

Original article

# Does Advoy.com™ help patients with primary immunodeficiency diseases; experience that their life situation has improved?

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## Abstract

Lifelong immunoglobulin therapy for patients with primary immunodeficiency diseases are more often provided at home. We explored the impact of living with a chronic disease, the life situation as well as using Advoy, a new web-based patient diary with messaging function. Twelve adults from Sweden wrote an essay each about their disease and how it is to be an Advoy user. The text was analyzed with directed qualitative content analysis. The respondents stated that they were living on a border; hence their lives were much better after starting their home therapy. Using Advoy made them feel more confident, since the overview and history of their treatment gave them information and understanding about their problems. It was hard to navigate on the Advoy site, and this made some of the respondents frustrated, so they used it only for plain treatment documentation. Improvements are needed in Advoy, in order to enhance self care activities.

## Keywords

primary immunodeficiency diseases; home therapy; life situation; advoy, qualitative content analysis

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## Conflict of interest

No conflicts of interest. We have had financial support and grants to conduct the study from Ryhov County Hospital and Sahlgrenska University Hospital and Linköping University Hospital as well as an unrestricted grant from Baxter Health Care Service.

Primary immunodeficiency diseases (PID) in humans were first recognized in the early 1950s (GLANZMANN et al., 1950; BRUTON 1952). Immunodeficiency diseases are characterized by undue susceptibility to infection. Many immunodeficiency syndromes are also characterized by autoimmune diseases (ELENITOBA et al., 1997; CUNNINGHAM-RUNDLES & BODIAN, 1999, GEHA et al., 2007). Patients with PID are living with a chronic disease and in most cases they are faced with the prospect of lifelong treatment. Studies show that quality of life increases when patients can treat themselves at home

(DALY et al., 1991, GARDULF et al., 1993; 1995 NICOALY et al., 2005; GARDULF & NICOLAY 2006, NICOALY et al., 2006). This evolution towards more independent patients makes the need of monitoring their treatment greater. Patients are today most often followed up with ordinary diaries in paper forms, registering number of days feeling well or not, days on sick-leave, hospital care and days on antibiotics. Doing clinical studies these comments are often made by the help of VAS-scales and later transformed into web-based registration by investigators.

Changing from clinical care to self infusion home therapy, however, often changes the possibilities to follow-up dramatically. Self infusion therapy is becoming more common and is for example used in England and USA, mainly with intravenous use and in Sweden, Denmark and Norway most often by the subcutaneous route. Self infusion therapy implies that the patient does not visit his physician as often, which sometimes leads to too long intervals to maintain a good follow-up. The patients asked us for a more formal contact after leaving the hospital care, as the number of visits at the clinic often diminished from once or twice a month to less than twice a year.

The communication between patients and health care providers must be easier and the overview of treatment must be clearer.

## Advoy

Advoy is a new web-based patient diary with messaging function. The diary was initially created for hemophilia in 2001 (COLLINS et al., 2003). Advoy has since then been developed and adapted for the use in PID in collaboration between Baxter, Ryhov County Hospital in Jönköping and Sahlgrenska Hospital, Göteborg in Sweden. This web-based diary has been used by patients in Sweden since 2003, and in 2006 there were 60 users (BJÖRKANDER et al., 2006).

Industry Business Machines Corporation (IBM) guarantees patient and treatment data confidentiality and although Baxter is the sponsor of Advoy they only have access to aggregate data.

The data is encrypted using secure socket layer (SSL). Encryption is the translation of data into a secret code. To read an encrypted file, you must have the key that allows you to read it.

Advoy is designed to simplify the communication between the patient and the healthcare providers. With weekly or bi-weekly intervals the patient enters treatment data in connection with the immunoglobulin treatment. Both the user and the healthcare providers can then view this data easily as text or as graphs to get an overview of the health status. Navigational menus make it easy to understand and use.

The advantage for the patient is that the system is web-based and can be reached and used whenever and wherever they want as long as there is an internet connection. Advoy offers a safe way of sending messages to the healthcare provider instead of regular "open" email.

The advantage for the healthcare providers is the accessibility of a web-based system. It also gives the option

of compiling data from all the clinic's patients and also in collaboration with other clinics. All data entered into the system is stored and can be retrieved at any time in the future. It can thus be a valuable tool for future scientific works.

Two objectives were outturning from the literature and the information about Advoy; Is Advoy a useful aid for patients to mastering their life situation and, does Advoy help patients with chronic disease to perceive their life situation as improved?

## Patients and Methods

### Study population

Approximately 160 people are diagnosed with PID in Gothenburg and Falun, Sweden, and of those about 60 are Advoy users. Thirty-two patients were invited to participate in the present study. The selection criteria were that the patient was adult; older than 18 years of age, and had at least 12 months experience of Advoy. They should also have mental capacity to understand the information given. Exclusion criterion was patients doing a break of immunoglobulin substitution to evaluate the indication for continuous immunoglobulin therapy.

