio recorded, text messaging, images) (Herron et al., 2019) and can be structured (or unstructured) to allow the respondent to prioritize what to share (Elliott, 1997). Capturing nuance and patient experiences over time is difficult through commonly-used qualitative methods such as one-off interviews and focus group discussions, as they are cross-sectional.

The digital diaries we report on in this paper were used within the larger mixed-methods Responsive and Equitable Health Systems—Partnership on NonCommunicable Diseases (RESPOND) study, which has generated evidence on the barriers to effective hypertension management faced by poor households in Malaysia and the Philippines (Palafox et al., 2018). The RESPOND study focused specifically on poor households due to evidence that the poorest individuals in the lowest wealth quintiles are especially disadvantaged in awareness, treatment and control of hypertension (Palafox et al., 2016). Along with repeat semi-structured interviews, participants enrolled in the qualitative component of the study were invited to complete digital diaries over a period of approximately 12 months (Palafox et al., 2018). The digital diaries used in our research consisted of 2-way communication via text messages between researchers and hypertensive patients. The aim of the diaries was to elicit longitudinal (over 12 months), nuanced narratives of hypertensive patients' experiences managing their hypertension and seeking (or not seeking) care for their condition.

An earlier paper from this study described the content of data shared via digital diaries, levels of participant engagement, and researchers' experiences when engaging participants (Mendoza et al., 2021). That paper reported trends in participant usage of the diaries (categorizing participants into active, semi-active and infrequent users), and flagged the difficulty in using diaries to capture in-depth narratives from participants about their experiences with hypertension. This paper complements that work, aiming to conceptualize the complex array of factors shaping participants' usage of the diaries by drawing on Strong Structuration Theory. The application of this sociological approach provides a vantage point to interpret participant actions vis-à-vis the diaries, along with meso- and macro-level factors driving action, yielding a

comprehensive account of how the diaries were perceived and used.

## Theoretical Approach

We draw on elements of Strong Structuration Theory (SST) (Stones, 2005) to interpret the complex factors shaping the adoption (or non-adoption) of digital diaries and how they were used by participants. Through his original articulation of Structuration Theory, Giddens (1984) sought to provide an account of human agency which recognized individuals as purposeful actors who understood their actions and the impact actions have on social structures. Giddens conceived of social structures as consisting of the 'rules and resources' from which human action and interaction arise (Giddens, 1976). These structures are internalized into individual views of the social world, which then inform action, or the choices made by individuals. Yet actions are not wholly determined by structure. Structures are both enabling and constricting; individuals can either perpetuate structures by acting in accordance with them or transgress structures by acting in unexpected ways.

Giddens' Structuration Theory has been refined by Stones (2005) to operationalize the concepts of structure and agency and make the concepts amenable to empirical work. With Strong Structuration Theory (SST), he suggests a 'quadrupartite' cycle of structuration consisting of external structures, internal structures, action, and outcomes (Stones, 2005). External structures are conditions for action. They refer to the physical, social and economic context within which action is contemplated and enacted. As the 'terrain of action,' external structures include social norms, laws, policies, rules, and instructions. Like Giddens (1984), Stones (2005) argues that these structures become internalized by individuals. These 'internal structures' are conceived as two elements in SST. First, conjuncturally-specific knowledge (or conjunctural knowledge) refers to perceptions individuals have of the social world (the terrain of action) and how they are expected to act within it. Second, general dispositions are individual world-views, personal morals, attitudes and beliefs. 'Conjunctures' between these two types of internal structures informs resultant action; individuals draw on what they know about the social world (conjunctural knowledge) and their personal attitudes to make choices on how to act in a given situation. These actions then impact both external and internal structures (by perpetuating or disrupting them), in an everlasting recursive loop of structuration between structure and agency. In the 'analytic approach' section below, we outline how these concepts were utilized to understand and interpret our data.

## Methods

This paper focuses exclusively on the participants of the qualitative research component in the larger mixed-method RESPOND study. Qualitative participants were purposively selected from a larger pool of respondents ( $n = 444$ ) in a

quantitative survey and screening exercise to cover a range of ages (aged 35 to 70), sex (male and female), location (rural and urban).

