

Practices Analysis and Digital Platform Design: An Interdisciplinary Study of Social Support

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Abstract People are turning increasingly to the Internet to find support and share their experience and feelings when they are undergoing hardships such as medical problems. The aim of our ongoing research project is to design innovative online social support services. In order to pave the way for this complex undertaking, several interdisciplinary studies were conducted in this framework: discourse analysis was carried out on online discussions focusing on social support, observers attended support group meetings attended by family caregivers, and interviews were conducted with these caregivers. The application of our findings to our design project is discussed.

Introduction

Social support involves giving advice, information, and emotional, psychological, or material support to people undergoing difficult situations (disease, stress, loss of work, etc.). Social support is often provided by relatives, friends, the family, or trained professionals (such as psychologists or social workers). However, a new trend has been developing on the Internet during the last few years: social support is now being provided by peers, who are neither relatives nor professionals, mostly on Internet forums. There now exist many medical websites where people with medical problems can exchange information (more than eight million connections¹ were made in June 2008 with the French web site Doctissimo), forums dedicated to pregnant women, weight problems, bringing up children, etc.

¹Nielsen Net Ratings – Doctissimo – <http://www.doctissimo.fr>

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In view of this emerging trend, it was proposed to define and apply new principles for developing innovative online services to meet the current social demand which has arisen for the following reasons: traditional social links have been loosened (people tend to live in large cities, far from their families), self-administered medical care is on the increase, and traditional medical systems are finding it hard to provide all the needs of patients with serious diseases.

Although the aim was initially to set up general online social support services rather than services focusing on a specific type of problem, we started off by analyzing the specific needs of a group of people, which is allowing us to be familiar with the social support activity. These people are the family caregivers of patients with memory disorders (Alzheimer's disease in most cases) in the Aube region (N-E of France), where a dedicated healthcare network named "Réseau Pôle Mémoire" (RPM) was launched in 2001.

Serious neurodegenerative diseases such as Alzheimer's disease (AD) greatly reduce the patients' autonomy as their cognitive abilities gradually decline. Patients' relatives find it hard to cope with playing the role of caregivers, for which they have not been prepared. As shown by several surveys on French caregivers' situation [1, 2], apart from the financial cost of the disease (due to patients' need for assistance with housework, adapting the home, etc.), it makes heavy demands on the supporting spouse or relative in terms of their time and attention. The assistance these caregivers provide takes up a large part of their time and energy and leaves them little opportunity of escaping and taking care of themselves.

Caregivers express the need for help, apart from the need for financial assistance, which is generally felt to be the responsibility of social institutions. They clearly lack means of expressing their distress, finding a hearing and discussing their problems in order to obtain information and comfort [1]. Some of the best candidates for providing this hearing are other caregivers who are facing similar problems. The only means available so far for obtaining support of this kind are the support groups run by associations. To make up for this lack, some caregivers are turning to Internet forums and discussing their problems online with people in similar situations.

Due to caregivers' lack of time, providing a web-based system available at all times seems to be a particularly relevant response, since it gives them a space where they can share social support with peers. In addition, receiving social support on a daily basis enables people to talk about their problems immediately rather than letting worries accumulate for a long time before they find a hearing. This aspect is in line with the idea that the benefits of social support provided by peers are mainly short-term benefits [3]. The anonymous communications mediated via the Internet with people living elsewhere might motivate people who are reluctant to participate in face-to-face support groups or unable to do so for various reasons [4]. Online services of this kind would usefully complement the services already proposed by medical healthcare networks, as they would improve caregivers' access to information and help them cope with their distressing situation.

The challenge here is to succeed in understanding and implementing an activity (social support) which it is difficult to describe. It was therefore proposed to design a tool for family caregivers which would be as intuitive as possible. It was assumed

that the more we keep in mind actual social support practices in designing our platform, the more intuitive and user-friendly it will be for caregivers.

For this purpose, we therefore carried out an “action-research” project in which several disciplines (sociology, conversational analysis and psychology) were combined with computer science. This project was based on analyses of several kinds, the aims of which were as follows: (1) understanding computer-mediated social support activities, (2) understanding the specific needs of the set of family caregivers for whom we are designing the platform, and (3), developing the platform.

This paper was written in line with these three objectives: after explaining our definition of social support and deploring the lack of previous studies on online social support (Section State of the Art), the present approach to online social support practices is described in Section Understanding Online Social Support Practices. This approach is based on a functional analysis of existing online services dedicated to social support, completed by an analysis of online social support exchanges on the internet, focusing on the issues involved in running online discussions in order to achieve successful social support. Section Social Support Among Family Caregivers is devoted to the specific needs of the group of family caregivers for whom we are designing the platform, based on the observation of the social practices of family caregivers attending support group meetings and the semi-directive interviews which were carried out with some of these caregivers in order to define their day to day practices and determine their needs in terms of social support. The contribution of these descriptions and analyses to our design project is clearly stated at the end of each section. The findings obtained are presented and the implications for our design project are discussed in Section Implications for Design and Discussion.

State of the Art

Defining Social Support and What It Involves

Barnes and Duck [5] have defined social support as an exchange of verbal and non verbal messages, which transmit emotion or information in order to reduce people’s uncertainty or stress. Lending somebody social support either directly or indirectly implies recognizing the value of this support. Even if social support is of a purely informational nature, it is based on a spirit of affection/sympathy, which makes it comforting [6]. The authors of several studies on social support have proposed a typology of the different kinds of support:

- Emotional support (providing comfort, friendship, love, and sympathy [7]) which is a basic component of social support
- Informational support (providing information, advice, opinions, judgments [8]) which help people to assess and understand their problems [9]
- Tangible support (providing instrumental or material help, such as goods or services)

As mentioned above, the present research project involves *computer-mediated* social support, which has attracted considerable attention in the literature since the early 1990s.

