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Social Representations of Digital Health Technology in different contexts: Why People
Keep or Quit Using It?

Running title: Digital Health Technology and Social Representations in cancer context

Authors:

Géraldine Escriva-Boulley¹

Camille Bernetière²

Marie Préau¹

Françoise Paquienseguy²

Tanguy Leroy¹

¹ Laboratory: Social Psychology Research Group [Groupe de Recherche en Psychologie Sociale] (EA 4163)
Psychology Institute [Institut de Psychologie] –University of Lyon

² Laboratory: Information and Communication Sciences Lyon Research Team [Équipe de Recherche de Lyon en Sciences de l'Information et de la Communication] (EA 4147)
Institute of Human Sciences [Institut des Sciences de l'Homme] – University of Lyon

Corresponding author

Géraldine Escriva Boulley

Groupe de Recherche en Psychologie Sociale (EA 4163)
Institut de Psychologie – Université Lyon 2
Bâtiment V (1er étage)
5 avenue P. Mendès-France
69676 – Bron (France)
escrivageraldine@gmail.com

Abstract

Objectives: The use of digital health technologies (DHT) is increasingly ubiquitous in intervention studies aimed at reducing health risks or improving the management of chronic diseases such as cancer. However, although DHT clearly show promises for a variety of applications, one third of users quit using DHT less than six months after the purchase, which may limit their effectiveness. This study aims to identify social representations (SR) of DHT, and to highlight why individuals adopt or are reluctant to adopt DHT, as well as the reasons for their drop-out.

Methods: Five focus groups were lead with 18 participants (Mage = 43.72 years, Women = 13) whose personal uses of DHT were heterogeneous and controlled. They completed three tasks designed to elicit a wide range of SR of DHT.

Results: Results showed that individuals' concerns about DHT were focused on four themes: 1) health versus well-being purposes, 2) price, 3) data protection and, 4) difficulties for the elderly. The main reason for adopting DHT was that their use met a need, an interest. Most participants made a fairly strong distinction between the DHT which promote health and those promoting wellbeing. Reasons for reluctance and drop-out were related to a lack of knowledge, information, transparency and mastery.

Conclusions: These findings may help DHT designers to understand what kind of information are needed and relevant to users. This study also highlights users' SR of DHT, as well as their expectations and fears which should be taken into account when implementing interventions.

Keywords: cancer, drop-out, focus group, health, internet of things, maintenance, oncology, reluctance, wellbeing

Background

The use of digital technologies (i.e., computer programs, websites, smartphone applications or wearable devices) is increasingly ubiquitous in health intervention studies (1). The increase of users, its economic feasibility and round-the-clock availability makes it a potentially viable option in a wide variety of health settings (2) from risk reduction (3,4) to the management of chronic diseases (5). In the context of cancer, studies about digital health technologies (DHT) is particularly relevant because the potential for DHT to help patients manage cancer is accepted (6), few tailor-made cancer-focused DHT currently exist, but several DHT for cancer are under development. Thus there is a need to investigate this field of research. Otherwise, DHT may thus be used by individuals who suffer from a disease as well as those who do not but aim to avoid illness or seek wellbeing. For instance, studies highlighted the efficacy of DHT to manage sides effects of cancer treatment (7) or to improve physical activity (3).

Although, DHT have the potential to personalize healthcare, to allow autonomous health management, to change health behaviors and to promote well-being, one third of users quit using DHT less than six months after the purchase (e.g., 7–10), which may limit their effectiveness. Therefore, there is a need to better understand why individuals adopt or are reluctant to adopt DHT, as well as the reasons for their drop-out. To enhance the knowledge about these reasons is important to design better health interventions and increase their effectiveness.

Most previous studies which investigated these reasons did it from the perspective of healthcare providers. In contrast, studies conducted with users are scarce (12). Classic behavior theories (e.g., technology acceptance model, the theory of planned behavior) were used to identify the reasons that may lead to the use or the intention to use DHT.

For instance, using a survey, a unified theoretical model identified five key factors: performance expectancy, effort expectancy, social influence, facilitating conditions, and threat appraisals (12). These factors are also highlighted and completed by data from non-theoretically based studies about the use of DT in general, or DHT especially which used surveys (8,13,14), interviews (10) and comments posted on online marketplaces (15). According to these studies, users start and keep using DHT because of perceived benefits, potential DHT features enhancement (10,15), curiosity and novelty (10) and because they had developed a routine of using it (8,10). On the contrary, attrition was due to their passive nature, appearance and obtrusiveness, the high frequency maintenance (10,13), the lack of users' needs (e.g., users feel that they do not really need it (10,15)), the lack of knowledge about DHT and how to access and use the data provided (10), and concerns about data sharing (14). To the best of our knowledge no study investigated reasons for reluctance towards adopting DHT.

