



Parkinson's disease: Content analysis of patient online discussion forums. A prospective observational study using Netnography

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ABSTRACT

Objectives: To assess the users' characteristics, discussion contents, and the atmosphere of virtual peer communities.

Methods: A qualitative, prospective study was conducted using the Netnography method. The most popular, publicly accessible French discussion forums were investigated. The web users' quotes were collected from May to October 2018. Data analysis triangulation was performed by two researchers using the NVivo 12[®] software.

Results: The users discussed their experience with Parkinson's disease (PD) in a warm atmosphere. 23 discussion threads were analysed: 302 messages posted by 70 users (70% were females; the average illness duration was 6 years); 115 encoded nodes were created. Five user profiles appeared: leader, follower, expert, mixed, and undetermined. Common preoccupations were a lack of time and listening from the physicians' side. Three themes emerged: managing symptoms, living with PD, and sharing illness experiences. Users sought actively for a cure to limit or stop disease evolution, using alternative and complementary therapies to optimize their daily condition.

Conclusions: Online forums foster person's informal learnings about coping with PD. Healthcare professionals can use these learnings to optimize person-centred support.

Practice implications: During consultations, healthcare professionals should invite persons to discuss their online activity, informal learnings, beliefs and expectations towards therapeutic strategies.

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1. Introduction

In 2020, more than 10 million people worldwide are living with Parkinson's disease (PD) [1] and by 2030, this number will have risen by 56% [2]. The French government aims to improve healthcare pathways for persons with PD (pwPD) [3]. At the moment of diagnosis, they are on average 58 years old. Motor-, and non-motor symptoms decrease the quality of their professional, social- and family life [4]. PwPD are facing multiple stress factors, especially psycho-social ones, and need appropriate holistic support [5]. In this context, peer support groups exist to help

persons towards illness acceptance [6]. The Internet fosters democratization and creation of virtual communities, disseminating medical knowledge through which persons are encouraged to acquire skills in self-care [7]. Healthcare professionals (HCP) are exposed to an increasing media coverage and popularization of health. They must adapt to a new profile of persons [8]. A French survey showed that 93.2% of the interviewed citizens had browsed the Internet in the last year to get information related to their health [9], among them, one third looked up online discussion forums [10,11].

Online discussion forums encourage exchanges between pwPD and relatives. Beyond the psycho-social peer support, based on shared illness experiences, online forums allow the users to acquire collective medical knowledge and expertise, [12]. PwPD are active web users in this context, but research on their virtual exchanges is sparse. Exploring pwPDs' discussion threads allows insight into their illness experience, common preoccupations,

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Table 1^aThe web users' characteristics and analysis of measurable variables (n = 70 pwPD + caregivers).

	Missing values	Results	Min-Max	remarks
Gender	2	Females n = 49		Represent 70%
Age (average)	49	58 years	32–73	
PwPD or relative	2	PwPD n = 59		Represent 87%
Professional status	60	Ongoing professional activity n = 6 Retirees n = 4		Nobody from medical careers
Year of PD diagnosis	41	2013	2002–2018	

PwPD = people with Parkinson's disease.

^a Only web users for whom verbatim allowed to establish characteristics were included in the table.

beliefs and knowledge regarding PD, and expectations towards HCP. Taking into account these elements, could optimize the person-centred accompaniment.

The purpose of this study was to assess the users' characteristics and profile, the discussion contents, and the general atmosphere of the virtual peer community.

2. Methods

A qualitative, prospective study using Netnography was conducted for six months from May 1st to October 31st, 2018. Qualitative research is appropriate to analyse social interactions among involved actors in healthcare settings [13].

Netnography is a qualitative research method that analyses the free behaviour of individuals on the Internet, using web-based data from virtual consumer communities to provide useful insights about their communicational interactions related to their consumption objects or discussion topics [5,14]. In the absence of direct implication of a researcher, topics were freely chosen and discussed without any taboo. The study met the qualitative research scientific criteria according to Drapeau [15] and 18 out of the 32 criteria of the Consolidated criteria for Reporting Qualitative research (COREQ) [16]. A web-based study is relevant to explore persons' opinions, because the internet is a widely used source to seek health-related information [17]. Among 69% of French web users, nicknamed "health web surfers", one third of them gathered information from online discussion forums [18].