### Data collection

A request, as well as instructions and questionnaires were mailed/distributed by one of the nurses involved in the Advoy programme (we as researchers were not involved in the contact with the patients). The questionnaire consisted of background variables and subjects were asked to write an essay on their experience from using Advoy for a while. Two leading questions were asked, followed by some clarifying questions:

Please tell us in your own words how Advoy has affected you and your life situation, both positively and negatively. We also want to know if you have any suggestions on how to improve Advoy.

### Ethical considerations

The participants are informed primarily with written patient information. They have, however, the option of additional information, if they wish, by taking contact with us by phone or letter. Informed written consent is sent back as well as the questionnaire if they are willing to participate. Participation in the study is voluntary. If patients choose to relinquish participation it will in no circumstances affect the continued treatment or self-care via Advoy nor will it affect the normal care or relations to the care givers. All data/material will be

coded and code keys are kept separate from the data. Ethical approval was received from the Regional ethical review board registration number M6-07

### *Qualitative content analysis*

Considering the explorative aim of the study, the respondents' essays were analyzed as a whole using modern techniques of directed qualitative content analysis (HSIEH et al., 2005; MAYRING, 2000). Qualitative content analysis can be applied to e.g. transcribed interviews, texts, narratives, letters, documents, protocols and media (KRIPPENDORF, 2004).

Content analysis is one of the classical procedures for analyzing textual material, no matter where this material comes from. A central idea in this kind of analysis is that an amount of words in the text are sorted into much fewer content categories (WEBER, 1985). In content analysis, the use of categories is often derived from theoretical models that are categories not necessarily developed from empirical material. Categories could instead be brought to the material from theoretical models (FLICK, 1988). Word usage is explored aiming to discover the range of meanings that word can express in normal use.

The answers/essays from the patients are analysed with a qualitative content analysis (HSIEH et al., 2005; MAYRING, 2000; 2004). As the text material was read, statements with similarities were clustered and summarized into tentative life situation, positive and negative categories based on the questions used. The tentative categories with all respective statements were reviewed in detail. Unclear statements were explored with respect to the original context: living with PID and using Advoy. Through iterative in-depth discussions with stepwise re-categorizations and repeated validations vs. the complete primary data, a more logical and complete structure gradually emerged. Any discrepancies were resolved through discussion; no measure of inter-rater reliability was used. After completion of this process the material was put aside for some weeks of complete time-out. In a later and final stage of validation, the complete sentences from the original text material were again reviewed in their original context and condensed into final categories, including some final adjustments. Thus all the categories were validated through systematic reviews of the material. To confirm and illustrate the categories and subcategories selected, quotations related to the respective categories were presented through the work process. The quotes used in the results section were drawn to illustrate themes emerging from all respondents' statements. The categories are described in order to clarify the meaning of the units and the categories and their impact on the

patients' life situation. Trustworthiness could be enabled by using quotations from the written essays; showing fit between participants view and researchers representation of them and establishing that data; findings and description/interpretations are clearly linked (LINCOLN et al., 1985).

## **Results**

### *The respondents*

Out of 21 respondents, 14 (67%) wrote anonymously an essay responding to the questions. The respondents were aged between 22 and 64 with a mean age of about 50 and median of 53. The respondents comprised 11 women and one man. Ten were married or cohabitant and four were single; 11 (79 %) had children and five (42 %) had grandchildren.

Eleven respondents were employees in various levels; one was a student and two were retired (early retirement).

The respondents had had their diagnosis PID from to 2 to 30 years before and had been Advoy users between one to 5 years.

The findings are presented as three categories according to the research questions: the life situation, positive aspects of using Advoy and negative aspects of using Advoy.

### *The life situation*

The respondents stated that their life situation was affected by their disease, even though some of them tried to ignore the disease and would not allow it to take place or focus in their lives. They wanted to take on a positive perspective, living a 'normal' life and thought it would be better to talk about a health diary instead of a patient diary. The majority of the respondents stated that they are living quite a good life now when they have got the treatment with gammaglobulin infusions. Instead of having continuous infections during the year they are now concentrated to one to three weeks during wintertime. The treatment made them feel a kind of freedom, which improved their quality of life.

One effect mentioned in the text was tiredness. As one respondent wrote; *I am tired of being tired*. Having the diagnosis PID was to live on the border, constantly being tired and misunderstood. This tiredness made the respondents become isolated. They had to relinquish some activities because of this tiredness but also because of the risk of infections. This tiredness also made them feel slighted, regarding taking in new information and learn about new tasks.

Another aspect mentioned was lack of knowledge and understanding, both in society and the health care system.

One respondent wrote: *...it is difficult to explain and give information to people around. There is a huge confusion. Immune deficiencies seem to be equal to HIV.* It was also hard to be forced to justify their tiredness and 'indolence' to people around, explaining that they had a chronic disease.

### **Positive aspects of using Advoy**

There were some aspects mentioned over and over again; synopsis of treatment and accessibility. Regarding the synopsis of treatment the respondents stated that it was valuable to have an historical overview, to see documentation of how they have felt and what they have done. This synopsis gave them important information about their problems and they felt that they had control over bad periods. This documentation could also facilitate tracing batches with contagion if needed.