As described elsewhere (Seguin et al., 2022), the qualitative element of the study drew on two interviews per participant: a baseline interview followed approximately 12 months later by a follow-up interview. The interviews were conducted by JM and GL and focused broadly on constructing a retrospective ‘patient pathway’ from symptoms and diagnosis to current treatment (or no treatment), identifying barriers and facilitators to hypertension control. Qualitative participants were invited to keep digital diaries using their mobile phones over a period of 12 months in the interim between interviews. Diary methods have been used in previous health research to track healthcare experiences, with proponents suggesting diaries provide rich data and mitigate recall issues which impact interview data collection (Thomas, 2015). Though diary methods have traditionally featured handwritten accounts of participants, digital research diaries recorded on devices such as mobile phones are now being increasingly used. The digital diaries in this study involved communication between participants and two local researchers (JM and EM) through text messages, focused broadly on their every-day experiences with hypertension. For instance, researchers used text messages to gain insights on medication commencement/cessation, notable health events (such as hospitalization or diagnosis of other conditions) and engage participants discussions on challenges in controlling their hypertension. Interviews and digital diaries were completed in 2018-19, mainly in Tagalog.

The digital diaries were supported by a bespoke online platform co-developed with ‘On Our Radar’, an organization that builds platforms to enable communities to share their experiences digitally (On Our Radar, 2021). Texts submitted by both researchers and participants were automatically uploaded onto the online platform, allowing researchers to respond to individual or multiple participants. Digital diary messages and interviews were anonymized, transcribed in the original language and then translated into English. Transcripts were exported into NVivo for coding.

### *Analytic Approach*

Following Giddens (1984) and Stones (2005), we used ‘methodological bracketing’ as a tool to delineate between an agent’s conduct analysis, and an agent’s context analysis. Context analysis focuses on external structures, or the ‘terrain of action’ which provides the rules and resources (and possibilities and limitations) within which action takes place. Considering context allows researchers to acknowledge the causal powers and influences independent to the agent. Consistent with other SST theorists (Greenhalgh & Stones, 2010; Rushforth & Greenhalgh, 2020) we differentiate between macro- and meso-levels of external structures in our approach. We conceive of the digital landscape in the

Philippines and our research study within it as macro- and meso-level external structures respectively. We drew on existing empirical work and grey literature to outline the main features of the Filipino digital landscape. Study documents (including consent forms, participants information sheets and digital diary infographic) explaining the rationale and ‘rules’ for the diaries, along with initial conversations with participants about the diaries are outlined in this section.

We follow the context analysis with conduct analysis which draws primarily on digital diary and interview data. Conduct analysis focuses on the agent, in this case, the research participant, and their actions, general dispositions and conjunctural knowledge. The action of interest is whether and how participants used the digital diaries. Participants’ actions, dispositions, and knowledge about external structures were coded in NVivo, following a deductive process. Throughout the conduct analysis, we draw upon existing research to locate our observations within the wider literature, possible relevant external structures, and potential outcomes of their action (i.e. impact on internal and internal structures). This analytic process yields ‘cycles of structuration’ consisting of linked actions, internal and external structures, and outcomes.

### *Ethical Approval*

Ethical approval for the study was granted by the Observational Research Ethics Committee at the London School of Hygiene and Tropical Medicine and the Research Ethics Board at the University of the Philippines Manila. Written informed consent was provided by all participants prior to their baseline interview.

### *Findings*

We drew upon data from 42 participants consisting of 42 baseline interviews, 31 follow-up interviews and 37 digital diaries. Thirty-one completed both interviews and a diary. Participants ranged from 39–69 in age, with an average age of 54. Twenty-six were female and 16 male. Twenty-two lived in an urban area and 20 in a rural area. All resided in poor areas in Quezon Province and Valenzuela City in the Philippines.

Participants’ frequency of engagement was presented in our previous study (Mendoza et al., 2021), with participants classified into three categories: active users (those who regularly sent entries), semi-active users (those who sent entries once or twice a week) and infrequent users (those who sent entries occasionally). We employ this categorization in our findings below. Pseudonyms are used to refer to participants. In passages containing quotes, ‘Int’ refers to interviewer and ‘P’ to participant. Participants commonly referred to their prescribed medication as ‘maintenance,’ and the act of ingesting medication to ‘drinking’ it, and used the term ‘high blood’ to refer to hypertension (Lasco et al., 2022).

## Context Analysis

In keeping with Giddens' (1984) and Stones' (2005) bracketing approach, this context analysis focuses on the 'terrain of action' consisting of the rules and resources, possibilities and limitations, within which action occurs. We focus on two levels of context: the macro and the meso.

### *The Philippines digital landscape: Digital divide in the world texting capital*

The Philippines is sometimes called the 'texting capital of the world' (Paule, 2004; Uy-Tioco & Cabañes, 2021). There is a high level of phone ownership (Silver et al., 2019), with an estimated number of mobile connections equivalent to 138.2% of the population in 2021 (reflecting multiple connections for some citizens) (We Are Social, 2021). These statistics paint a picture of ubiquitous mobile phone usage, an environment presumably conducive to a research methodology dependent on participants communicating with researchers via mobile phone.