Online discussion threads from the four most visited French pwPD discussion forums (*forum.franceparkinson*; *carenity*; *entrepaticiens*; *doctissimo*) were integrally transcribed *verbatim* to be analysed regarding form and content.

Inclusion criteria were messages written in French, posted during the observation period, a minimum of two people discussing a theme related to PD, and public data.

Exclusion criteria were closed discussion forums requiring a subscription to access.

Discussion threads were manually copied in "Word®". Users' first, last, and nicknames were deleted to anonymize their identity. A new identity code was created using S for *web-Site*, followed by a Roman number I, II, III, or IV corresponding to the number of the site (in order of decreasing popularity), I for *Internaut*, followed by an Arabic number in the order of the posts. For instance: the first user, who consulted the website: <http://forum.franceparkinson.fr/> was named SII1. In parallel, a table of the users' characteristics was created for each website to collect the following information: the newly created identity, gender, age, job, duration of PD, medication, geographic location, presence of close relatives, if present: what kind of relatives, number of posted messages since the beginning of the discussion, and number of posted messages since the beginning of the observation period, user being a pwPD, or a relative. Names appearing in posts, which were not related to the user were replaced by an "X". Appearing symbols such as emoticons or smileys were deleted, in the absence of a real verbal

authentic transcription. Posts which related information that could violate rules of anonymity and confidentiality or harm people, were deleted. Data were analysed separately by two independent researchers, assisted by the NVivo 12® software. Data collection was stopped when theoretical data saturation was achieved, when no new topics were added by the user.

The data analysis was guided by the following research questions:

- Who discussed? => users' characteristics
- What was discussed? (content analysis) => common preoccupations
- How it was discussed I? (personal writing style) => users' profile
- How it was discussed II? (netiquette, social behaviour) => atmosphere

First, a users' speech was independently analysed by two different researchers. Meaningful words and word associations were identified and gathered as "nodes". Once a week, both researchers came together for a triangulation of their data analysis, before an axial coding was performed to determine themes. In case of rare discrepancies between the researchers, a consensual version was obtained by cross checking their points of view. This study was a *Non-Intrusive, Web-Based Research* without any direct implication of the researchers. As the online data were public and free of access [19], the study did not need approval from the French ethical bodies.

3. Results

3.1. Users' characteristics

The user's socio-demographic characteristics were assessed.

Thirty-two discussion threads were analysed (n = 302 posts (P) by 70 users (Table 1)), and 115 nodes encoded.

3.2. Users' profile

According to their writing style and behaviour (quantity and frequency of posts, word choice), we identified the following five user profiles (Table 2).

"The leader" monopolized discussions, launched new themes, answered directly to users, referring to them by names: "Hello,

Table 2The web users' profiles (n = 70^a).

1	"leader"	n = 15	13 F/2M	21%
2	"expert"	n = 10	4F/5 M/1X	14%
3	"follower"	n = 30	22 F/8M	43%
4	"mixed"	n = 9		13%
5	"undetermined"	n = 6		9%

F = female; M = male; X: undetermined gender.

^a 70 verbatim allowed to establish a profile.

I8); “Have seen the hypnotherapist and slept well the night after!” (P38 SII I1). Infrared therapies were also advised. Some deplored that those kinds of alternative therapies are poorly accessible:

“Unfortunately, those “therapeutic alternatives” which help us are expensive!” (P30 SI I12).

PwPDs were generally satisfied with alternative strategies, to the point that some of them stopped their PD treatments without any medical advice and replaced them by dietary supplements.

