

The personalised discharge letter

the experience of patients and parents from the Filadelfia Epilepsy Hospital

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The personalised discharge-letter. The experience of patients and parents from The Epilepsy Hospital Filadelfia

Keywords: : Discharge Letter, Everyday Life, Epilepsy, Patient Perspective, Qualitative Research, Quality of Life

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Authors contribution

Christina Louise Lindhardt has contributed with conducting the interviews, the analysis and main responsible for writing the article.

Marie Louise Mærkedal has conducted a larger part of the interviews and been in the analyzing process. Further she has conducted to the methodology part of the article and the discussion.

Signe Madsen, has conducted the patient contact, analyzed and participating in writing the article

Conny Brandt has conducted to the analysis and the writing up the article as a whole.

Ethical approval was obtained from the Ethical Committee of Science in the Zealand Region and notified to the Danish Data Protection Agency. According to Danish law, all participants

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gave informed consent. Personal data have been stored according to good clinical practice. Primarily we had ethical concerns including patients with epilepsy who had co-morbid illnesses. Due to this, we excluded this category of patients from participating.

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Conflict of interest

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Abstract

Objective: To examine the experience of a discharge letter received by patients suffering from epilepsy and parents with children who suffer from epilepsy.

Design: Qualitative research inspired by a phenomenological methodology approach.

Setting: Face-to-face interviews with patients and parents of epileptic children in their own homes.

Sample: Participants (total n=11).

Methods: In-depth interviews were recorded verbatim, transcribed and analysed.

Results: Two themes were identified: i) it was written about me, ii) a sense of feeling secure. By being discharged with a personalised letter, the participants felt seen and heard. The discharge letter enabled them to contact their doctor and the Philadelphia hospital more efficiently if needed. Parents indicated that the discharge letter bridged the uncertainty that they often experienced when dealing with the child's school or authorities in general.

Conclusions: The discharge letter enables the participants to make the transition into everyday life with the best and most up-to-date information about themselves and their current condition as an epilepsy patient. The discharge letter empowers the patient or parents to face everyday life. The discharge becomes a kind of passport to the outside world when encountering the general practitioner, the school, or in other circumstances where the patient engages. The discharge letter becomes a patient-centred tool proving that enhanced communication and understanding between healthcare professionals, patients and parents succeeds. This example could be transferable to other hospitals to heighten the patient's self-efficacy and quality of life after being discharged from the hospital.

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Introduction

Epilepsy is a common neurological disorder with comorbidities such as depression and cognitive difficulties. (1, 2). Research with the patient's perspective in focus is sparse both nationally and as well as internationally (3). In Denmark, the prevalence of this disease is approximately 50,000 – and the number of epilepsy cases increases every year. Epilepsy is a disorder which less commonly discussed, and epilepsy may lead to social isolation, pessimism, low self-esteem, and shame. Frequently, psychological problems, as well as mental and mood disorders, follow the condition (4). The patient's perspective and the experience of being a parent to either children or adults is less explored (5).

The Epilepsy Hospital Filadelfia (hereafter Filadelfia) has a status as a national medical centre treating both children and adults with epilepsy and adults suffering the effects of acquired brain injuries or comorbid illnesses. Filadelfia is the only highly specialised Danish hospital in the medical field of diagnostics and treatment of patients with epilepsy. Furthermore, the hospital offers a dedicated social program for inpatients and outpatients to help them in their daily lives. The hospital facilitates the only individual school for children and young people with epilepsy in Denmark. Filadelfia's expertise is based on many years of specialisation in the diagnostics and treatment of patients with epilepsy (6).

These individual facilities for patients provide unique opportunities and create a vibrant and productive research environment. The healthcare professionals at Filadelfia are both qualified nurses and auxiliary nurses, in this article referred to as nurses. Both groups are in charge of discharging the patients and thus writing the discharge letter. Filadelfia's philosophy is based upon three values: respect, seeing the patient as a whole and health promotion (7). On average Filadelfia has 1,243 admissions as well as 5,806 ambulatory patients per annum (2018 figures).

