“There is no need to tell me too much”: chronically ill patients’strategies of controlling information inflow

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Abstract

Chronic disease patients’ satisfaction with information and activity of information seeking behavior are connected with subjective well-being and successful adaptation with the disease. However, it is mainly the aspect of the content of information that has been discussed, whereas delivery time and amount of information have received very little attention. The present article discusses how and why patients try to control the inflow of disease-related information and how to maintain patient’s active participation in their disease-related communication process.The empirical analysis is based on the patients’ own descriptions of their information needs and “non-needs” that became evident in the qualitative text analysis of in-depth interviews conducted with Parkinson’s disease patients in Estonia. Our study reveals that patients want information to be accessible and in an amount that suits their contextually raised needs.

Key Words: Parkinson Disease, Health Communication, Adaptation, Information Seeking Behavior, Chronic Disease

Introduction

Chronic, age-related diseases have become prominent in the modern world (Lozano et al. 2012, Weiss and Lonnquist 2010) and they affect a wide circle of the social relationships of diagnosed people and their loved ones, as well as employers, teachers, journalists etc.

In management of chronic diseases, it is critical to help patients adapt to their disease. Adaptation is a complex, multidimensional and holistic process proceeded by a whole life readjustment, due to physical, social and psychosocial implications caused by the development of the disease (Larsen and Hummel, 2013:88; Bendelow, 2012:72) The uniqueness depends on personal traits, past experiences, culture, and values. In addition to physical interventions, successful adaptation also requires other aspects of daily life– cognitive, emotional, behavioural and psychological – to be also taken into account (Larsen and Hummel, 2013:91).

Adaptation may vary widely interpersonally, but is not a linear process, which runs through different stages (Price, 1996) and may be accompanied with forced identity change due to bodily changes (Brink, 2009).

The adaptation process involves understanding the illness’ personal meaning for the individual and for the social structures involved (Bendelow, 2012), and re-defining selves in society throughout the stages of the disease via “shifting normalities” (Sanderson et al., 2011), which is closely linked to the readiness to participate in communication.

Most studies reveal that well-informed patients diagnosed with chronic illness subjectively experience a better quality of life (e.g. Kutner et al., 1999; Cubo et al., 2002; Shimbo et al., 2004; Dowding et al., 2006). A study on patients with chronic neurological diseases including PD has shown that limitations in communication and sharing experience may fail to satisfy information needs (Baylor, 2012). The research with Parkinson disease patients associated higher patient satisfaction and improved health outcomes with well-informed patients who were able to actively take part in decision-making regarding their disease management (Grosset, 2005). Information-seeking activity reproduces itself, because it decreases uncertainty and increases self-efficacy (Sundar, Rice, Kim and Sciamanna, 2011) and people are encouraged to take the responsibility for their health (Nettleton, 2010:138), which is favoured by the accessibility of information. Less scholarly attention is paid to the other side of the coin – to the patients who are passive in the information seeking. Monitoring (seeking) and blunting (avoiding) as coping strategies have been pointed out in information seeking research (Galarce, Ramanadhan, Viswanath 2011:171), which means that people choose an information seeking strategy that help them the best to adapt with the disease. The strategies used in different stages of adaptation and the strategy change have not been widely discussed by scholars. The study of Galarce et al. (2011) has shown that blunting can be very effective from a psychological point of view and hence the motivation to change it may be low. One explanation offered is that the information concerns mostly biomedical advice to improve the symptom control (disease-related information) while often the actual information needs might be related to the management of daily aspects, also called illness-related information (Kutner et al., 1999). Some studies give hints that the reason for choosing avoidance can be caused by information delivery– experimental studies indicate that very detailed, comprehensive information may have a negative impact on physical performance and subjective quality of life (Ward et al., 2004).

In general, there is a need to more thoroughly investigate the disease-related information seeking passivity and blunting. The growing usage of the Internet in health related information seeking (Sundar et al., 2011;

Galarce et al., 2011; Thon and Ullrich, 2009) likely make the situation more complicated: from one side, the patients can regulate the time, source, level of anonymity and amount of information, but from the other side webpages often do not comply with current readability guidelines: only 1% of the top information webpages on PD are fully comprehensible (Fitzsimmons, 2010). In this context, the social reasons of utilization of the blunting strategy in the longer time perspective and the possibilities of its change to the monitoring strategy deserve more scholarly attention. The study introduced below aims to contribute to the discussion with two questions:

1. How do chronically ill patients try to control the inflow of disease-related information in different stages of their illness both in the patient-physician and patient-patient communications, and
2. Why do they do this?