Mucuna Pruriens (MP) was frequently consumed. MP is a tropical plant extract, described to be a natural source of L-dopa which can diminish shaking. SI included 5 posts entirely dedicated to its use and 44 posts mentioned it on SII. The word *Mucuna* was the fourth most frequent word revealed through the speech analysis (Fig. 1): “I had prescriptions of Modopar® which I replaced by *Mucuna* to stop shaking.” (P22 SI I14); “Your neurologist is against *Mucuna*? That’s it . . . Some are convinced of its efficacy, others think that it is not efficient because it doesn’t reach the brain . . . I can tell you that it works. I still take my medication, but less.” (P192 SII I1).

Some pwPDs advised their peers to replace their medication: “I think that you are taking a lot of Modopar®. It would be good to try some *Mucuna*.” (P11 SII I1). Others adopted an expert position: “It works, because it is natural L-dopa which our organism extracts from food, only medication time is important. If you are under polymedication and your daily dose of dopaminergic agonist is 400/600 mg L-dopa, a titration of 200 mg to 15%, 60 mg of *Mucuna*, won’t give you a big effect. [. . .] that is the unexplained reason why your neurologist is against it.” (P201 SII I6). In addition to dietary supplements, many users recommended specific diets promising general benefits, especially containing low iron and sugar but high on unsaturated fatty acids, vitamins and potassium. “One of the keys to stop the loss of our dopaminergic neurons is a hypo toxic diet. Don’t forget feeding our brain first!” (P90 SII I6)

3.4.2. Sharing among peers

Throughout the discussions, the participants revealed their inner selves and shared their experiences and feelings.

Some regretted the lack of possibilities to communicate: “I deplore that online discussion forums are sparse.” (P13 SI I1) Others were grateful: “Thank you, it is really important that we don’t feel alone.” (P32 SII I1) Peer support was aimed: “I think that only people with PD can really understand what our daily life is like.” (P15 SI I6)

Many questions concerned future plans with PD: “What will I be like in 10 years?” (P4 SI I4)

Changes in daily life were expressed: “My life is not the same anymore . . . pain, tiredness, being unable to do acts of daily life “the same way as before.” (P12 SI I6). Coping strategies such as hiding symptoms were shared with peers: “At this stage, it is not so visible, so I don’t see why I should inform my children or colleagues.” (P9 SI I8); “I try to hide my “bizarre” attitude in my movements. I’ve got some tricks.” (P14 SI I11). The possibility of a normal life despite PD was mentioned: “Yes we can live normally with that illness.” (P4 SI I4).

PwPDs shared their daily experiences with others, professional, social or family relatives. Professional life was discussed: “I have been doing 80% of my usual work because of my tiredness. [. . .] very difficult because I’ve got [..] a lot of responsibilities. But I did not reveal my disease to my boss.” (P4 SI I4); “I informed my colleagues straight away and my superiors were super. My working time was adapted, and I finished my career fully relaxed until retirement.” (P11 SI I10).

For a better understanding of PD and therapeutic solution research, pwPDs shared scientific news in diverse domains: ongoing local clinical trials, pharmacology, physiopathology and neuroscience. Multiple sources of documentation were posted to

help each other to improve daily life with PD: 11 websites, 12 books, and 1 pharmacist thesis were referenced.

3.4.3. Living with PD

The PwPD described their personal daily life experience with PD, which was a frequently discussed topic with 28 encoded references.

Changes in couple’s life were openly addressed: “When I got my diagnosis, I suggested splitting up to my partner, because I had the feeling I was being “dishonest” with him!!! Finally, we got married, it was a way of saying to PD: you see . . . you can’t stop us!” (P15 SI I6); “My husband adopted the attitude of “the ostrich burying his head in the sand”. When I don’t feel good, he tells me that it is the weather and he never ask me about my appointments with the neurologist, I go there on my own.” (P8 SII I4).

The diagnosis announcement and treatments were discussed. PwPDs shared their experiences regarding their relationships with HCP: “I am not saying that they do not do their work but there is a lack of listening.” (P25 SII I5); “Doctors who listen to us are so rare.” (P17 SIV I4); “I’ve got the feeling that doctors remain deaf to our suffering.” (P39 SI I21). Regarding neurologists, they seemed to be disappointed because of a feeling of incomprehension and a lack of time to discuss: “Neurologists voluntarily ignore the benefits of food due to ignorance and certainties based on their allopathic training.” (P102 SII I6); “When I explain this phenomenon to neurologists, I get the impression of being an alien.” (P39 SI I21).