Studies on Computer-Mediated Social Support

Most studies on computer-mediated social support come under the heading of social or experimental psychology, medicine, computer-mediated communications, and computer science. Fewer studies have addressed this topic in the field of management science, HCI, or CSCW. The situations observed in these studies have mostly had a medical context, and deal with the social support provided to ailing people, their relatives or the healthcare staff involved. Several studies have dealt with the benefits and drawbacks of computer-mediated social support. The benefits described include the accessibility of the media [10–12], the availability of the participants [13], the abolition of geographical distances and frontiers, the asynchrony (which makes it possible for people to log in whenever it suits them), the disinhibitory effects of anonymity [6, 13], etc. The drawbacks mentioned include the need to have a computer which is connected to the Internet, the decontextualization of the information dispensed, which can lead to misunderstandings, and the doubtful authority of some would-be helpers.

We have identified several gaps in these studies. First we noted some methodological weaknesses in the way social support situations are analysed. Many previous authors have analysed patterns of communication using various methods such as content analysis, interviews and questionnaires [8, 14, 15]. Some of the analyses presented in the literature are not sufficiently fine-grained or are not sufficiently pragmatic, since no attention is paid to the sequential pattern of organization of social support exchanges, for instance. Secondly, at the instrumental level, there are some weaknesses in the design processes, which have not usually been based on analyses of real-life social support activities. Besides, as we will see in the next section, most of the tools used so far are very generic, and include very few functions specifically designed to deal with at least one of the aspects of social support.

Understanding Online Social Support Practices

Functional Analysis of Existing Online Social Support Services

Thirteen websites providing information and communication services contributing to social support practices were selected on the basis of their representativity and analyzed. The aim was to identify the functionalities proposed by these websites. It was attempted to include an equal number of research projects (Hutchworld [16],

Krebsgemeinschaft [17], CHESS [10]), classical discussion forums (five), and web2.0 generation platforms (five) showing features typical of most social networking systems. These platforms were selected either because they explicitly claim to provide social support or because their focus (healthcare, social problems, etc.), their contents and the communication facilities they provide are relevant to developing social support practices.

Whenever possible (we were able to have access to some research projects only via the authors' publications), a user account was created on these sites. It was thus possible to test normal users' experience of the functionalities, contents and presentation of most of these sites. The data collection phase was conducted from March to September 2008. It is necessary to specify the date because the presentation and functionalities of some platforms are constantly being updated.

We started by assuming that online social support services (leaving aside the question of the underlying models) consist essentially of eliciting interactions between users. On this basis, we drew up a two-dimensional analytical grid giving the functionalities used to directly or indirectly mediate communication and interactions versus the way in which these functionalities and the content in general are presented on the platform.

To sum-up,² 27 functional components were identified that were common to most of the platforms studied. Some functional components can be part of larger functional entities that serve more specific goals. In these groups of functionalities which are common to several platforms, a general trend was observed: several functionalities tend to be combined in order to provide more specific situations than those available on classical discussion forums. Some platforms allow users not only to exchange messages, for example, but also to ask and answer questions, to give and receive advice and to share experience.

An interesting result obtained in terms of the platform design was that the innovations observed on these platforms are not based on novel technical solutions (3-D and video contents were quite rarely encountered on the platforms we studied, for instance). In other words, these platforms are based on similar text fields and checkboxes to those initially used when the Internet was launched. The systems studied rely on combinations of components (e.g., an asynchronous communication system combined with assessment functionalities is used to obtain an advice-sharing functionality) giving functionalities which encourage the users to take part in the online communication situations just as they do in the usual face-to-face situations.

As the result of our analysis, the kind of innovation we are aiming at in this project is more a question of combining well known web components to obtain relevant functionalities than applying the latest technological advances.

²The complete results, the list of websites analysed and the data set on which this study was based are available at the following URL: <http://www.orkidees.com/missWiki>. See also [18] for detailed results and analysis.

In order to complete our survey of current online social support practices, it is now proposed to complete this review by analysing the interactions which take place on web-based forums focusing on social support.

Analysis of Online Social Support Exchanges

In order to determine exactly how social support is provided on a forum, the exchanges taking place on three different French-speaking discussion forums were analysed. The corpus taken from the two first forums contributed to define patterns of interaction within online social support. The analysis of the third forum helped us to focus on the role of information seeking in the online social support activity.

Defining Patterns of Interaction. The first of the two forums was part of an extremely popular French website dedicated to health information, Doctissimo [19]. The first ten messages in 12 discussion threads were analyzed. The topics of these threads were various and representative (diet, blood pressure problems, etc.). The second forum selected was edp (“enseignants du primaire” – primary school teachers) which promotes mutual assistance between French primary school teachers. The first ten messages in eight representative discussion threads on this website were also analyzed. The topics were again quite varied and representative (the choice of textbooks, doubts about teachers’ own competence, etc.).

A two-step process was adopted here: first we used a persistent observation method adapted to CMC research by Herring [20]. This method consisted in regularly consulting social support forums and gathering samples for a long period. The next step consisted in performing discourse analysis and pragmatic analysis on samples. Discourse analysis on conversational exchanges makes it possible to define how social support sequences are organized. Pragmatic analysis consists in identifying the speech acts which constitute each episode in the sequence.