Our investigation is sociological by nature – we are not seeking out psychological explanations (that certainly are also there). We proceed from the premise that the patient's decision to limit or block the information inflow, that is to step out from the communication process in the Luhmann's sense[1], can be related to a wider socio-cultural context and caused by communication management, hence the key to change may be also related with communicative tools.

After introducing the methodology, we explore and interpret the empirical findings and finally offer suggestions regarding the timing and media of delivery.

Method and empirical case

The study is based on a secondary analysis of the transcripts of 36 in-depth interviews with Parkinson disease patients in Estonia, within the international InfoPark research project (Taba et al., 2003). The reason for secondary analysis of this particular data was to utilize the rich collected empirical data, which had not been previously analyzed from a sociological perspective. The researched situation is universal in nature and therefore useful in investigating the communicative problems, which occur generally in chronic diseases.

The interviews used a semi-structured format that made them comparable, but still permitted enough freedom for the informant to communicate his/her unique experience. Questions were divided into four main parts: (1) the period before diagnosis, (2) the period when the diagnosis was given, (3) the period after the diagnosis and (4) the patient's general information needs. Informants were selected using the databases of the Department of Neurology of the University of Tartu. All of the interviews except one were carried out in patients' homes, so that patients, in their everyday environment, would feel relaxed. The content of the interview was introduced and informed consent was obtained before the interviews. Clinical practitioners, including authors no. 3, 4 and 5 of the current study, conducted the interviews, which may have had an impact on the results. The mean duration of an interview was 1.5 hours.

The analysis was done by authors no. 1 and 2 of this article. A qualitative textual analysis was utilized to analyze the interview answers and focus group material. Respondents' comments were coded and analyzed comparatively according to the cross-case method. The coding scheme (Miles and Huberman, 1994; Miles et al., 2013) was developed deductively after reading the interview texts. In the coding, multiple *units of analysis* were used, i.e. sentences and phrases in the form of statements, configurations of terms, explicit and implicit assumptions expressed in particular stylistic and grammatical constructions, and metaphors and vivid images.

In the coding, the text units were divided into thematic categories on two axes. One axis described the information seeking strategies and consisted of codes: a) rejection versus readiness to accept new information, b) the type of the missed or avoided information and c) the wanted or unwanted arrangement of communication. On the other axis we put the different stages of the disease when the particular strategy appeared. In making periodization, we used the simple model following the questionnaire structure: (1) the period before diagnosis, (2) the period when the diagnosis was given, (3) the period after the diagnosis (see Table 1).

In the quotations given below, only the number of the respondent is provided. This analysis focuses on the two last periods because the first period had specific features that go beyond of the scope of current article.

[1]Luhmann's conceptualization of the communication process points out that understanding rather than intended meaning plays the central role (Seidl, 2004). Thus, it is not the communicator but the receiver who decides on the meaning of a message (Baecker 2001).

Table 1 ***The coding scheme of interview texts***

	Information inflow		Information content		Time, amount and channel of receiving information	
	rejection of new information	readiness to accept new information	type of the information sought for	type of the avoided information	the wanted arrangement of communication	the unwanted arrangement of communication
getting diagnosis						
first years after the diagnosis						
later years after the diagnosis						

Results

The analysis of the interview texts revealed that the patients' information-related strategies varied during different stages of the illness, depending on the progression of the disease, the level of (medical) knowledge, previous life experience and social relationships, etc. The results are presented following the temporal structure of codes.

The early period with diagnosis

The fatigue of rationalisation and fatalism was more likely to arise with freshly diagnosed patients, for whom uncertainty became a part of everyday life.