Many valuable tips, and tricks were shared (18% of all the posts), such as: changing one’s perspective on their daily life with PD: “Here is a trick regarding our perception of the way others look to us: Look at a PD person and think about your own glance at them. I met other people with PD who were worse than me. I found them brave and beautiful despite their handicap.” (P11 SI I10). Advice was shared between pwPDs who were still working: “If your colleagues judge you, explain your feelings and what PD is not! A disease of the elderly, because that is what most people think.” (P7 SI I6).

4. Discussion and conclusions

4.1. Discussion

Our study gave insight into virtual peer communities of pwPD. Generally, the pwPD looked for advice (e.g. sleep quality), solutions, information, answers, peer motivation (physical activity), complementary psycho-social support, and sharing experiences with peers in a warm atmosphere, which is known to be an integral part of online forums [5,20,21].

A certain disappointment regarding HCP, especially a lack of time and empathic listening, motivated the pwPD to join the peer communities through which they learn together, and from each other how to improve several aspects of daily life with PD [21].

PwPD aimed to achieve personal well-being despite PD, through PD symptom management and limited intake of allopathic medication [8], and sought to learn about alternative complementary drug and non-drug strategies.

For instance, the users learned that acupuncture was an effective complementary therapeutic strategy. Research supports the use of acupuncture as a safe and useful complementary symptomatic therapy [22,23], confirming that the virtual peer community may provide reliable solutions to manage symptoms.

According to Tough, the majority of our learnings takes place in informal situations, in our case, between medical consultations [24,25]. Schugurensky describes the type of learning in informal situations according to the intention and awareness of learning [26]. Therefore, learning in online forums can be considered as self-directed, or autodidact.

This type of learnings sometimes happens in a specific context, driven by a feeling of hopelessness due to PD. Some pwPD consider that they have nothing to lose but everything to win, which may lead to risky behaviours [27].

Self-medication is widespread in such a context [28].

Many pwPD in our sample seemed to be ready to take certain risks to stop PD evolution or diminish their symptoms. Strict restrictive diets were promoted among peers. Self-medication, especially with MP, was widespread and promoted among them [29]. Some pwPD, self-declared experts, or leaders advised peers to completely stop taking their allopathic treatments and replace them with MP.

Following this recommendation, some pwPD may present an underdosage of dopamine and therefore risk dangerous but avoidable complications, such as falls.

PwPD bought MP online and calculated an approximate dosage, (corresponding to $\frac{1}{4}$ of *Modopar*[®]), which seemed effective to them.

Although, the dosage was low, a certain benefit can be explained, sometimes close to placebo effect [30,31].

HCP, suspecting a placebo effect can leverage this opportunity to improve their relationship with pwPD, through comprehensive dialogue to identify the reasons for use of MP. HCP can then invite pwPD to provide information about an eventual placebo effect and its benefits, especially on global well-being. At the same time, HCP can support the pwPD's initiative while reiterating that, in case of an important underdosage of PD treatments, a certain risk, especially for falls, can exist, requiring complementary treatments according to the stage of PD.

However, we acknowledge and emphasize the capacities and knowledge of pwPD which can be leveraged to better meet their needs.

HCP can transfer these capacities to other domains to promote pwPD's autonomy.

In this context, it is useful for HCP to know the web user profile of the pwPD they support. The internal and external, positive or negative motivations and reasons for a pwPD to become a "leader" or a "follower" in a peer community must be explored and taken into account, in order to foster person-centred support. According to their personal experiences and acquired skills in self-management, the "leader" and the "follower" might have different expectations of HCP.