When the respondents wrote about accessibility, the e-mail function (message function) was highlighted. The possibility to write questions and get an answer promptly was valued as significant. Having this accessibility made the respondents feel confident. There was a feeling of having a direct connection to the staff. As one respondent wrote; *Advoy did not improve my life, but I feel that I am recognized.*

Advoy facilitated the accessibility; being on the Internet, it can be reached and used whenever and wherever they want as long as there is an internet connection.

### **Negative aspects of using Advoy**

Most of the respondents wrote that the menus in Advoy were hard to handle. They asked for simplification, making it easier to find the areas to document in, for today it is necessary to jump continuously between different functions. If there is tiredness in the respondents due to their disease, they do not manage to sit at the computer and make the documentation correctly. Some of the respondents made a confession and wrote that they only document their infusions or only use the message function, since it is difficult to handle the menu. The diary was too difficult to use, so some of the respondents used a manual diary to document in.

The respondents also wrote about the frustration they felt regarding repeatedly filling in the same information e.g. drug, dose, time etc.

There was also frustration regarding how to manage to fill in the scale for quality of life. As one respondent wrote: *...to fill in how I have been feeling since the latest infusion is difficult, you manage to feel the total scale within a week. Shall I fill in a mean value???*

Some of the respondents wrote that they miss personal contact and feedback about how all facts in the Advoy system

are used. One example given: *...to fill in all these facts. Is it a control system to see if we are compliant? Who takes part of my information?* Advoy is built on that the patient is active and makes all the documentation accurate, but many of them scamp, as they wrote, since it is difficult and time consuming to make it correct.

### **Discussion**

This study shows that living with a chronic disease, such as PID, is affecting the persons' life situation in many ways. They are living with a constant tiredness and their daily life is restricted due to this, but also due to risks of getting infections. Some of the respondents meant that they were living on the border. This is something that we have not found in other studies.

However, several of the respondents stated that they were living a quite good life being in the immunoglobulin treatment with weekly or bi-weekly intervals, administrated at home. This treatment provides the patients with a feeling of a little bit more energy and feeling less tiredness. Similar findings have been reported before according PID and treatment satisfaction as well as life situation effects (GARDULF et al., 1993; NICOLAY et al., 2006). Regarding the measurement about quality of life in other studies (NICOLAY et al., 2006), it could only be speculated about what the respondents really measured, since they thought it was difficult to score in the scale. Since they could feel "very bad" to "very good" during one week, it could be supposed that they should score a mean value. Here, a matter for further thinking: What are the patients in other studies measuring?

This study showed that Advoy is a helpful tool for persons with PID. It is constructed as an instrument for high quality security standard for home treatment with immunoglobulin but also as a diary that can be used both by the client and the caregiver. This notation book with graphical presentation allows the patient to see the consequences of various action methods over time. This was appreciated by the respondents, since this overview gave them information and understanding about their problems and they felt more in control. This is in agreement with another study (COLLINS et al., 2003). The possibility of tracing batches with contagion via the documentation in Advoy made the respondents feel more secure in handling their treatment at home, if an episode of infective immunoglobulin would happen again, as previously. Accessibility and getting prompt answers made the respondents feel confident: they were well informed about the treatment and its side effects. Similar findings have been reported before (KITNER et al., 2006). The attitude to immunoglobulin substitution at home is positive.

Advoy facilitated the accessibility by being on the Internet. Patients and treatment staff can enter and review data anywhere in the world, as long as there is an Internet connection. This finding is in agreement with a pilot study reported before (COLLINS et al., 2003).

Most of the respondents wrote that the navigation around the site was hard to manage. There is a need for improvement, this was also an issue mentioned in that reported pilot study before (COLLINS et al., 2003). Since there were difficulties in managing the navigation around the menus, the respondents did not use Advoy correctly. They selected what to document and how to use Advoy. The diary was too difficult to use, so some of the respondents used a manual diary instead.

Some of the respondents wrote that personal contact and feedback about how all facts in the Advoy system are used were lacking. The respondents also wrote about the frustration they felt regarding repeatedly filling in the same information about their treatment. There were respondents asking if all these questions and facts to be filled in Advoy were for the treatment staff; in order to check upon the patient being compliant. Well, it seems that information is missing or not totally clear showing if patients affected by antibody deficiencies should be carefully monitored in order to assess clinical efficacy and, if possible, to avoid related side-effects (GEHA et al., 2007).

Advoy is built on that the patient is active and makes all the documentation accurate. So there are some improvements to be done regarding navigation around the site, clear information and repeated information and feedback with respect to all facts documented. The Internet offers important opportunities to treatment staff and patients to improve their communication and develop the management of a chronic disease, as reported before (COLLINS et al., 2003).

Internet can be interactive, and this may contribute to a better management of the disease and better self care activities. As the respondents wrote, *Advoy did not improve my quality of life, but the home treatment did. If Advoy is used accurately then I will be given information and facts that give me control over my disease and my life situation.*

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