In the period shortly after the diagnosis, strategies of resistance were typical among our informants. Patients tried to avoid the unpleasant content - information about the disease diagnosis was interpreted in an oppositional mode (Hall 1980). The patient might refuse to acknowledge the diagnosis and doubt the diagnostic techniques used, as clearly represented in the following example:

> *R7: I was not satisfied with what I was told (the diagnosis). I kind of assumed that there would be more tests or something... That maybe I had some other disease. That blood samples should be taken and ... And other tests should be done, but no other tests were done.*

This example reveals not only a feeling that not everything was as it should be, but also a suspicion that the doctors were not doing everything they could and should, and hence the patient was not ready to accept the diagnosis, believing that it might not be the "final truth". Here the rational aspect – a lack of (rather specific) information about the diagnosis tools – is intertwined with the fear of the diagnosis of a fatal disease and hope for a better solution (a less threatening disease). It is questionable as to how much the explanation about the rationale of the diagnosis could help the patient in this situation, but certainly her wish to cut off (further) communication about the disease is evident.

In the following excerpt, the informant avoids naming the disease and uses "it" instead, to avoid any content. This mode of expression makes it possible for the informant to doubt the diagnosis, and indicates that the disease is sensed as a "black box", a hostile entity that is not "dissolved" into daily micro-practices:

> *R4: I'm not interested in <u>it.</u> Why be enclosed within <u>it</u> more than I have to be.*

Here the illness is clearly portrayed separately from the person's everyday life, with no motivation to "domesticate" it. The expression "I have to be" signals that the information given so far is sensed as a forcible interruption by powerful others.

Thus, in the early years after the diagnosis, patients often strive to block content, progression and symptoms of the disease with very few attempts to regulate the time, amount, or channel of the information. The patients generally felt that the information offered and the information they can interpret are very disproportional. Feeling that the inflow cannot be controlled, efforts are made to recode the information by using accusations and non-naming.

We also found another type of strategy where the content of the available and missed information are mismatched. For example, a former doctor who was a participant in this study, and who had medical knowledge of the nature of the disease, accused doctors of not telling enough, not warning about the possibility of rapid progression and being unrealistically optimistic:

> *R6: I knew this before. The doctor had nothing new to tell me/.../But I think that doctors should inform patients about the seriousness of the disease and that it will only progress. They (doctors) should not be too optimistic/.../*

This example proves that even if the patient has a sufficient amount of disease-related (biomedical) knowledge the patient will still have problems adapting to his/her illness, both emotionally and socially. Communicatively relevant messages at this stage should be addressed to the social "self", while messages addressed to individual's physical coping may be

interpreted as a forced adoption of the "sick role" (Parsons 1951), which is perceived to lead to social isolation and therefore may be blocked. This example is in line with the study by Ward et al. (2004), where it was clearly seen that education in patients with progressive neurological conditions may have negative effects, i.e. information does not necessarily guarantee success in the coping process.

The attempt to control the inflow of information is closely linked with the fear of social stigmatization. The following excerpt from the interview clearly illustrates the logic of argumentation: in order to feel more self-confident when dealing with other people, the patient tries to keep her disease-related knowledge superficial:

> *R25: I decided at once that I was not going to expose my disease /... / the patient does not have to know all the little details and all the nasty possibilities; for your own peace of mind, it is better to know only superficially.*

The fear of being stigmatized is expressed by "expose my disease", indicating a lack of rational understanding that it is not physically possible to hide PD, as the symptoms will become visible sooner or later. In a way, others also label the disease, e.g. it may be believed that patients whose symptoms are visible are exposing them deliberately and this is something to despise. This may cause avoidance of adaptive and helpful information not only from experts but also from co-patients, leaving the individual lonely and isolated:

> *R12:I tended to cry /.../ only prayed to the Heavenly Father to take me away /.../ Yes, I have been (invited to the PD Patients' Society). I don't want to go there, I don't want to go anywhere, I don't feel (a need for communication). I am so lonely here.*

The patient is reinforcing the feeling of solitude and isolation by refusing to join the PD Patients' Society or to communicate with others at all. This is one of the most serious problems that may hinder adaptation of the disease to the individual's life. The management of the fear of social stigma involves relationships with big groups of people: co-workers, neighbors, imagined "others" from media representations etc. This is connected with wider societal and cultural conditions that reach far beyond the patient's education and communication. One of the possible solutions may be providing psychological support in order to provide an opportunity for the patient to discuss personal illness-related issues. Yet, it is noteworthy that one limitation on psychological help is the fact that people might not be ready to talk about their disease or related difficulties (Vihalemm and Lubi, 2013). Still, the questions remain of how and if to involve people in the communication process, in order to activate them as information receivers. Otherwise, the state of rejection may last for years after the diagnosis, and apparently the current options (the doctor, brochures, web pages and a patients' society) do not cover the whole spectrum of possible information needs, especially of those related to simple everyday aspects and social relations.