A "leader" would likely be more proactive and independent than a "follower", who may require more external guidance from a leader among peers, or an HCP. But we must keep in mind that a "follower" can be very active in following a leader, if the messages are interesting to follow. Thus, the HCP can elaborate a therapeutic alliance with both profiles if the "leader's" reasons to follow their own ideas, and the reasons of the "follower's" reasons to follow a leader, are explored. However, more research is needed to determine, and to meet the specific needs of each profile.

We recognize the role and interventions of *expert patients* who to help pwPD to cope with their chronic conditions [32–34].

Expert-patients use their own learning and experience about their chronic condition, to provide objective peer-support to other persons [35,36].

In our sample, "expert profiles", sometimes emitted opinions, likely to make feel other pwPD uncomfortable. Therefore, it could be interesting to open the dialogue among the web users.

The doctor's–pwPD relationship and the person-centred approach can be improved by exploring the pwPD's personal life context, needs, preferences, self-medication, and eventual online activity. The pwPD's interest in existing complementary treatment strategies, drug or not, should be clearly discussed, including inherent risks and benefits, before a shared care project is elaborated together. The pwPD is then free to adhere or not to the shared care project [21].

To foster, or improve the therapeutic alliance, the HCP must keep in mind that pwPD come to consultations with all their prior informal learnings.

Such learnings may have been acquired in online peer forums, while HCP may not be systematically informed about their participation in virtual peer communities and their eventual use of alternative treatment strategies [21,37].

It is important to recognize and value learning from informal situations. The majority of our learning takes place out of school [38]. Tough [24,25] underlines that 80% of learnings are informal. Regarding HCP, informal learning presents up to 72% of care activities [39]. Schugurensky [26] declares that: "The biggest part of significant learnings, which is used in everyday life, is acquired in the informal sphere, source of small interest and research." (2007, p.14) Furthermore, he defines informal learning as every learning acquired outside of any formal- or informal educational program.

HCP could in turn consult forums and/or ask and discuss with pwPD about their web use. Such discussion requires that HCP question their own "allopathic" beliefs, to understand and support the pwPD's choice of alternative treatment strategies. In such a way, an existent therapeutic alliance can be reinforced.

Furthermore, pwPD's discussion threads can be considered as examples of citizen scientific research, to foster novel areas of future research into the safety and efficacy of alternative, complementary, or allopathic therapies. Complementary therapeutic strategies deemed helpful to pwPD using this online discussion group, could become research topics.

4.1.1. Strengths and limitations

This study was to our knowledge the first one in France. Collecting *quotes* from four different online forums allowed us to create a diversified study sample of web users. The average age of the users was 58.11 years old, which is the average age of PD diagnosis in France [3]. The study population is not representative of the French general population because web users, and especially forum users can be considered as a subpopulation. Nowadays in France, internet access is unequal throughout the country. This digital disparity is due to economical, geographical, social, cultural, or generational circumstances, or to handicap and creates a selection bias. Many forum visitors remain anonymous and passive, just reading posts silently. Due to the respect of the users' anonymity, their characteristics were difficult to describe, and our method does not allow to collect private posts, triggering a data loss.

4.2. Conclusion

Virtual peer communities, through which pwPD find empathic, and solidary peers to advise and listen to them, are growing. Social peer support is very important for coping with PD and fosters useful informal learnings which must be taken into account by HCP.

4.3. Practice implications

When pwPD visit online forums, we should try to understand their reasons and the type of information they needed, to make an inventory of their knowledge. Then, we can explore how this knowledge was gathered and constructed, and how it improves their daily life with PD. We can then support them towards achievement of their self-defined objectives through dialogue that explores the different ways to achieve their goals.

HCPs should be aware of pwPD's online activities and support those [21] because social peer support is very helpful. At the same time, HCP must keep in mind that some of them could sometimes not acced to reliable information, about alternative or

complementary care strategies. A little web guide to reliable websites could secure their information research.