The healthcare professionals observed at Filadelfia that the patients and parents of children (hereafter named parents) expressed they felt left on their own and therefore less informed about their admission to the hospital. The patients and parents described the period after being discharged from the hospital as being very difficult, and subsequently, the patients and parents were frequently visiting their general practitioner to seek guidance (8). A "discharge education" for admitted patients and their parents is

1 mentioned in the literature. This entails a co-ordinated education based on individualisation of the
2 individual patient's knowledge, needs and cognitive skills (8).
3 To investigate this phenomenon of patients experiencing a lack of information, Filadelfia initiated a new
4 method in 2015, the personalised discharge letter. This is to be used in the daily clinic when patients are
5 dismissed from the hospital. The Health Authorities in Denmark had simultaneously recommended a
6 mandatory discharge letter (epikrise in Danish) (9) which is a tool used in communication between
7 doctors when discharging patients in Denmark generally (9).
8 The discharge letter was inspired by the Danish Quality Model (IKAS 2006) (10) to improve the
9 inclusion of patients in the transition from patient to a citizen. In the national survey of patient
10 experiences (LUP) (11), it was described that the patients and parents lack information when visiting
11 Filadelfia or being discharged. Simultaneously, an intern survey (2015) at Filadelfia showed a need for
12 improved communication with the patients. This relates to both written and oral communication, as well
13 as the transition from patient to a citizen. It was intended to increase patient involvement at Filadelfia.
14 The personalised discharge letter is aimed at making the patient's transition to life at home as smooth as
15 possible. The content of the discharge letter is an overview documenting the patient's admission to the
16 hospital. It contains information about their specific admission and epilepsy, as well as specific
17 information about training or situations related to the patient's admission. The content of the discharge
18 letter differs from the mandatory discharge letter (epikrise), which focuses on the patient's future
19 treatment. The discharge letter is designed in a particular format with a checklist with the patient's health
20 data and specific admission. The discharge letter is written directly to the patient him-/herself by the
21 patient's contact person at Filadelfia. Common terminology has been used in all the letters to avoid
22 misunderstandings and errors. The department for adult epilepsy and the department of child epilepsy at
23 Filadelfia were involved in the content. (Table 1)

24

25 Table 1. The content of a personal discharge letter – an example

26

27 Study design and population

28 The research project is a qualitative study inspired by a phenomenological approach focusing on patients'
29 and parents' experiences.

30

31 Ethical considerations

32 Ethical approval was obtained from the Ethical Committee of Science in the Zealand Region and notified
33 to the Danish Data Protection Agency. According to Danish law, all participants gave informed consent.

34 Personal data have been stored according to good clinical practice. Primarily we had ethical concerns

1 including patients with epilepsy who had co-morbid illnesses. Due to this, we excluded this category of
2 patients from participating.

3 4 Material and methods

5 This study was conducted between June and December 2016 by researchers from University College
6 Absalon. The researchers had previous research experience with in-depth qualitative interviews. The
7 sample size was not calculated before data collection. It was determined during the research process based
8 on the theoretical saturation point. This is the point in data collection when information from the
9 participants bring no further additional insights to the research questions (12). In this study data saturation
10 was evident after 10 interviews. However, an additional two interviews were carried out to ensure that all
11 areas were covered.

12 The research nurses at Filadelfia included the participants. A total of 7 adults (4 women and 3 men) at the
13 age of 23 – 67 years suffering from epilepsy and 5 parents (mothers) with children (4 boys and 1 girl) at
14 the age of 2 – 14 years suffering from epilepsy. Inclusion criteria were all adult patients suffering from
15 epilepsy, who had been hospitalised at the Epilepsy Hospital Filadelfia and all parents with children
16 suffering from epilepsy, who had been hospitalised at the Epilepsy Hospital Filadelfia. The inclusion
17 criteria required that participants should be capable of understanding and speaking Danish. Exclusion
18 criteria were adults with an acquired brain injury or co-morbid illnesses and suffering from epilepsy, who
19 has been hospitalised at the Epilepsy Hospital Filadelfia.