However, these statistics obscure a pervasive 'mobile divide' regarding phone usage and digital literacy within the Philippines. Usage and digital literacy are strongly socially stratified, with disparities disproportionately affecting the socioeconomically (Uy-Tioco, 2019; Uy-Tioco & Cabañes, 2021). Despite the high number of mobile connections, approximately 20% of Filipinos lack access to mobile phones (even shared), while 7% share a phone with others (Silver, et al., 2019b). Sharing of mobile phones between family members is especially common among the urban poor in the Philippines, as the cost of the phone and credit is prohibitive for many families (Portus, 2008). Unreliable phone signals (especially in rural areas) are an issue for over half of Filipino citizens (Silver, et al., 2019b). Unaffordability remains a problem; over a quarter of Filipinos reported difficulty paying for their phone use in 2018 (Silver, et al., 2019b). In fact, the vast majority of mobile connections (96.7%) are pre-paid accounts. Access to electricity to charge a phone is a further problem for approximately one-third of Filipinos (Silver, et al., 2019b).

### *The research study: Rules governing digital diary use*

The 'rules' pertaining to the usage of digital diaries were communicated to participants through study documents (participant information sheet, consent form and diary infographic), during face-to-face interviews, and through text messaging. The information sheet stated that keeping a digital diary was optional (not mandatory) and that it was up to participants whether to initiate contact with the research team and whether to respond to messages sent by the research team (see Appendix A for the English-language version). Participants were informed that they would receive mobile credit to

enable participation, and that a carer could submit entries on their behalf.

Participants were provided with this sheet at the conclusion of their baseline interview during a conversation with a researcher about the diary. Below is a sample of a conversation introducing the digital diary to a participant:

We will return next year to talk to you again, in 2019. But in the middle of that, starting from now till next year, we want to invite you to take part in the digital diaries, we have a cellphone number that you can text about anything you experienced with your high blood. Just text your experiences about your high blood. And every month we will send you load [mobile phone credit].

Consistent with the information sheet, the consent form signed by all participants stipulated that they did not have to submit anything they did not want to share and could stop keeping the diary at any time without giving a reason (See Appendix B for English-language version). Participants received a copy of the information sheet and signed consent form for their records.

Participants opting into the digital diaries were given an infographic providing further instructions for using the diary (see Appendix C for English-language version). The infographic contained the mobile number to be used for submissions and instructed participants to share their personal experiences with and/or feelings about hypertension, and their experiences as patients in settings including local health centres and hospitals. It explained that participants would receive mobile credit to enable them to participate and stated that the diaries were not intended to be used to get medical assistance. It advised participants to visit their health centre, clinic or hospital if they felt unwell, rather than attempting to use the diary to access assistance.

The initial message sent to elicit diary entries focused on exploring topics raised by the participant during their baseline interview. The following message was typical:

"Good morning/afternoon, this is the RESPOND project, thank you for joining the text diary. [insert tailored message about something interesting/relevant that came up in the interview]."

The protocol for researchers specified that the following message would be sent each week until a reply was received:

"Good morning/afternoon, this is the RESPOND project, welcome to the text diary. We are looking forward to your first entry. How are you doing today?" If after approximately 1 month no reply was received, the following message was sent on a monthly basis: "Hi, we are very interested in your thoughts on high blood! We are looking forward to your first entry. How are you doing today?"

The monthly messages sent by researchers were combined with a confirmatory message stating that 'load' (mobile credit)

had been sent. Credit was sent to all participants on a weekly basis in the amount of 60 PHP (US\$ 1.20), regardless of whether they sent messages. A thorough description of our approach to communicating with participants is published elsewhere (Mendoza et al., 2021). Though the frequency of participant engagement fluctuated, contact from the research team took place at least monthly for non-responsive participants, and more frequently for responsive participants. Researchers were instructed to direct participants away from providing clinical information (including blood pressure readings), and instead elicit information on their views of causes of symptoms and of treatment, and their experiences of living with hypertension and of accessing the health system.

The digital landscape and ‘rules’ of the digital diaries form the strategic terrain of action which bear upon the three cycles of structuration detailed in the conduct analysis below.

### Conduct analysis

In each cycle of structuration outlined below, we start by identifying participants’ actions regarding the digital diaries. We are specifically interested in whether and how participants used them. We contextualize these actions within the internal structures of participants: their general dispositions and conjunctural knowledge. Messages from the study team acted as a moment of conjuncture, where participants drew upon their perceptions and their conjuncturally-specific knowledge of external structures to act. These internal structures are then contextualized within the external structures above, as well as other external structures relevant to the cycle. For each cycle, we suggest how the actions may perpetuate or disrupt the internal and external structures which informed the action.