The following findings were obtained on how a social support sequence is organized:

First, as in the case of question-and-answer exchanges, most of the exchanges analyzed were ternary exchanges: this means that an initial message (posted by participant 1) is followed by one or several reactive support messages. These reactions/responses are followed by a final message of assessment (a feedback message) from participant 1. With this message of assessment – when it is positive – participant 1 closes the exchange and states that he or she has found the support helpful. The macro-illocutionary act which is performed in this message of assessment is a gesture of thanks. Sequences of this kind constitute successful exchanges.

Some exchanges are binary: the request for support is followed simply by one or several reactive support messages. When a pattern of this kind occurs, it is not possible to determine whether or not the exchange was successful, because the author of the first message does not confirm whether the response received was helpful.

These exchanges sometimes include a sub-sequence of negotiations between the participants, when Participant 1 is asked to reformulate his/her request, for example.

A pattern of this kind can be said to be a mutual adjustment mechanism, which is introduced in order to achieve a satisfactory social support exchange.

Lastly, some exchanges are not completed because the questions put forward receive no answers. This can occur, for instance, when a message contains too many questions. Messages of this kind do not trigger any answers because they require too much effort.

We now complete these results by presenting those of the pragmatic analyses we conducted. The social support exchanges analysed using this approach were found to contain messages of various kinds consisting of several micro speech acts.

Messages of request, whatever the kind of support requested, were found to generally contain the following micro-acts:

- Greetings: nearly all the requests (73%) opened with greetings (“hello” or “hi”).
- Presenting the problem (82%): the participant who is asking for support devotes a part of his/her message (generally the beginning) to the description (“I am suffering from baldness....”) or the narration (“after taking several kinds of drugs”, etc.) of his/her problem.
- Presentation of the negative consequences of the problem: the participant describes how the problem affects his/her life. The consequences can be physiological (“It has made me hoarse”) or psychological (“I’m afraid that the girls I like will not like me any longer”).
- Statement of the request: generally (54.5%), the participant who is asking for support explains or describes (more or less explicitly) the support he/she is looking for (“I would like to hear about other people’s experience if possible”). People seeking for informational support often ask the canonical question (“is there a risk of heredity for my son?”).

Messages of support are generally composed of the following micro-acts:

- Greetings, as in the messages of request.
- Providing support is both the macro-illocutionary act which constitutes the message itself, and the main micro-illocutionary act contained in the message (85%). Support can be given in several ways:
 - By expressing wishes and encouragement (“don’t give up”) which is a canonical way of providing emotional support.
 - By contributing information (for example, by describing a similar experience to that of the applicant), which is obviously the expected response to a request for informational support.
 - By summing up the situation: the seriousness of the situation is questioned and the fact that other people encounter the same problem is mentioned (“your situation is not so very exceptional”).
- Anticipating the success of the support. It is surprising to see how often the providers of support express their conviction that the person who is asking for support will find it on the forum (“there are a lot of nice people here who can help you if you need”).
- Closing terms or friendly expressions (“love”).

Messages of assessment generally contain:

- Thanks: This was certainly the most frequent micro-act encountered in messages of assessment (58%).
- A description of the support and its effects: participants asking for support show that they are satisfied with the support provided and sometimes state that it belongs to the expected category of support (“a warm welcome”, “helpful advice and experience”).
- A description of the situation or the person’s psychological state or their state of health: usually (67%), when assessing the support provided, the participant gives some information about the result (“I feel a little bit better now”).

By following this pattern, participants intuitively obey a set of rules which have to be followed in order to achieve a successful social support exchange. This pattern is in fact a norm for achieving social support, and each participant expects the others to comply with this norm. This normative dimension is confirmed by the negotiations which occur when the rules are not obeyed. For example, when an initial message does not contain a clearly expressed request, the act of request is not ratified by the other participants: for example, Participant 1 writes: *I TAKE glucophage eight-hundred and fifty milligrams all the time. I am tired. my blood sugar level is one.thirty I put aspartam sweeteners in my coffee, thanks for your answers.* Participant 2 answers: *and so what??? What is your question?*

To conclude, the micro-acts underlying these patterns of interaction set up the psycho-social conditions required for social support to be provided. Micro-acts set the conditions for successful online social support. In face-to-face social support, these conditions are generally determined by the context (the relationships between the participants, knowledge about the participants’ situation, etc.). In computer-mediated communications, where the context is not really known, the pragmatic aspects of the messages exchanged makes for a kind of re-contextualisation. For example, greetings are often exchanged, as between people in a close face-to-face social support relationship (support between intimates [21]). The final message of thanks can be said to be a way of achieving reciprocity, which favours social support in face-to-face situations; receiving support increases the likelihood of providing support [22].

The Importance of Information Seeking in the Online Social Support Activity.

The third forum, named Bladi.net, is dedicated to the Moroccan Diaspora. About a hundred of messages from the “mutual aid” section were analyzed [23].

This corpus highlights the importance of information seeking. We observe two different aims of this activity; the first one is basic; people ask for information. The second one is an assessment, people ask for an opinion to decide between X and Y.

In the first case, people use forums as they would do for search engines. They ask for instance further information on how to do paper-work (e.g. for a visa). In the second case, they are also waiting their pairs to assess the information. Thus, they ask to the other users to judge, to evaluate, to settle the services, products, companies or professionals. Here, forums operate as assessment websites.