These studies have examined behaviors related to DHT regardless to individuals' characteristics. However, research showed that users' gender as well as health related factors and experiences may influence the use of DHT (16). In the same vein, none of these studies investigated social representations (SR) related to HDT. SR are sets of ideas or opinions consensually shared by a social group about a same social object (16,17). By studying SR, one may gain access to significant practices which may only be understood in their specific cultural and social contexts granting them relevance and legitimacy (17).

To investigate SR, the focus group (FG) methodology have proven to be relevant (18) as it provides a less interaction with the researcher, it enables peer-to-peer discussion and it allows participants to freely react to each other's responses, thus permitting a deeper insight into individuals' behaviors and experiences. In addition, FG methodology requires

grouping participants according to targeted characteristics, allowing researchers to observe the confrontation of several socio-cultural contexts. To the best of our knowledge, no study has used such a methodology so far to examine SR of DHT. Using this qualitative individual-centered design, the aim of this study is to examine SR related to adoption, reluctance to adopt, and attrition of the use of DHT, considering health status, experiences with DHT and health habits. Such a study design has been chosen to ensure a strong diversity of the collected opinions rather than to test specific hypotheses. Our only hypothesis is that some SR are common and should be found in every FG, showing their stability and their potential reproducibility.

Methods

Participants

Participants were enrolled via an online collaborative research internet platform dedicated to cancer. All participants were provided with full ethical information about the study, signed a consent form and were invited to complete an anonymous screening survey.

Based on the latter, a purposive sampling was performed (gather individuals with shared characteristics). Such a sampling provides rich data relevant to the research question (18,19) as it guarantees the heterogeneity of opinions expressed. Using this strategy, five FG were designed, including five to seven participants (supplementary material Table 1 for details). The “*health status*” group (FG1) included participants taken into account cancer conditions, the “*use of DHT for men*” (FG2) and “*use of DHT for women*” (FG3) included participants who owned DHT taken into account their frequency of use and the gender, the “*quantified-self*” group (FG4) took into account practice of

quantified-self and the “*physical activity*” group (FG5) took into account the level of physical activity. Physical activity was chosen as a target health behavior because of its impact on health, and because it is the most targeted health behavior in DHT settings (20).

Protocol used during focus group

First, the purpose and the proceeding of the FG were reminded. Discussions were moderated by a trained researcher. Participants were invited to perform three activities. They were asked what DHT mean for them, and then they chose images of DHT and explained their choice (supplementary material Table 2 for details). The “personas” method was also used (20). Personas are archetypical characters (potential users) presented with information about their needs, behaviors, and preferences (21). Although persona are fictional, they represent generalizations of key characteristics and goals of potential users (22) (supplementary material Figure 1 for example). All FG were transcribed verbatims from videotapes of the sessions and anonymized.

Data availability statement

Data are available from the corresponding author upon reasonable request.

Data analysis

A thematic analysis (23) was performed to explore participants’ SR of DHT, as well as their reasons to adopt, avoid, or drop-out DHT according to their personal experience. Transcripts were closely examined and descriptive codes were used to identify key emergent themes and ideas related to the study objectives. Codes were then gathered into higher-order concepts or subdivided as understanding progressed. Descriptive accounts were produced to explore the content of key codes and comparing data across groups and individuals. A double coding as well as an iterative review of

coding and themes were performed to ensure the reliability, accuracy, and consistency of the analysis.

Results

Of the 72 screened participants, 25 finally agreed to participate to the scheduled FGs and 18 of them, aged 26 to 65 years, actually participated to FG ($M_{\text{age}} = 43.72$ years, $SD_{\text{age}} = 12.75$ years, $N_{\text{women}} = 13$). Twelve participants owned a DHT (health and sport), 12 practiced physical activity and 13 had no personal history of cancer (Table 1). Except for sex ($\chi^2 = 5.12$; $p = .02$), individuals who participated to FG did not differ from other 54 participants.

The common themes emerging across groups and accounting for the adoption, the reluctance to adopt, and the attrition of the use of DHT have been grouped into four key themes: 1) health versus well-being purposes, 2) price, 3) data protection, and 4) difficulties for the elderly.