### Cycle of structuration: Frequency and mode of engagement

The dominant action observed regarding the digital diaries was an overall (though not universal) low level of participation, as also described elsewhere (Mendoza et al., 2021). This may be due to the lack of signal discussed above. For instance, Benilda (51-year-old female), who lived in a rural area, noted lack of signal sometimes prevented her from sending and receiving messages. It is possible that other participants (especially those in rural areas) may have been discouraged from communicating due to unreliable connectivity.

Some participants agreed to keep a diary yet warned researchers at the outset (during the discussion about diaries at the end of the first interview) that texting did not appeal to them. For instance, during the introduction to digital diaries in her baseline interview, Rosario (56-year-old female, infrequent user) explained “I only use calls, I don’t text [laughs]. I only use the calls [laughs] [...] I just call, I don’t text.” Jose (61-year-old male, infrequent user) had a similar reaction,

stating that he only used his phone in emergencies, and “I do not use the text.” Predictably, both participants were very infrequent diary users.

The low frequency of messages from most participants was linked to their general dispositions towards the sending of text messages. Negative or ambivalent attitudes towards texting were evident, especially when compared to other modes of communication. In her follow-up interview, Angela (53-year-old female, infrequent user) stated that it was easier to “tell a story” through a voice message than text message. Cecilia (45-year-old female, infrequent user) shared this preference, commenting “talking to a person is better than just texting with each other.” In our earlier study we observed that participants aged 50–70 were more engaged in the diaries than those aged 49 and younger (Mendoza et al., 2021), which suggests that older age was not a barrier to texting.

At the outset of the study, the potential inability or unwillingness of some participants to engage via SMS was anticipated, and the messaging platform was intended to include a voicemail option for participants. However, platform developers encountered technical issues in the Philippines which meant that voicemail entries could not be submitted. This technical issue negatively impacted the amount and arguably the depth of messages received by the research team. Though a very high use of SMS is evident in the Philippines (Capistrano, 2013), it is being superseded by other forms of social networking (Magno, 2018), including Facebook messenger which is available almost free of charge to Philippine smartphone users (Consunji, 2013). It is plausible that participants would have submitted more entries over messenger or other apps, or through our platform had it been equipped to handle voice messages.

Participants’ assumptions about the type of information the researchers wanted to collect may have also contributed to the low frequency of messages. This points to their conjuncturally-specific knowledge of the research study; they may have assumed reporting on a condition which is largely asymptomatic would be of little interest (Lasco et al., 2022). This assumption may be rooted in local concepts of hypertension as a condition which comes and goes, rather than a chronic condition which is present even when symptoms are absent (Lasco et al., 2020). The ‘rules’ of the digital diaries, which invited participants to ‘share their experience’ and/or feeling about living with hypertension, and reinforced by messages from the study team, did not shift participants’ understanding of what kind of data was worthwhile to send.

Consistent with Giddens’ (1984) conceptualization of structure, the sharing of mobile phones was both enabling and constricting for digital diary participation. Phone-sharing interfered with participation for some participants. Angela (53-year-old female, infrequent user), who shared a phone with her sister-in-law, was quite disengaged from the diary, sending very few responses to prompts from the researchers. It is plausible that she was unable to send messages because she did not have regular access to her shared phone. However,

sharing did not necessarily hinder participation. Jasmine (42-year-old female, semi-active user) shared a phone with her husband, who worked as a seaman and was often away from home for long periods of time. She stated, “I rarely hold my cellphone.” Nonetheless, Jasmine was fairly responsive to the messages sent by researchers. For some, participation in the study was actively facilitated by the person sharing the phone. Jomel (64-year-old male), who was very engaged in the digital diaries, revealed in an interview that he dictated the messages to his son, who typed them and sent them on his behalf. Similarly, Bernard (39-year-old male, semi-active user), who did not know how to use his phone to send text messages, had his wife text with the researchers. Had these men not shared their phones, few or no messages may have been sent. The sharing of phones and the submission of messages through family members reflects and perpetuates the collective, family-oriented approach toward treatment of chronic conditions often seen in South Asian cultures including the Philippines (Sohal et al., 2015). Conceived here as an external structure, this collective orientation implies a close link between individual and familial identity (Bhandari & Titzmann, 2017), where family members are expected to support their loved ones to manage their health.

The overall low level of involvement led to the restructuring of certain elements of the research practices and procedures for the use of the diaries, representing a shift in the external structure subsequent to participant (in)action. The researchers sought to increase participation by adding a raffle draw for additional mobile credit, with participants sending more messages having a better chance of winning. This did not discernibly increase participation, which may indicate participants’ internal structures (notably their ambivalence towards texting and personal understanding of the type of information the researchers wanted) were more important in shaping behavior than monetary incentives.