Contribution to Design

The results of the above functional analysis of existing online services dedicated to social support led us to design our social support platform based on mundane functionalities. By mundane functionalities, we mean those quite unremarkable functionalities which have come to seem quite intuitive and ordinary. They are often simple, minimalistic and loosely defined, and yet they mediate richly layered social interactions because of their high-level of adoption. We can for instance quote chatting, “questions and answers”, uploading a document, commenting.

More specifically, understanding the factors making social support exchanges work yields new insights for designing an online social support platform. This platform will have to provide suitable conditions for mediating successful social support exchanges.

Based on our analysis of efficient patterns of interaction, it is now possible to define the main episodes of which online social support exchanges should consist, along with the corresponding functionalities, which will form the core of the platform. For instance, the initial results of the conversational analysis presented above suggest that “asking a question” and “sharing experience” are important components.

These results also showed that reciprocity is a key to successful in online social support exchanges. It was therefore concluded that this factor should be implemented on our platform, in other words, that reciprocity between users should be encouraged, by providing “alert” features which could help users to easily keep up with new contributions, for instance.

This analysis of online social support also pointed out that information seeking and the assessment of this information is an important feature, which has then to be implemented on our platform. From our point of view, this is reinforcing the importance of the component: “asking a question”. The need for assessment can be fulfilled by a section where “official” documents (as procedures or institutional websites for instances) could be share.

In addition to this generic knowledge about online social support practices, we needed to obtain detailed information about the actual social support practices and the expectations of the group for whom we were designing the first version of our platform. These practices and expectations are described in the following section.

Social Support Among Family Caregivers

The main aim of the “Réseau Pôle Mémoire” (RPM) launched in 2001 by a group of healthcare professionals in response to the many problems arising in the diagnosis and management of Alzheimer’s disease (AD) patients in the Aube region (N-E France) is to coordinate the work of the many professionals (neurologists, general practitioners, social workers, psychologists, etc.) involved in the care and support of these patients. Secondly, it dispenses care by performing neuropsychological screening activities (cognitive tests and diagnosis) and follow-up with patients and

their caregivers. The network is also responsible for informing professionals and the public about memory disorders and their treatment: it organizes training sessions for professionals and family caregivers and medical symposia for professionals, and publishes documents (such as booklets and website information) targeting various audiences.

Observation of Face-to-Face Social Practices Among Family Caregivers

The RPM runs monthly support groups for spouses and children who act as caregivers in order to provide them with a space where they can talk about their experience and discuss their problems. The training courses run by the RPM for caregivers also provide an opportunity of meeting other people in similar situations. At each session in these training courses, representatives of all the health professions (physiotherapists, speech therapists, occupational therapists, neurologists, and psychologists) involved in the care and support process explain how they work and give practical advice about how to deal with patients and solve caregivers' everyday problems.

Here we describe the situation of two typical family caregivers:

- In the first case, the caregiver is the spouse, who spends a great deal of time caring for the patient, since patients and their spouses generally live together (70% of the spouses who are caregivers devote more than 6 h a day to their partner). These caregivers are 71 years old on average [2] and the patient they care for is approximately the same age. Despite the existence of specialized centers that can take care of patients for a day or half a day per week, caregivers have a heavy load to carry. They have to be available day and night and it is difficult for them to leave their spouse alone. Their children often live and work far away and cannot easily help them. In any case, spouses who are caregivers all say they want to protect their children from the burden of care giving.
- In the second case, the caregiver is the patient's son or daughter. These people provide care of various kinds, depending on whether the spouse, who is the main caregiver, is able to cope with the situation. Children who are caregivers can take care of their ailing parent during the holidays, assist their mother or father with their everyday care, visit the parent at the nursing home, or share the daily assistance with other brothers and sisters. But this situation is also difficult, whether or not they have to provide regular support (which they often do on a weekly basis), because it adds to the many other responsibilities they already have to carry at their age (the children in the above survey were 52 years old on average [2]), such as their work, their own family, and their children and grandchildren.

Two support groups exist for these two kinds of family caregivers; the spouse caregivers' support group, which has been in existence for about a year, mainly includes caregivers who have attended at least one session of RPM training at which health

professionals explained how they contributed to the care and support of AD patients. The children caregivers' support group has been in existence for over 2 years and closer relationships have been formed among its members, although the assistance with which they provide their parents is of various kinds and the burden they carry differs from one person to another. The existence of two separate groups corresponds to common practices [3].

The two care-giving situations and the relationship with the recipient of the care are very different (in terms of whether the caregivers live with the patient, their age, whether or not they have a job, etc.). The members of the two support groups have no contact with each other, although there are no hard and fast rules about this point. Each group consists of about 15 members, who attend some or all of the regular support group meetings held on the first Friday of every month. The afternoon session is intended for spouses who are caregivers and the evening session, for children who are caregivers. The way these support group sessions are organized is roughly the same each time: the caregivers meet around a table at the RPM office, where they are served with cakes and drinks, which are sometimes provided by the caregivers themselves. The ensuing discussions are led by the network coordinator, who is a psychologist. She gives everybody an opportunity to speak in turn and dispenses accurate medical information.

The two RPM caregivers' groups, which include about 30 persons in all, correspond to only a small proportion of the 600 patients currently catered for by the RPM. Some of the support group members occasionally call each other between group meetings, but most of them have no direct or indirect contacts apart from their monthly meeting at the RPM office.