Later years after diagnosis

Shortly after or during the early years following the diagnosis, part of the patients used the strategy of avoidance of any frightening content about the disease in order to manage (that is postpone, disguise) the new situation emotionally and socially. In later years the patients tried to independently regulate the time, amount and channels of information. Our interviews revealed that patients who have lived with their diagnosis for a longer time, prefer the freedom of asking for information themselves, i.e. a chance to define when they get information and the amount of information received each time. Having control of the communicative situation creates a feeling of freedom and security, while "forced informing" intensifies defensive reactions, as in the following example:

> *R4: /.../ if you feel ill, you will say so, and if you don't say so there is no need to disturb you, that you have this problem and, oh, what you should do now.*

The interviews provided a rich empirical evidence of the need for gradual PD-related information that is circumstantially more flexible. Respondent no. 7 doubted his diagnosis. His acceptance of the disease increased with the increase in knowledge about the disease. His sources were mainly a special brochure and his doctor. The information flow involved reading the brochure and, when symptoms appeared, he went to discuss them with his doctor. Still, he remained hesitant about the need for information in the sense that he expected to get rather positive information and basically had the same opinion as R4 in the excerpt above (e.g. "*there is no need to disturb you*").

The tendency to be hesitant also characterized respondent no. 28, who claimed that she did not believe how severe PD was until the symptoms started to appear. This indicates the relationship between disbelief and emotional acceptance of the disease, and here the need for information was not perceived. Informational needs arose only in connection with the actual symptoms and progress of the disease:

> *R28: Now I need to know in more detail how far this disease can progress and what I have to do. And I hope to find out from the doctor who deals with this. Due to the changed (physical) situation, a real need for information had arisen and now the patient could acknowledge the depth of information that was needed and hence was ready to accept it. This clearly shows the leverage point that should be taken into account in the communication process and in activating the patient within it.*

In addition, patients claimed that the communication flow should be continuous, as expressed in the following example:

R14: Well, I don't know if it's possible to say something general. There are different symptoms. Everybody has it differently. Not the same. Stages are different. Information about the disease should be continuous and constant.

This example clearly points out the need for gradually, yet constantly, provided information. The main sources named by the same respondent later in the interview were literature, doctors and even a film that was mentioned by other respondents, which shows the need to observe other patients while providing the opportunity to observe in an anonymous way:

R15: Definitely a film would be good. As they say, seeing is believing.

Still, it is important to note that the film should be available for both group and individual viewing, e.g. on the Internet, which once again provides the opportunity for smooth adaptation with relevant information in a secure environment, as well as with flexible progress that suits the individual.

In general, the goal in the communication process should be leading patients to find answers to their questions and solutions to their problems through suitable sources (a patients' society, the Internet etc.). Situations change throughout the patient's lifespan and so do the information needs during the disease span, especially interpersonally, which shows the need for different approaches besides the conventional ways of distributing disease-related information. Various sources – in-depth interviews, professional experience[2] and a previous survey we conducted (Vihalemm and Lubi, 2013) - reveal that the need for information increases along with the progression of the disease, which can bring a new trend into the adaptation process: avoidance and denial can be replaced by active seeking for information from multiple sources. The involvement of other patients who have successfully re-socialized can provide valuable assistance for other patients, at least in everyday-life aspects and in social adaptation.

In addition to the information that is distributed via medical personnel, the PD Patients' Society, as a communication channel, is also available. It is a suitable structure that provides varied and multi-modal information. In addition to cognitive information (e.g. lectures by experts), other methods are used: observation of other PD patients' behavior, and listening to and sharing immediate experience. The alternative form of expertise that originates from another patient's life experience is valued as an addition to, or as a replacement for, medical expertise. This expertise is valued when it helps the patient to maintain positive self-esteem and increases hopes for maintaining or improving the quality of life.

[2]Authors no. 3 and 5 are practicing neurologists; author no. 4 is a practicing neurology nurse.

R3: Meetings with other PD patients are useful in gaining perspective on what others are doing, how they eat and how they behave technically.