Though overall participation was relatively low, some participants were semi-active or active users (Mendoza et al., 2021). For these participants, the ‘mobile load’ was viewed as enabling participation. As Imeda (48-year-old female, infrequent user) noted in her interview, “I only can send a text message when I have a load.” Though the load was appreciated by many, it was not necessarily required to enable participation. For instance, Fernandez stated “I told you that you don’t have to bother sending a load since I can afford it and I feel embarrassed” (64-year-old male, semi-active user). In the sections below, we turn to an analysis of the ways in which the diaries were used by participants: as tools to monitor hypertension and obtain health advice.

### *Cycle of structuration: Digital diaries as tool to monitoring hypertension*

Participants used the digital diaries as a tool to monitor their hypertension. This was evident in the large proportion of diary entries featuring blood pressure readings and reports of

medication being taken, with some participants incorporated such entries into their daily routine. James, a 64-year-old male ‘active user’ explains:

I will check my blood pressure and take my maintenance after the text diaries. And that’s what I like about it. [...] [Int]: So, you usually take your medicine in the morning? [P]: Yes, I take it in the morning so that I won’t forget. Together with the diary, it’s included there [laugh] [...] [Int]: So, let’s talk about the text diaries. How is your experience in using it? [P]: It’s good because I can keep track of my health by sending information to you. [...] Because I joined the text diaries, [...] I felt more responsible in checking my body.

Consistent with these remarks, James’ almost-daily diary messages were heavily focused on reporting the results of various blood tests and blood pressure readings. He sent dozens of messages simply stating his name, date, time, and reading, such as: “March 16, 2019 6:35 Am The BP I have 116 over 95.” In response to this specific message, the researcher asked a question about any contacts with their physician or other type of health provider, marking an attempt to shift the conversation to their experiences with their management of hypertension. Nonetheless, the next day James sent another blood pressure reading, along with an extensive list of results from a recent blood test.

These monitoring activities/submissions reflected a belief amongst participants that the digital diaries represented a tool which enabled them to monitor their hypertension and treatment. They seemed to view the messages sent by the research team as a reminder to take their medication, seemingly regardless of the content of the researcher’s message. This view is exemplified in a quote from Jomel, a 64-year-old male ‘active user.’ He stated, “They [the researchers] monitor my condition while I’m still alive. [...] It’s like they keep on reminding me.” This is despite the lack of messages from researchers explicitly reminding participants to take their medication.

Some participants perceived an *obligation* to take blood pressure readings and report them to researchers. This reflects their conjuncture-specific knowledge of the research study and their place in it, as compliant patients expected to report their medication-taking behavior and blood pressure readings. For instance, Antonio, a 44-year-old male and semi-active user, frequently checked his blood pressure specifically to provide an update to the study team. In his follow-up interview, he stated, “I have to check my blood pressure every week in order to give you an update, right? [...] [I]t was helpful. Instead of me not checking my blood pressure, I was urged to in order to give you an update.” Though the researchers did not ask for his blood pressure readings, various statements in his diary show the participant viewed the messages from researchers as prompts to take them, such as “Good evening. *Thank you for the reminders.* My BP is okay, 130/80” (italics added).



It is perhaps unsurprising that many participants seemingly viewed communication from the research team as a reminder to take responsibility for their own condition. A 2020 meta-analysis on mHealth technologies to promote self-management of hypertension found that tailored 2-way communication was associated with better management (Li et al., 2020). Though our study was not designed as an intervention, the frequency of contact from researchers (perceived as ‘reminders’ by participants) and the tailored approach may have encouraged monitoring behaviour.

Participants’ internal structures reflect the promotion of self-management of chronic conditions in the Philippines, conceived here as an external structure. The self-management of diabetes has been encouraged as a cost-effective way to prevent, control and monitor diabetes (Ku & Kegels, 2014), particularly in resource-constrained rural locations (Ardeña et al., 2010; Paz-Pacheco et al., 2017). Some authors perceived this focus on self-management of chronic conditions to be a part of a larger neoliberal rationale emphasizing individual responsibility in self-improvement (Ellis et al., 2017), shifting attention away from the duty of state and healthcare providers to ensuring good health outcomes (Renedo & Marston, 2015). Participants’ views and usage of the diary as a monitoring tool is entirely consistent within an environment where individual responsibility for their own care is encouraged. Their usage both reflect and perpetuates the ideals of self-management and individual responsibility as a value and good disease control practice.

### *Cycle of Structuration: Digital diaries as tool to obtain Health Advice*

Many participants used the digital diaries to ask for health advice. For instance, Beth, a 45-year-old female and a semi-active user, asked “I just wanna ask if my BP is high, can I drink medicine even if I already drank earlier this morning?” As set out in the protocol (which had been approved by ethics committees), the researcher replied that they could not give medical advice yet approximately a month later Beth again asked for health information: “why do I feel like my head is heavy and there’s a jolting pain in it?” Again, this prompted the researcher to remind them that they were not able to provide medical advice.