The caregivers have a lot to say about their experience with their ailing spouse or parent and about their daily care practices, and they often give each other advice. They express their opinions about institutional issues (nursing homes, insurance policies, etc.) and medical practitioners. Spouses who are caregivers often refer to the training they underwent at the RPM. They mention the knowledge and the benefits of the insights thus gained about their spouse's disease. The treatment available and the latest scientific knowledge about these diseases are frequently discussed during the meetings chaired by the RPM coordinator, who is an authority on the subject.

Although the experiences and events they talk about are sometimes emotionally quite intense, the level of mutual listening was not found to be very high in the spouse caregivers' group. The fact that it includes fairly elderly people who may have hearing problems may partly explain the lack of interest they were found to show in their peers' stories. However, according to the psychologist who is the RPM coordinator, from the psychoanalytical point of view, this also reflects the difficulty spouse caregivers have in accepting their husband's or wife's disease. However, we do not have enough clinical knowledge to discuss this aspect in greater detail. At the practical level, the many digressions which tend to occur oblige the coordinator to intervene frequently and to manage the caregivers' interventions more than with the other group. The children caregivers' support group seems to be a much more closely knit group. They discuss the crises and upsetting episodes they have experienced with the other members of the group. They also talk about the friendly events

they have enjoyed together (such as the New Year party, members' birthdays, etc.) at their monthly meetings at the RPM office.

To supplement these findings and ideas, we conducted semi-directive interviews with caregivers participating in the RPM support groups. Interviewing family caregivers helps to understand their day-to-day practices outside the monthly support group meetings. Their description of the way they are coping with their ailing relatives and the burden they often feel is a key to understanding their needs, which can be either clearly expressed or more latent.

Semi-Directive Interviews with Family Caregivers

Interviews were conducted both inside and outside the RPM with caregivers (including persons whose parents were suffering from other diseases such as cancer, and caregivers who use existing forums to help them manage their situation). We focus here on five interviews with spouses acting as caregivers inside the RPM.

These spouses knew we were working with the RPM network in order to design web-based information and communication services. However, the questions they asked generally focused on the caregivers' experience and not only on their use of ICT and what they thought about it. Most of the caregivers were not very familiar with the use of computers and therefore had few expectations about how ICT might help them, and designers therefore have to bring their needs to light.

The interviews in question consisted of four parts:

- An account of the onset of the disease, its development and how the caregivers are coping with this hardship
- A description of the care with which they are providing their relative, what help they are given, and what additional support they would like to have
- A description of the caregivers' relationships with the patients' doctors and health professionals in general
- Their use of information technology, the Internet, existing online social support, and their needs in this respect

A detailed review of these interviews, with a description of the day-to-day care practices and an attempt to define the kind of collective the caregivers are forming can be found in [24]. We are focusing here on the expressed and latent needs of the family caregivers we met.

First, what are spouses who are caregivers looking for at the support group? The following two points emerged here:

- First, caregivers come to the support group to talk with other people but also to talk about themselves. The group is therefore not an end in itself but a means of feeling better, as far as possible.
- Secondly, they come to learn, to understand Alzheimer's disease more clearly, and to acquire useful information helping them to anticipate difficult situations with their ailing husband or wife and to deal with their patient more effectively in the future.

Few of their needs were clearly expressed. They encounter many difficulties but they cope with them as best they can day after day. Since spouses who are caregivers experience many difficulties in their everyday life from which it is hard to escape, one specific need emerged from the interviews: the need for a respite care service for caregivers, whereby the spouses of Alzheimer patients could be replaced occasionally at home by somebody who will look after them and occupy them (by playing with Lego?, puzzles, or cubes, for example, as proposed by one of the caregivers interviewed). This service would not have to be provided by a specialized institution, and could be used for just a few hours (not necessarily for a whole day each time). The aim would be to give caregivers a chance to “breathe”, to go out to a cinema or the theatre with friends, for instance. This result refers to the French context, where such services explicitly intended for caregivers’ relief do not exist. There are general task-oriented services, as housework assistance or housekeeping services for instance, but there is a lack of a global management of such services focusing on relief. This need was formulated along with the disadvantages of the specialized institutions who look after patients on their own premises and above all, the caregivers complained about the cost of these services (Francis, 58 years old, said they cost about €80 per day). The caregivers have to take the patient to these institutions by car. They are sometimes far away and traveling with a patient is difficult.

Some other needs were less clearly expressed by caregivers, and these latent needs were brought to light by our analysis.

In the first place, the caregivers mentioned the fact that they had benefited from the “*tips*” and “*advice*” received at training sessions and support group meetings. The tips and advice were about problems such as what to do when the patient is wandering around at night, or why, at a certain stage in the disease, it is important to keep the main doors locked at home and sometimes to close the shutters. The support group constitutes an ideal place for caregivers to exchange *tips* and *advice* with each other. These exchanges of good practices were rarely explicitly mentioned by the caregivers, but were often referred to when discussing a specific topic or talking about the problems encountered since the previous support group meeting; the caregivers never said they needed tips and advice on an Internet platform, but consistently showed how much they appreciated those provided by the support group and the training courses they followed.