Health versus well-being purposes

This first theme deals with a distinction participants drew between DHT specifically targeting health and those addressing well-being: “*Compare to DHT for wellbeing, DHT for health are serious. We are not looking for fun, here* (FG5)”. This SR of DHT is used by participants to explain the adoption and the drop-out of DHT according to its necessity *versus* futility. DHT for health are for individuals with a health condition or a disease, not for healthy ones: “*If you are healthy there is no interest, but if you have a disease and you need to check things every day it may be practical* (FG5)”. On the contrary, ill patients are supposed to need DHT as they are beneficial: “*He is sick, thus*

1 *his relation [to DHT] changed, he has an everyday obligation (FG2)”; “[DHT] helps*
2 *individuals in their disease or monitor their disease. (FG4)”. On the contrary, DHT for*
3 *wellbeing are viewed as less necessary: “There is a futile aspect. [...] it may be a cause*
4 *of drop-out. For me [DHT] are more for wellbeing are gadgets (FG4)”. When talking*
5 *about DHT for wellbeing, participants highlighted the fun and social aspects as much as*
6 *the frequency of use: “One can use DHT punctually, [...], not for an everyday use*
7 *(FG1)”. However, participants acknowledged the role of DHT promoting wellbeing as*
8 *an opportunity for preventing diseases: “In my mind this is for individuals who have a*
9 *disease. But at the same time, it could permit to prevent disease, for physical monitoring*
10 *(FG2)”. Besides, it is noteworthy that participants of the “health status” group (FG1)*
11 *made a less clear distinction between DHT dedicated to health or wellbeing than those of*
12 *other FGs. Indeed, they viewed DHT for health and wellbeing as being as much useful*
13 *but having different purposes “After cancer, [DHT] should be used more to improve*
14 *lifestyle and less for medical follow-up (FG1)”. FG1 is also the only group who discussed*
15 *the opportunity of using DHT to communicate with other health professionals than*
16 *doctors.*

18 *Price*

19 All participants evoke price as a reason for their reluctance to use DHT: *“I wait*
20 *for the price to decrease to buy it (FG1)”. Several SR are associated to this issue. First,*
21 *participants mentioned the quality/price ratio: “The more expensive, the more reliable it*
22 *is (FG5)”, “It’s expensive and it doesn’t work as well as expected (FG3)”. Second, they*
23 *pointed out the usefulness/price ratio: “I’m not convinced of the utility and [...] the*
24 *relationship between utility and what it will cost (FG3)”. Due to this price issue,*

1 according to participants, buying DHT is not possible for everyone: *“The price is too*
2 *high, at 20 years old you can't buy a DHT at 400-800 euros (FG3)”*. Finally, participants
3 proposed a solution to overcome this barrier: *“The question of price is a very interesting*
4 *one to rise. It's reserved for those who can afford it, there's no reimbursement (FG4)”*,
5 *“Health insurance authorities should reimburse more for sick people (FG2)”*.

6 7 *Data protection*

8 This theme led to the same controversies and nuanced opinions in each FG. All
9 participants raised the issue of data protection, especially when it came to health data.
10 Their concerns were about what was done with these data, who uses them and to what
11 purpose: *“DHT collect data and stock it somewhere, it's frightening (FG5)”*, *“This is not*
12 *only altruist [...] or for one's health [...] I think there is something else, but I can't define*
13 *it (FG1)”*. Some respondents feared that their health data may be turned against
14 themselves: *“This is awesome for health insurance authorities. [About the connected*
15 *toothbrush] they can see he didn't brush his teeth, they will not reimburse his dental care*
16 *(FG2)”*, *“Imagine... you have hidden your disease to your boss, and he finds out (FG5)”*.

17 However, data collection was not systematically perceived as a threat: *“I don't*
18 *care [about data protection] (FG3)”*. Indeed, participants view ways to protect their data:
19 *“There is a lot of solutions to protect your data (FG4)”* and consider DHT as possibly
20 helpful for health research: *“In health, it doesn't bother me [...]. I believe that [...], it has*
21 *a long-term use, it can help other people (FG2)”*. However, this agreement for sharing
22 data only concerns health data, not wellbeing data: *“[...] in a disease setting it's ok, but*
23 *when you jog every day, it's personal (FG5)”*.