Beth’s actions are consistent with an underlying belief that the digital diaries represented a line of communication for health advice. This underlying belief was evident in statements made in interviews. Fernandez, a 64-year-old male semi-active user, was asked about his perceptions of the digital diary in his follow-up interview. He responded, “I think that I’m able to take care of myself more because I can get advice from you. [Int]: You get advice from us. [P]: Yes. [...] To be more health conscious. [Int]: Do you want to get advice from us? [P]: No, I’m already getting from you.” This statement implies that Fernandez viewed the diary as a tool to obtain

advice; he even recalls receiving advice from the researchers. The fact that no such advice had been provided speaks to the strength of his belief, which was held despite a lack of health advice provided or even requested. Fernandez’s messages focused on his blood pressure readings, interaction with the health system, and eating habits; he did not request health advice. Nonetheless, his response in his interview reveals that he believed he could use the diary to get it.

As implied above, when asked for health advice, researchers followed our ethics-approved protocol and explained that they could not provide it. Their response represents an attempt to shift participant’s conjunctural understanding of external structures, from their belief that the diaries could be used to access health advice to a belief which matched the general dispositions of researchers: that the diaries were for recording experiences living with hypertension.

The lack of impact of the researchers’ clarifications on subsequent participant behaviour was telling; many participants requested health advice on several occasions despite consistently being told this is a research study that cannot provide them with advice. In fact, some participants disputed this challenge to their understanding of the diaries by suggesting researchers *should* provide health advice. Jasmine, a 42-year-old female semi-active diary user, implies below that by sharing her experiences, it was a reasonable expectation to be provided with health advice. She noted in her follow-up interview,

[P]: Since you are studying this, I think it is better if you can give us a feedback or response when I share something.

[Int]: You want to receive advice from us.

[P]: Yes. Since we share our experiences and our diseases, it is better if you will give us feedback. Since you are always asking, and we are always responding.

[Int]: So, if we can use the text diaries in order to talk to the patients and give advice?

[P]: It’s better. Since you study those things, maybe you can come across the solutions that you can share with us when we share [with] you our experiences. We know that you know the answer to the questions that we ask, so it is better if you can give us a feedback or response.

[Int]: It is better if we have advice? [...]

[P]: Of course, since it is a disease and we know that you have knowledge about the solutions to it. [...] Since you are researchers, maybe you have connections with the doctors who can answer our questions and give us advice.

Jasmine seemed to perceive that medical advice was being withheld (‘we know that you know the answer to the questions that we ask’) by the researcher. Her statement reveals her view of the researcher as someone who knew the answers to her medical questions (possibly a clinician), or at least had contacts with doctors who could provide advice.

Jasmine's statement (and similar statements made by other participants) represents an attempt to alter the external structure formed by the research study. Her statement challenges researcher's understanding of their own role and represents resistance to adopting the researcher's understanding of the digital diaries. It also speaks to the positionality of the researchers vis-à-vis the participants. On positionality, there were several physicians on the research team, a fact known to at least some participants (though no physicians were involved in communicating with participants in the diaries). Moreover, the participant information sheet explained that the study was being conducted by health-focused departments at universities. Based on these features of the external structure, participants may have reasonably viewed the research as a clinical activity, and therefore asked clinical questions and submitted clinical data (see section above).

Similar to the structuration cycle above, the neoliberal ideal of individual responsibility in self-improvement, of being proactive in one's own health care matters, acts here as an external structure. This ideal is consistent with requesting health advice through the digital diary. A second relevant external structure is the relative lack of access to care for many Filipinos (especially poor Filipinos) (El Omari & Karasneh, 2021), especially in rural areas. A systematic review on the influence of health systems on hypertension awareness, treatment and control shows the importance of having a regular care provider and health care facility on hypertension outcomes (Maimaris et al., 2013). Participants' usage of the diaries to attempt to access health advice from a small team of researchers with whom they communicate and form a connection over 12 months is understandable, in consideration of a context characterized by a relative lack of regular care providers. Being denied health advice from the research team perpetuated the 'rules' governing the digital diaries, which stipulated that the diaries were not to be used to seek health advice. We found no evidence that participants chose to use the study as an alternative to seeking medical help, so we have no reason to suspect that anyone suffered physical harm by participating.

## Discussion

This paper represents a comprehensive examination of the usage of digital diaries via mobile phones amongst socio-economically marginalized people with hypertension in the Philippines. Progressing beyond a dichotomized analysis of barriers and facilitators of their usage, we have instead drawn upon Strong Structuration Theory to contextualize participants' digital diary usage within their internal structures, as well as the external structures of the research and the wider social context shaping their perception and use of the diaries. Further, we have suggested how participants' actions have in turn perpetuated or changed the external structures, acknowledging the recursive relationship between structure and agency.