Another problem encountered by spouses who are caregivers is that of understanding the impact of the patient’s medical treatment. At the support group meetings, they often questioned the RPM psychologist about the reason for each of the drugs prescribed and the possible side-effects. The neurologists and general practitioners in the group are the only persons authorised to prescribe treatments and doses, but caregivers are interested in discussing the treatment in order to be able to help their ailing spouse to support it.³

The last point worth mentioning is the need we identified among these family caregivers for help with administrative procedures, which are very hard to complete: hospital admissions, applying for a place in a specialised institution, applying

³ It is worth noting that treatment for Alzheimer’s disease only recently became available.

for monthly financial assistance, applying to benefit from the activities of a dedicated centre, and coping with death and the formalities involved, for example.

Contributions to Design

The above observations and interviews helped us to understand a typical group of family caregivers, their daily life and expectations, and how they receive or provide social support, especially during support group meetings. This information is of vital importance when designing a support system for these persons.

This field study confirmed some of the findings we made upon analysing online social support exchanges and brought to light some new findings:

First, experience sharing is also identified as a key point by the caregivers themselves. What links the members of the support group together is their experience of Alzheimer's disease from the caregiver's point of view, especially as they feel no-one else can understand what this experience is like unless they have been in a similar situation: "If you have not been through it yourself, you cannot understand what it involves" was an expression which cropped up frequently in the interviews.

Secondly, the need for information was expressed very strongly. In fact, most of the needs clearly expressed by the caregivers we met were related to information seeking and information management. For instance, they were interested in *tips* and *advice*, as mentioned in our account of the support group meetings, they would like to learn about the side effects of the patients' medicine and how to improve the patients' well-being, and they would like to be given some help with the paper-work they have to deal with. This gave rise to the idea that the social support platform should include a section for exchanging documents and information. This section could be structured in line with the categories of information listed above (medicine, well-being, and paper-work).

Finally, reciprocity was again identified as a key factor in social support; the caregivers clearly stated that they came to the support group to talk about themselves as well as with other people.

Implications for Design and Discussion

Presentation of the Mock-Up

As announced in Sections Contribution to Design and Contributions to Design, the main findings which emerged from our analysis of computer mediated social support systems and our field studies were used to inspire the design of our social support platform.

This does not mean that the results were translated directly one by one into functionalities, as functionalities are complex combinations, and the models and data on which they are based are often complex too. However, the results of our

analyses (the need for reciprocity, for instance) determined several design options. Some of our findings have not yet been introduced into our platform design and may be useful later on in the project (they may help to determine some of the details of the structure of social support messages).

The first stage in designing our platform consisted in producing a mock-up in order to collect feedback and comments from potential users (Fig. 1). In this mock-up, the project designers have taken into account some of the findings made in the above preliminary studies. For the moment, the platform consists of four main sections: (1) Users' personal pages (in line with the idea that self-fulfillment is a key to successful social support), (2) Document sharing, (3) Questions and Answers, mainly to provide informational support, (4) Personal stories and experience sharing. These four sections all contain a transversal communication functionality (*side discussions*).

Since we do not have room here to explain the inspiration of each functionality present in this mock-up, we will simply present here four examples showing how the findings obtained in the above studies were applied to the platform design and the choice of functionalities.

Reciprocity as a key to successful social support: As shown in previous studies on the use of greetings in computer mediated social support and as explained above, reciprocity is a key to successful social support (Fig. 2). This led the project designers to think about how to encourage reciprocity among the users of our platform. This cannot be achieved by simply using a single “reciprocity functionality”, nor is it