PwPDs expressed their interest and need for scientific expertise from PD experts. It could be interesting to create pwPD-to-doctor online communities [35] in addition to their freely chosen online peer group. Through those online forums, risks and benefits of allopathic, complementary and alternative therapies, new technologies, ongoing clinical trials could be discussed. As persons consider information from physicians and peers as two distinct sources [35], “expert-patients” could be involved in those online platforms.

Furthermore, pwPD need to be supported to raise their concerns with HCP through an empathic relationship, in order to elaborate shared care projects together [40].

Authors' contributions

SB, NM and CC developed the original proposal for the study. CC did the data collection and triangulation with SB. SB supervised the study. SB drafted the initial manuscript. NM, DD, CM, LD and OC reviewed and expertized the content. JB did literature review. All authors (8) revised the manuscript for important intellectual content and approved the final version.

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Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

All authors (8) revised the manuscript for important intellectual content and approved the final version.

CRediT authorship contribution statement

Sabine Bayen: Conceptualization, Supervision, Validation, Visualization, Writing - review & editing. **Cassandra Carpentier:** Investigation, Methodology, Writing - original draft, Software. **Jan Baran:** Visualization, Validation. **Olivier Cottencin:** Visualization, Validation. **Luc Defebvre:** Visualization, Validation. **Caroline Moreau:** Visualization, Validation. **David Devos:** Visualization, Validation. **Nassir Messaadi:** Validation, Writing - review & editing.

Declaration of Competing Interest

The authors have no competing interest to declare.