## Observations on Engagement

We observed a relatively low level of participation in the diaries. This is perhaps unsurprising considering the details of the digital landscape in the Philippines, with a lack of access to mobile connections and the sharing of phones amongst the socioeconomically marginalized, along with unreliable mobile signal especially in rural areas (Silver, et al., 2019b). However, we note that sharing a phone did not necessarily prevent participation. In fact, the submissions of some participants were regularly facilitated by family members, reflecting the collective, familial approach to the management of illness especially in Asian cultures (Pamungkas et al., 2017; Sohal et al., 2015).

The relatively low level of engagement could have been mitigated by more intense co-production in developing the communication platform and the engagement strategy, with greater involvement of end users specifically aged 35–70 in co-designing the platform. Issues such as the weak mobile signal in some remote areas of data collection could have been brought to the attention to researchers through this strategy. There were changes in the technical specifications of the Filipino telephone service after the study started, which restricted the ability to leave audio messages. However, future studies using diaries should explore whether this function could be enabled to be more inclusive for those participants who prefer leaving voice messages to texting. Co-production could have also shed light on participants' internal structures which may have discouraged participation, such as uncertainty over whether details about their asymptomatic condition were of interest to researchers.

On this topic, the low level of engagement may stem from the lack of perceptible *changes* while living with hypertension; it is possible for people with hypertension to live for years with the condition and experience no discernible change in symptoms or treatment. As others have suggested, diaries are particularly well-suited to capturing *changes* in the process of living with chronic illnesses (Sargeant & Gross, 2011). The exploration of hypertension with digital diaries may not have been the best methodological approach. The comparatively high level of engagement observed amongst patients involved in studies using diaries focused on other, more acute conditions supports this point (Bernays et al., 2014; Furness & Garrud, 2010; Woodall et al., 2016). Thus, a digital diary method may not be suited to study patient experiences with chronic health conditions that are perceived to be part of normal life which do not significantly disrupt day-to-day lives. This is especially so for poorer groups facing acute daily disruptions in all areas of their life that take precedence over their largely asymptomatic condition.

Participants appreciated the mobile phone 'top-up' aspect of the diaries. This was evidenced by the many messages of thanks received via the diary submissions. Unfortunately, it appeared that some participants felt they 'owed' diary submissions in return for mobile credit top-ups (load), though

they were informed at the outset they could contribute as much as they liked. Also, it is possible that some participants were motivated to take part in digital diaries to receive the top-up. The ethical issues that arise speak to a long-standing debate on paying subjects to participate in research. Though monetary incentives make subjects more willing to participate, there is concern that payments induce individuals to take part in studies (and expose themselves to risks) that they would not participated in otherwise (Bentley & Thacker, 2004; McNeill, 1997). Some argue that research participants should be compensated for inconvenience and their time dedicated to projects, but the payment should not be so large as to be an inducement to participate (Wilkinson & Moore, 1997). The issue of incentives is especially sensitive when participants are poor, living in low-middle income countries (Angell, 1988; Del Rio, 1998). The participants in this study were deliberately recruited because they resided in poor areas and were therefore assumed to be low-income. The monthly mobile phone ‘top-up’ may have represented a significant financial benefit to some participants (though we note that some participants insisted they did not require the top-up).

There is ethical guidance to inform use of incentives, and how to calculate the amount, specifically for economically vulnerable research participants (Gelinis et al., 2020). The fact that payment motivates someone to participate in research is not problematic. It is concerning only when the incentive distorts participant decision-making which invalidates their ability to give informed consent (Gelinis et al., 2020). Though it is difficult for us to gauge whether the offer of mobile top-ups impacted on participant decision-making in this project, evidence from other studies suggests no correlation between offers of payment and participant perceptions of risk involved in study participation (Bentley & Thacker, 2004; Cryder et al., 2010). Moreover, not providing fair compensation to economically vulnerable participants could amount to exploitation, given the time taken to devote to research (and away from other tasks) (Gelinis et al., 2020). As such, we are reasonably confident that though the offer of mobile top-ups may have motivated participants to take part in the diary study, this did not cloud their judgement to the extent that their consent was invalidated.

### *The Field of Contested Position-Practice Relations*

The diaries were used by participants in two main ways: as a tool for monitoring their blood pressure readings and treatment, and as a means for asking for health advice. This speaks to the gap between researchers’ understanding and assumptions about what the diaries were for, versus participant understandings and assumptions. Stones (2005) advises that amongst groups of agents (in this case, participants and researchers), the quadripartite process of structuration is happening in many places at the same time, with each agent uniquely situated in relation to external structures. Their position is constantly in flux as they interact with other agents.