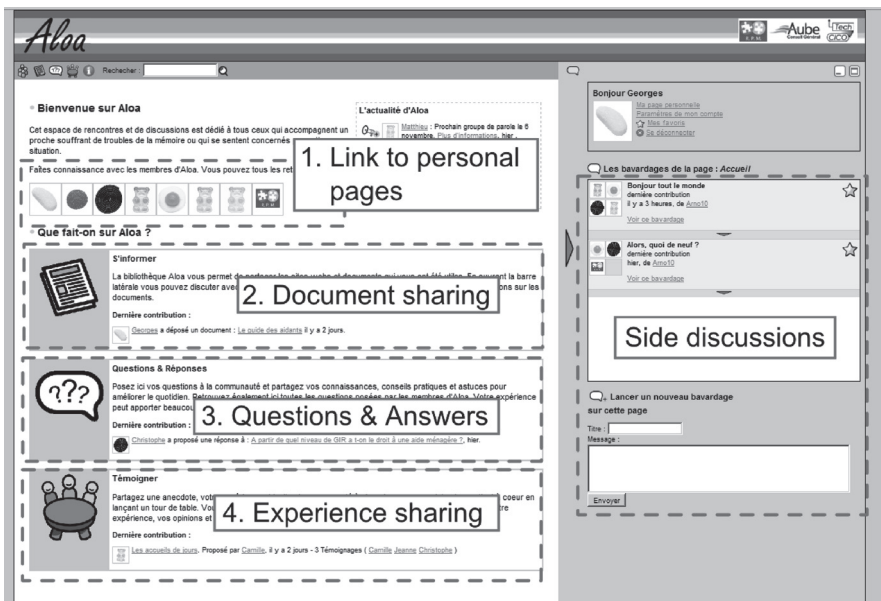


Fig. 1 The homepage of the mock-up of our social support platform

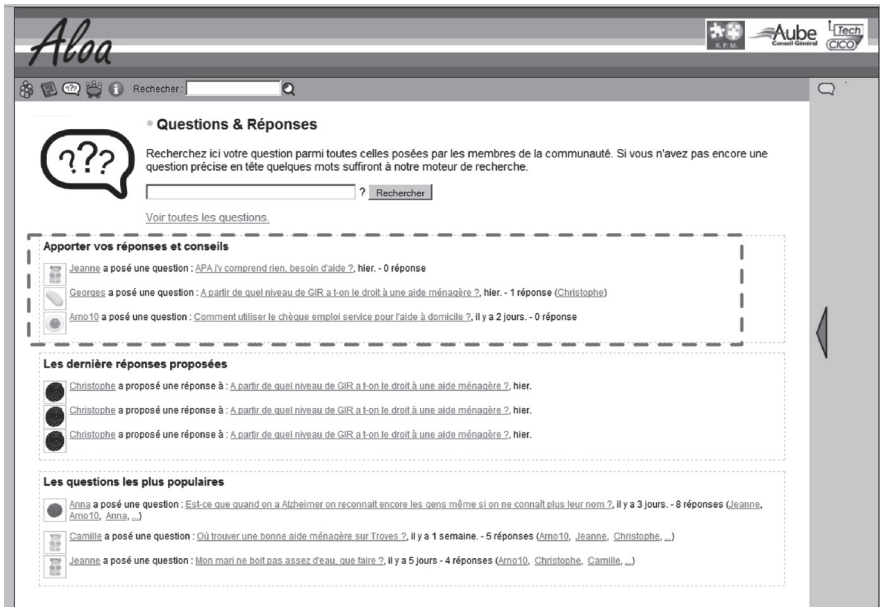


Fig. 2 Requests that have received few or no message of support are highlighted. This is one of the ways in which we implemented the fact that reciprocity is a key to successful social support

possible to compel users to act in a reciprocal way. The idea was to make people aware of each other's contributions (messages) in order to multiply the opportunities for reciprocity. By highlighting on the homepage and at the top of each section the number of requests that have received few or no messages of support, we can hope to encourage reciprocity. Providing users with "mail alert" features that signal any messages they receive is another functionality which may serve this purpose (it also helps people to stay in touch with the platform). Besides, the platform provides a weekly and monthly digest; a kind of newsletter helping members to be aware of the activity of the group.

The central role of informational support: What we learned by observing real-life support groups, such as the fact that caregivers come there to learn more about diseases and how to deal with patients' day to day care, and the fact that requests for information are prominent on social support websites led the project designers to include sections dedicated to exchanging information. The first section is dedicated to document sharing and to online discussion facilities (Fig. 3). Users can read and upload interesting file documents or websites links with the ability to organize documents around topics through keywords. The section is bootstrapped with some part of the domain literature like for instance, patients associations and respite care services websites, socio-demographic studies about family caregivers and document about memory disorders. The discussions sidebar, which has its proper instance for each document, enables users to comment, share their opinion

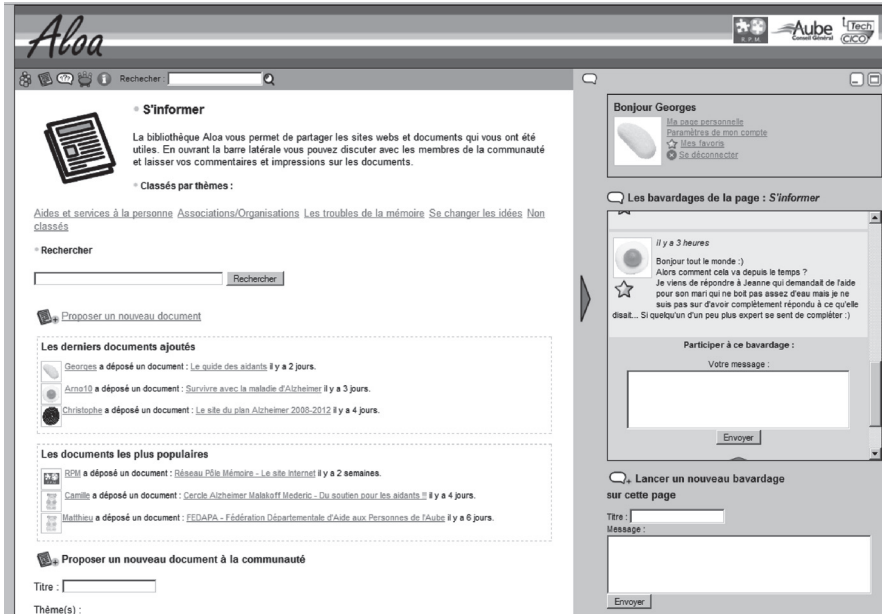


Fig. 3 Informational support – document sharing

and discuss the contents. The second section, which is dedicated to questions and responses (Q&A), is based on a metaphorical situation where users can ask other people questions via a one-line question text field followed by a larger text field for giving details. The rules and norms found to apply in situations involving the exchange of social support show how relevant this choice of metaphor and these technical features are, since our users are familiar with real-life situations of this kind, as compared with more abstract metaphors such as those on which forums and chat rooms are often based.

The central role of experience sharing: The importance of accounts on personal experience and stories in social support exchange has been emphasized both in the online social support analysis (i.e. description or narration of the problem, presentation of its negative consequences) and in the field analysis (i.e. caregivers come to the support group to talk with other people but also to talk about themselves). This led the project designers to create a “story and experience sharing” section where a user can post a new topic and share her/him story (Fig. 4). Other users are enabled to post their personal stories under the same topic. The “story sharing” form has also been designed keeping in mind the reciprocity factor, since it enables users to invite other people to share their experience on one topic through email alerts. Inside a topic, stories are sorted by authors, and each of them has a dedicated page to underline the personal dimension of such content. Discussions on the topic can be performed through the discussions sidebar.