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References

- [1] Statistics. Parkinson's Disease Foundation.org. Retrieved from: <https://www.parkinson.org/Understanding-Parkinsons/Statistics> [assessed May 9th, 2020].
- [2] F. Moisan, M. Wanneveich, S. Kab, E. Moutengou, M. Boussac-Zarebska, L. Carcaillon-Bentata, et al., Fréquence De La Maladie De Parkinson En France 2015 Et Évolution jusqu'en 2030. [Frequency of Parkinson's Disease in France in 2015 and Evolution by 2030.] *Bull. Épidémiol. Hebdomadaire*, (2018), pp. 128–140. (8–9). Retrieved from http://invs.santepubliquefrance.fr/beh/2018/8-9/2018_8-9_1.html.
- [3] Plan de maladies neurodégénératives, 2019. [National Plan of Neurodegenerative Diseases 2014–2019.]. (2014). Retrieved from www.gouvernement.fr/action/le-plan-maladies-neuro-degeneratives-2014-2019.
- [4] La maladie de Parkinson. Ministère des solidarités et de la santé. [Parkinson's disease. Ministry of Health and Solidarity.]. Retrieved from <http://solidarites-sante.gouv.fr/soins-et-maladies/maladies/maladiesneurodegeneratives/>.
- [5] C. Hamnerlund, A. Westergren, I. Åström, A.K. Edberg, P. Hagell, The impact of living with Parkinson's disease: balancing within a Web of Needs and Demands, *Parkinson's Dis.* 2018 (2018) 4598651 8 pages.
- [6] A. Attard, N.S. Coulson, A thematic analysis of patient communication in Parkinson's disease online support group discussion forum, *Comput. Human Behav.* 28 (March (2)) (2012) 500–506, doi:<http://dx.doi.org/10.1016/j.chb.2011.10.022>.
- [7] I. Harry, R. Gagnaire, J.-F. d'Ivernois, Analyse des échanges écrits entre patients diabétiques sur les forums de discussion. Intérêt pour l'éducation thérapeutique du patient. [Analysis of online forum discussion threads of patients with diabetes. Need of health education for patients.], *Distances Savoirs* 6 (3) (2008) 393–412, doi:<http://dx.doi.org/10.3166/ds.6.393-412>.
- [8] E. Bureau, J. Hermann-Mesfen, Les patients contemporains face à la démocratie sanitaire. [Contemporary patients face to health democracy.], *Anthropol. St.* 8 (2014). Retrieved from <https://anthropologiesante.revues.org/1342>.
- [9] Renahy, E., Parizot, I., Lesieur, S., Chauvin, P. INSERM UMR-S 707. WHIST: enquête web sur les habitudes de recherche d'informations liées à la santé sur Internet. [National Institute of Health and Medical Research. Web survey of web users' health related information seeking routines] Retrieved from https://www.inserm.fr/sites/default/files/2017-11/Inserm_Rapport_Thematique_EnqueteHabitudeRechercheInformationsSantetInternet_2007.
- [10] J.D.N. La rédaction, Le top 5 des sites de santé français, *J. du Net.* 30 (2012). janvier [The top 5 of French Health websites.] Retrieved from <https://www.journaldunet.com/ebusiness/le-net/1097551-le-top-5-des-sites-de-sante-francais/>.
- [11] Médiamétrie – Communiquée De Presse – Internet – L'audience De l'Internet En France En Mai, (2015). <https://www.mediametrie.fr>.
- [12] M. Akrich, C. Méadel, Les échanges entre patients sur internet. [Patients' exchanges on the web.], *La Presse médicale*, Paris, Masson et Cie (2009) 1484–1493.
- [13] I. Aubin-Auger, A. Mercier, L. Baumann, A.-M. Lehr-Drylewicz, P. Imbert, L. Letrilliart, Introduction à la recherche qualitative. [Initiation to qualitative research.], *Exercer* 84 (19) (2008) 142–145.
- [14] Y. Bernard, La netnographie: une nouvelle méthode d'enquête qualitative basée sur les communautés virtuelles de consommation. [Netnography: A new qualitative research method based on virtual web communities.], *Décisions Mark.* 36 (2004) 49–62.
- [15] M. Drapeau, Les critères de scientificité en recherche qualitative, *Prat. Psychol.* 10 (Mar (1)) (2004) 79–86.
- [16] A. Tong, P. Sainsbury, J. Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *Int. J. Qual. Health Care* 19 (December (6)) (2007) 349–357.
- [17] V. Renard, Collège National Des Généralistes Enseignants. Comment Améliorer La Couverture Vaccinale: Concertation Ou Obligation? [National College of Teaching General Practitioners. How to Improve Vaccination Coverage: Concertation or Obligation?], (2017). Retrieved from: https://www.cngc.fr/conseil_scientifique/productions_du_conseil_scientifique/comment_ameliorer_la_couverture_vaccinale_concerta/.
- [18] J.-B. Richard, Quelle Utilisation d'Internet Dans La Recherche d'Informations Santé? [Which Use of Web to Seek Information About Health?], (2015). Retrieved from <http://inpes.santepubliquefrance.fr/jp/cr/pdf/2015/Richard.pdf>.
- [19] M. Blackstone, L. Given, J. Levy, M. McGinn, P. O'Neill, T. Palys, et al., Élargir Le Spectre: l'EPTC Et Les Enjeux Éthiques De La Recherche Sur Internet. [Extending the Spectrum: EPTC (Statement of the Policy of Three Advice and Ethical Issues of Web Research.)] *Com Trav Spéc L'éthique Rech En Sci Hum Un Groupe Trav Groupe Consult Interagences En Éthique Rech* <http://www.gerethique.gc.ca/ressources-reports-rapp-ee>, (2008).
- [20] R. Ghorbani Saeedian, I. Nagyova, M. Krokavcova, et al., The role of social support in anxiety depression among Parkinson's disease patients, *Disabil. Rehabil.* 36 (24) (2014) 2044–2049.
- [21] A. Benetoli, T.F. Chen, P. Aslani, How patients' use of social media impacts their interactions with healthcare professionals, *Patient Educ. Couns.* 101 (March (3)) (2018) 439–444.
- [22] S.H. Lee, S. Lim, Clinical effectiveness of acupuncture on parkinson disease: a PRISMA-compliant systematic review and meta-analysis, *Medicine* (Baltimore) 96 (January (3)) (2017) e5836.
- [23] H. Noh, S. Kwon, S.Y. Cho, W.S. Jung, et al., Effectiveness and safety of acupuncture in the treatment of Parkinson's disease: a systematic review and meta-analysis of randomized controlled trials, *Complement. Ther. Med.* 34 (October) (2017) 86–103, doi:<http://dx.doi.org/10.1016/j.ctim.2017.08.005> Epub 2017 Aug 12.
- [24] A. Tough, The Adult's Learning Projects. A Fresh Approach to Theory and Practice in Adult Learning, University of Toronto: Ontario Institut in Studies in Education, Toronto, 1971.
- [25] A. Tough, The Iceberg of Informal Learning: New Approaches to Lifelong Learning, Working Paper n° 49, University of Toronto: Ontario Institute for Studies in Education, 2002.