Difficulties for the elderly

Participants commonly assumed that the elderly experienced more difficulties in using DHT than the youths. One reason is that DHT evolve faster than the elderly can follow *“It’s a little disturbing at first, when you are not used to it (FG2)”*, *“She thinks it’s going too fast, and she’s too old (FG3)”*. That explains reluctance -to smartphone technology- even when other DHT are used: *“For instance, my father uses a laptop, but he doesn’t want a smartphone (FG1)”*. However, participants highlighted that DHT may be useful for the elderly: *“It could be useful, when you go on a walk for instance, [...] when you have a certain age you have to be careful about your [physical activity] leisure (FG5)”*. To this purpose, all participants agreed that the elderly need training: *“They are afraid of [technological] progress because they are not enough accompanied, there is a lack of pedagogy (FG4)”*.

Discussion and Conclusions

DHT are presented as a real opportunity to improve health and wellbeing as they may lead individuals to reflect on themselves, based on data from their behaviors, and as a consequence, DHT may help people change their health behaviors. However, the use of DHT does not last long, which may limit their effectiveness on health. Using a focus groups methodology, the aim of this study was to highlight some SR of DHT, and to identify what individuals focus their attention on as well as their beliefs and practices in regards to DHT.

Results have shown that four themes were particularly important for participants: 1) health versus well-being purposes, 2) price, 3) data protection, and 4) difficulties for the elderly. Individuals thus seem to focus their attention on these themes to assess DHT

1 and decide to adopt them, maintain their use or drop them out. Actually, when it comes
2 to assess the usefulness of a DHT, there is no validated comprehensive tool to help
3 individuals to identify which ones are effective and of high quality (24). These four
4 themes may be added to the assessment criteria proposed by McKay et al. (24), namely a
5 description of the usability and functionality, a critique of the potential to promote
6 behavior change, and the quality of the health-related content. In other words, potential
7 users should be able to access information about whether the DHT is designed to improve
8 health or wellbeing, what are its usability, functionality and effectiveness considering its
9 price, and how data protection is ensured. Moreover, people should easily get access to
10 an educational and accessible tool about “how to” fully use the DHT (e.g., tutorial, short
11 notice of use). Besides, through the four themes found in this study, the reasons for the
12 adoption, reluctance, and drop-out of DHT may be highlighted.

13 *Reasons to adopt a DHT*

14 To adopt a DHT, its use must be meaningful for individuals. For instance, in the
15 present study adopting and keeping using a DHT makes more sense when it is designed
16 to improve health rather than wellbeing. This result is consistent with previous results
17 showing that individuals with a health condition are more prone to use health related
18 resources alike DHT (25). In addition, participants emphasized that in case of disease, the
19 use of DHT may prove to be of vital necessity. Another interesting result of the present
20 study is that, while most participants make a fairly strong distinction between DHT
21 according to their purpose (health *versus* wellbeing), participants from our *health status*
22 group agreed to consider health and well-being as the two sides of a same coin. Indeed,
23 for individuals who suffer or have suffered from a disease such as cancer, wellbeing is
24 clearly one of the issues of the care protocol.

Although some kind of interest is needed to adopt a DHT designed to improve wellbeing, participants also found that using such a DHT was more joyful than using a DHT designed to improve health, which is viewed as more serious. Furthermore they saw DHT designed to improve wellbeing to lead to social relation with family and friends, while DHT designed to improve health lead to relation with health professionals. Participants also emphasized the difference between the need for an everyday use of a DHT designed to improve health and the punctual use of a DHT improving wellbeing. These results are in accordance with the data from a previous study highlighting that behaviors related to the use of DHT should be seen as a dynamic process going beyond the simple distinction between adoption and drop-out (26). The irregular practice, named intermittent discontinuance, has to be taken into account as the efficacy of a DHT depends on its continued usage to keep track of users' health status and efficiently provide health advice (26). Determinants of intermittent discontinuance are neutral satisfaction (i.e., the use of the DHT produces neither pleasure or displeasure), neutral disconfirmation (i.e., achieving the minimum instead of the desired expectation from the DHT) and attitudinal ambivalence (i.e., difficulty for users to clearly decide if assessments of a DHT are positive or negative) (26). Although, the present study increases knowledge about these variables by providing a better understanding of users' representations and expectations of DHT, there is a need to examine further, whether the purpose of the DHT (improve health or wellbeing), data protection, price and age of the users affect behaviors related to use of DHT.