Other patients' experiences are valued only if they come from patients at the same stage of the disease, and especially not at later stages of the disease. Otherwise, denial occurs, which proves once again the need for situational or gradual communication:

R15: Well, yes, some other patients would suit well. There is no need to tell me too much, because if I got to know too much, I would feel resentful later.

The need for observation is similar to previous comments regarding the need for a film but, as mentioned by R15, observation of other PD patients might turn into a disadvantage if latter stages of disease are seen without proper psychological preparation.

In general, the analysis revealed that, especially in later stages of the disease, patients' attempts to adapt the disease to their personal lives require varied and multi-modal information from different sources. Patients can personalize the disease-specific information given in the patient-physician communication by themselves when the physician acknowledges personal variability and encourages patients' involvement in the healing process. Patients' societies provide a good structure for patients at this stage, as they offer wide sources of information, both verbal information from experts and an opportunity to observe other PD patients' behavior, listening to and sharing immediate experience. In the later stages of re-socialization, patients are also eager to find out about the wider social context of the disease and the scientific work related to it, topics that enable them to step out of the role of patient. Thus patients' societies can act as a re-socializing agent in the later stages of the disease.

Discussion

The complexity of adaptation with chronic diseases set high demands to communicative tools. The effect of psychological adjustment on the quality of life of patients is claimed to be even higher than an effect of the severity of the disease (Suzukamo, 2006). The access to high-quality evidence-based, patient-focused and clearly communicated information is an integral part of management of chronic disabling diseases that enables patients and their families to become more knowledgeable and to adapt with the disease. The essentiality of knowledge is obvious in the case of a chronic disease (Hummel, 2013:323) and often it is misapprehension by healthcare professionals to assume that while information is provided, there is competency to process it or a provision of information that would ensure adequate knowledge and skills to adopt necessary changes for management and control of the chronic disease (op cit: 324). Information needs arise on a situational basis and people become gradually re-skilled to continue their daily activities or transform them because of diminishing physical capabilities, which is challenging the communication process through the constant need for available information.

Team management is a modern standard in chronic diseases (Guo, 2009) and specific standardized education programs for patients with PD and their caregivers have been developed (A'Campo. 2010), but the dynamic, situational disease-related information needs still may come into conflict with the existing structures of information provision: fixed days of visits and procedures, patients' information books and booklets, and other ways of "packaging" classified information for patients. Our study indicates that to solve this conflict, patients, especially during the first years of diagnosis, try to control the incoming information in order to maintain their emotional and social status quo, to avoid or postpone the "normality shift" (Sanderson et al. 2011). When they cannot control the amount of frightening information they may try to recode its content, which may accumulate problems further. Our study showed that the avoidance strategy can be used both in the case of doctor-patient communication or patient-patient communication. Our (retrospective) interviews indicate that (active) participation in information circulation seems to be spiral-like, proceeding from a few situational queries into multimodal and multichannel strategies of arranging personal knowledge. This finding is consistent with other studies' findings showing that the existence of some tacit information affects whether patients continue to seek information, i.e. people who are used to seeking information to their questions, do this again (Galarce et al., 2011). The more flexible ways of information delivery (in small amount, in suitable time and situation) could help in changing the strategy of avoidance step-by-step: receivinga little piece ofinformation, one wants toknow more.

Although other patients as experts are often appreciated, (Galarce et al., 2011; Sundar et al., 2011) and the sharing of experiences between patients with incurable neurodegenerative diseases has become increasingly privileged as a source of knowledge and support (Mazanderani, 2012), our study, showed that the patient must first overcome emotional and psychological barriers, which are linked to the fear of "facing the future". Hence the patients' motivation to join patients' societies or informal communication networks may be weak,especially in societies where disease-related stigmas are stronger or the development of a civil society has been slow.

The control over information inflow offers a certain shell for normality that protects patients from unwanted content and amount. The arrangement of temporally and spatially more flexible information transfer has a good potential to change the usage of blunting as a coping strategy – which marks the end of the communication process – into more active and open strategy.

Funding

This research was supported by the Estonian Science Foundation through grant no 8347, IUT 20-38 and by the European Union through the European Regional Development Fund, Center of Excellence CECT and the Grant 3.2.1001.11-0017.

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