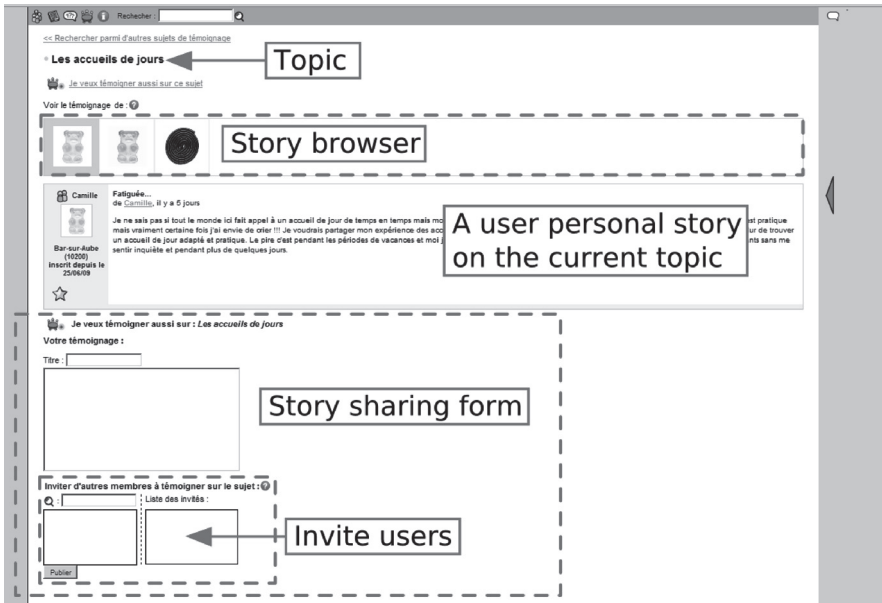


Fig. 4 Stories and experience sharing space

Tips and advice: Our interviews with caregivers and our field studies on support groups showed how important it is for caregivers to exchange tips and advice. The relevance of encouraging the exchange of good daily care giving practices based not only on the participants’ own practices but also on more formal information such as the training documents provided by the healthcare network led the project designers to propose a functionality enabling users to mark the contents of the platform (documents, Q&A threads and members’ stories) as “useful tips” in order help them browse easily among these precious contributions and retrieve them via a simple link.

Discussion

Although the present platform design was informed by interdisciplinary studies, it obviously has some limitations since designers have to make choices and thus impose some features on the users’ practices. In our current mock-up, in line with the importance of caregivers’ stories and experience sharing observed in social support practices, we decided to allocate a space to exchanging stories. However the researchers responsible for analyzing online social support exchanges drew our attention to an important aspect identified in their study, which should not be overlooked: sharing stories and personal experience (i.e., describing a problem and its negative consequences) is often used by participants to introduce their request.

This story often constitutes a preliminary phase before the act of asking a question occurs. Our Q&A functionality enables users to ask more detailed questions. However, since our story sharing functionality is in a separate space, it is disconnected from the opportunity of asking questions and does not let users easily go through this common sequence, even using the side-discussion. Further studies are required to address this point to restore the connection between questions and personal stories.

In the present case, the interdisciplinary studies on which the platform design was based cannot be regarded as a self evident corpus from which designers can directly extract data to be translated into functionalities. The initial review of design artifacts (mock-ups, prototypes) [25] carried out by the researchers involved in the various preliminary studies to determine how previous designers have translated their results brought to light many interesting ideas and opportunities for innovation, such as the question of connecting story sharing to Q&A.

The present mock-up based on our findings has been presented to the RPM coordinator, who authorized us to test it on some of the caregivers attending support group meetings. Their feedback, along with the comments of other stakeholders in the project, will help us to start an iterative process of development. Although the present group of end-users consisting of some of the family caregivers attending RPM support group meetings is relatively small, it is proposed to ultimately make this system available on the Web to caregivers who do not belong to this particular healthcare network.

Conclusion and Future Perspectives

Here we present a fine-grained analysis of face-to-face and online social support practices, including conversational analysis of online social support exchanges, field studies on meetings of a family caregivers' support group, and interviews with family caregivers. All the results of these different studies contribute to the design of a web-based platform for online social support.

This approach has several original aspects. First, its interdisciplinarity; In fact, from our point of view, designers of computer-based systems often seem to have directly applied the results of interviews with end-users and the descriptions of the corresponding face-to-face situations. In our project, the data and results coming from the analyses conducted by researchers in psychology, conversational analysis and sociology, were discussed with researchers in computer science, and not mechanically and simplistically translated into functionalities. Moreover, thanks to the conversational analysis of online social support exchanges, the medium into which social practices are being "translated" is taken into account. Finally, the data taken from the interviews go beyond the design of a platform. For instance, they question the role of health-related websites, which are providing information to patients and by then change their relationships with their practitioner. One can also mention the implementation of "respite care" services which is a matter for

the public health policy. Our study is then included into a broader process of intervention research.

The next step in this study will consist in integrating the results of new interviews carried out by the sociologist in our team with caregivers outside the RPM who are regular users of discussion forums. These findings will be used to improve the present mock-up.

Secondly, the iterative process of development will involve assessing the platform. We plan to study the evolution of the RPM group of family caregivers on whom this tool has been tested. One of the topics on which it would be interesting to focus in the future is that of technological tools as catalysts for communities.

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