Reasons to be reluctant and to drop-out DHT

Reluctance to adopt DHT and drop-out were related to a lack of knowledge, information, transparency and mastery of the DHT. For instance, they need to know how

1 to use DHT, what use they can have of them, how to interpret data and what happen to
2 data. Compared to DHT designed to improve health, in which patients are quite well
3 accompanied in their use of the technology, users of DHT focused on wellbeing, have to
4 figure out by themselves how it works and why it is important. Although several studies
5 have shown that the elderly refrain from using DHT because of their lack of knowledge
6 (e.g., 30,31), all users also face a readability issue (24): information from DHT may be
7 misunderstood, viewed as harder to understand than those obtained with unconnected
8 objects, which may lead people to drop-out DHT. Besides, DHT designed to improve
9 wellbeing are considered to be fun, easy to understand, and easy to change for another
10 DHT. Therefore, information provided by such tools are not viewed as relevant to
11 improve health, broadly speaking. In a previous study, that point was described as a
12 reason to drop-out the DHT (29) whereas in the present study, it is also a reason for
13 reluctance to adopt a DHT. Hence, there is a need to educate people about the
14 opportunities that DHT could offer to improve health and wellbeing, to highlight the
15 necessity of a continuous use of DHT, and to help users to better understand the data
16 generated. Future studies should fulfill each of these requirements to enhance
17 maintenance and effectiveness of DHT.

18 The data protection issue has already been underlined in several studies (e.g.,
19 13,25,27). Consistently, present results highlight participants' concerns about what is
20 done with their data, who uses them, and to what purpose. These are reasons both for
21 reluctance to adopt DHT and drop-out. However, the present study brings an innovative
22 result: all participants did not share such fears. Some participants did not perceive the
23 threat and were quite confident about DHT security. Furthermore, individuals were more
24 prone to widely share health data, considering it may be helpful for health research.

Complementary and quantitative studies are needed to examine whether these reasons may affect the maintenance, reluctance or the drop-out of DHT.

Study limitations

While the present study brings new valuable knowledge to the field, this study also has several limitations. First, the sample size is quite small while acceptable for a qualitative study. However, data are consistent with results from previous studies and the focus groups methodology has been helpful to highlight innovative results. Future studies should acknowledge these findings and assess their actual relevance. Second, participants were recruited from an internet platform that originally targeted breast cancer patients, cancer survivors and their families. Thus, these three profiles were present in our sample, however participants were mostly female and healthy. Despite our efforts to constitute the most heterogeneous focus groups possible, the SR observed may not reflect those of all individuals. As a consequence, further research is needed to assess the representativeness of the SR reported in the present study.

Practical Implications

DHT aiming to improve health may be a part of a care protocol, helping patients manage a high volume of information and self-management tasks, facilitating the coordination and synthesis of information from different providers and about different conditions and the patients-care providers' communication, and support patients in their roles of self-advocate and expert (30). These possibilities have been reported by participants as easing the adoption and maintenance of DHT (30). Otherwise, patients who suffer from cancer can benefit from DHT for health as well as for wellbeing. For instance, in the present study, participants used a pedometer apps or relaxation apps during or between treatments.

General Conclusion

This study provides an in-depth understanding of the SR of DHT. Individuals' concerns leading them to adopt or not a DHT and to keep using it or not are: its benefits for health, its price, how it ensures data protection, and its usability. These findings may help DHT designers to understand what kind of information is needed and relevant to potential users. This study also highlights users' expectations and fears that should be taken into account when implementing interventions in health care setting involving DHT.

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2 was recruited via an internet platform named Seintinelles (Equivalent of USA-based
3 “Army of Women” platform).

4 National ethical committee approval: n° RCB 2017-A03360-53

5 *Conflict of interest:* Authors state no conflict of interest.

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Table 1. Characteristics of focus group participants

	N (%)
Number of participants	18
Mean age	43.72
Women	13 (72)
Illness	
Have a chronic disease (other than cancer)	7 (39)
Have cancer	1 (5)
Had cancer	4 (22)
Never have cancer	13 (72)
Own a digital technology	
Have	15(83)
Never have	3 (17)
Have a digital technology for health	12 (67)
Frequency of use	
Frequently	10 (56)
Regularly	4 (22)
Occasionally	1 (5)
Physical activity (yes)	12 (67)
Frequency of physical activity	
Frequently	5 (28)
Regularly	5 (28)
Occasionally	2 (11)