- [26] D. Schugurensky, « Vingt mille lieues sous les mers » : les quatre défis de l'apprentissage informel. [“Twenty Thousand Leagues under the Sea”: the four challenges of informal learnings.], *Revue française de pédagogie Recherches en éducation* 160 (1 September) (2007) 13–27.
- [27] J. Low, Managing safety and risk: the experience of people with Parkinson's disease who use alternative and complementary therapies, *Health: An Interdiscip. J. Soc. Study of Health, Illness and Med.* 8 (4) (2004) 445–463, doi: <http://dx.doi.org/10.1177/1363459304045698.1363-4593>.
- [28] N. Messaadi, Information numérique et gestion de la maladie [Digital data and disease management], *St. Publique* 28 (1) (2016) 77–82.
- [29] J.K. Hee, J. Beomseok, S.J. Chung, Professional ethics in complementary and alternative medicines in management of Parkinson's disease, *J. Parkinsons Dis.* 6 (4) (2016) 675–683.
- [30] J.M. Bensing, W. William Verheul, The silent healer: the role of communication in placebo effects, *Patient Educ. Couns.* 80 (September (3)) (2010) 293–299.
- [31] J.H. Ko, A. Feigin, P.J. Mattis, et al., Network modulation following sham surgery in Parkinson's disease, *J. Clin. Invest.* 124 (2014) 3656–3666.
- [32] N. O'Neill, G. Mitchell, A. Twycross, The expert patient, *Evid. Nurs.* 19 (April (2)) (2016).
- [33] E. Jouet, L'approche fondée sur le rétablissement : éducation diffuse et santé mentale. [Recovery-based approach: diffuse education and mental health.], *Le Télémaque* 49 (2016), doi: <http://dx.doi.org/10.3917/tele.049.0111>.
- [34] H. Romeyer, La sante' en ligne : des enjeux au- delà de l'information, *Communication* 30 (1) (2012).
- [35] F.D. Vennik, S.A. Adams, M.J. Faber, K. Putters, Expert and experiential knowledge in the same place: patients' experiences with online communities connecting patients and health professionals P2D, *Patient Educ. Couns.* 95 (May (2)) (2014) 265–270.
- [36] M. Eitzel, et al., Citizen science terminology matters: exploring key terms, *Citiz. Sci. Theory Pract.* 2 (1) (2017) 1, doi: <http://dx.doi.org/10.5334/cstp.96> [online].
- [37] A. Gurmankin Levy, A.M. Scherer, B.J. Zikmund-Fisher, Prevalence of and factors associated with patient nondisclosure of medically relevant information to clinicians. 2018, *JAMA Netw Open.* 1 (7) (2018) e185293, doi: <http://dx.doi.org/10.1001/jamanetworkopen.2018.5293>.
- [38] G. Brougère, H. Bézille, De l'usage de la notion d'informel dans le champ de l'éducation. [About using the concept of informal in an educational field.], *Revue française de pédagogie Recherches en éducation* 1 (158) (2007) 117–160 mars.
- [39] J.-P. Lanquétin, L'impact de l'informel dans le travail infirmier en psychiatrie. [The impact of informal on the psychiatric nurse activity.], *Rhizome* (October (49-50)) (2013) 5–6.
- [40] G. Mackenzie, M. Parkinson, A. Lakhani, H. Pannekoek, Issues that influence patient/physician discussion of complementary therapies, *Patient Educ. Couns.* 38 (October (2)) (1999) 155–159.