It is their interaction within this field of ‘position-practice relations’ that structures arise, change or dissipate. The gulf in understanding between researchers and participants represent the dynamism of this field as structures are perpetuated or diminished through agent’s interaction.

This dynamic field is evident through the actions of participants (their continued use of the diaries as monitoring tools and to request health advice) and researchers (reminding participants of the intended usage for the diaries) within the meso-level external structure of the research study. The researchers valued the diaries as ways to generate research data, specifically data on longitudinal day-to-day experiences and perceptions missed in the limited time frame that tends to be captured in interviews or focus group discussions, a position reinforced by existing literature (see Bernays et al., 2014; Broekhuis et al., 2020; Chen, 2011; Elliott, 1997; Herron et al., 2019; Jacelon & Imperio, 2005). The procedures for managing the diaries were articulated through information sheets, consent forms and an infographic, discussion at the conclusion of the baseline interviews, and throughout the digital diary data collection phase of 12 months (in interacting with individual participants if they transgressed the rules).

However, these rules only partially informed how participants understood the research and their place in it (i.e., their conjunctural knowledge of the study). Participant behaviour was informed by external structures which existed prior to the research study, such as the promotion of self-management of chronic conditions in the Philippines (especially in resource-constrained rural areas) that reflects to an extent a poorly resourced health system and the neoliberal ideal encouraging individual responsibility. The relative lack of access to care especially in rural areas (El Omari & Karasneh, 2021), paired with the beneficial outcomes associated with having a regular healthcare provider for hypertension (Maimaris et al., 2013) may have encouraged participants to seek medical advice. Based on participant actions, it seems these external factors were much stronger in informing behaviour than the rules introduced by the research study.

Behavior may have been informed too by features of the research study which may have been perceived to contradict information in study documents and from researchers that the diaries were for recording personal experiences with hypertension. The fact that some researchers were also medical doctors, and that the research was being conducted by medically focused university departments may have left the impression that the diaries were for recording clinical matters, and clinical advice may reasonably be expected.

Moreover, participants may have perceived that using the diaries for monitoring and asking for health advice *did* represent aspects of their experiences and feelings about hypertension, and therefore were within the rules governing the digital diaries. For participants with a largely asymptomatic condition, monitoring through blood pressure readings and taking their medication may be some of their most prominent

'experiences' related to their hypertension. Within a resource-constrained health environment, asking for advice about their condition may have also represented curiosity, worry, or other 'feelings' about their condition. Researchers instead assumed that experiences of living with hypertension would include details of their daily life, rationalizations for treatment (or non-treatment), any health system contacts and/or health emergencies, and how they are feeling about their hypertension (aside from any direct symptoms), and impact of their diagnosis on other areas of life (i.e., their family and/or livelihood).

Divergent views on diaries between researchers and participants has been noted elsewhere; Bernays et al. (2019) found that HIV positive adolescents in Uganda using diaries occasionally diverged from providing messages about their condition and treatment, instead sending messages about other aspects of their lives. As research participants inevitably reflexively engage with qualitative methodologies, including not only diaries but commonly-used semi-structured interviews (Knapik, 2006; Wolgemuth et al., 2015), the agency shown by research participants by using the diary as a monitoring tool demonstrates their engagement with the method.

## Conclusion

This paper illuminated the complex array of factors shaping participants' usage of diaries, informed by Strong Structuration Theory. We identified three structuration cycles: a low level of engagement driven by negative or ambivalent attitudes towards text messaging, and usage of the diaries as tools for hypertension monitoring and to request health advice. We also suggest how participants' actions impacted on the very structures which shaped their action, consistent with the recursive relationship between structure and agency espoused by Structuration Theory. This was particularly evident with regard to participants using the diaries to request health advice. Though they were informed that the diaries were not intended to be used for this purpose, some participants disputed this and frequently asked for health information. Though this was a small qualitative study, our overall findings on the critical role of macro- and meso-level factors on shaping how (or whether) diaries are used by research participants may be useful in informing future work utilising digital diaries used to capture personal experiences with long-term health conditions, or indeed to capture research participant experiences beyond the purview of public health.

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## Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this

article: LMP-V has been involved in clinical trials of antihypertensive medications that receive some funding from industry.

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## Ethical Approval


Ethical approval for the study was granted by the Observational Research Ethics Committee at the London School of Hygiene and Tropical Medicine and the Research Ethics Board at the University of the Philippines Manila. Written informed consent was provided by all participants prior to their baseline interview.

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## Supplemental Material

Supplemental material for this article is available online.

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