20
21 The inclusion period was June -September 2016, 13 participants fitted the criteria and could be included.
22 However, two participants declined participation when approached by phone and 11 participants
23 remained. The interviews (45 – 90 min) were conducted in the participants' homes and audio-digitally
24 recorded. A semi-structured interview guide was used to assist the interviewer in eliciting the experience
25 of the participant interviewed. Qualitative face-to-face in-depth interviews with 11 participants were
26 carried out using the following central question: "What was your experience of the personalised discharge
27 letter when you were discharged from Filadelfia hospital?" During the interviewing, reflective listening
28 was in focus to establish trust and encourage the participant to speak about the phenomenon. The
29 interview was conducted using a phenomenological approach where the participants were allowed to
30 reflect and to be aware of their thoughts and feelings during their experience. Time was allowed before
31 and after the interview for further dialogue if this was necessary. The recordings were subsequently
32 transcribed verbatim for analysis.

33 34 Methodology

1 A phenomenologically inspired approach was selected as the experience of the participants was sought.
2 According to Giorgi, once the data are obtained, these reflect the participants' experience at the time of
3 the interview and cannot be changed. Giorgi's method is therefore distinguishable from other methods
4 because of his belief that once the interview is conducted, the researcher should not go back to the
5 participant for proofreading and rely on her intuition (13). This makes Giorgi's method applicable when
6 entering into the participants' everyday life, where time is limited. (Table 2).

7
8 Table 2. Example of Giorgi's 5 step analysis

9
10 Data analysis

11 The analysis was inspired by the descriptive phenomenological method by Giorgi (13). First, the text was
12 read and re-read with an open mind to get a sense of it as a whole. Meaningful units were then chosen and
13 marked with the phenomena under investigation in mind. These units could appear as a piece of a
14 sentence or a longer section. Units were then selected separately by the researchers. A final list of units
15 was created. These units were then converted into sentences or words by the researchers - each unit being
16 contemplated individually and then merged. The final step was to incorporate and put the meaningful
17 units into themes and then the essential structure, the essence, was made clear. Validation was obtained
18 during the interview as a common understanding was established between the interviewer and the
19 participant. The researcher asked if what she asked during the interview was understood while keeping
20 her pre-understanding in mind (13).

21
22 Results

23 The two themes identified was "It was written about me" and "A sense of feeling secure". Overall, the
24 participants were positive about being discharged with a personal letter. The themes are presented with
25 illustrative quotations from some of the participants.

26
27 It was written about me.

28 The first theme identified how several of the participants expressed the discharge letter as personal. Their
29 names or their children's names, personal identity number and diagnoses were identified, and they
30 recognised their admission to Filadelfia. One of the participants said that the letter was life-changing, as at
31 that moment she saw her precise diagnosis written down:

32
33 "I think this was nice as I have never known what kind of epilepsy I have. I was informed through that
34 letter" (Participant 6, patient).

1
2 The letter became a kind of documentation of her diagnosis. The participant could tell her mother that she
3 was not responsible for her daughter's illness as the daughter was born with a genetic condition. Patients
4 often express that being participants in their illness both in the hospital and at home is of great
5 importance. They can communicate what is happening to their family and feel at ease with the process
6 along the way. The language used in the discharge letter was mentioned as a positive factor, as the
7 participants found the written words both understandable and informative using everyday language:
8 *"...I actually found it written clearly and simply"* (Participant 4, patient)

9
10 Other participants found it useful that the contact details of their contact person at Philadelphia were
11 mentioned in the letter, in case they needed to contact them. Participants described that the medication list
12 was important in the discharge letter. One participant found it helpful as an updated list of medicine was
13 available, whereas another respondent experienced that her list of medicine was missing and specifically
14 requested information about the side-effects of her medication.

15 A participant considered the letter to have been written in a rush and was not impressed with the content:
16 *"Roughly said, I feel I could almost have written it myself"* (Participant 2, patient)

17
18 Other participants felt they had been given sufficient time to ask questions concerning the letter.
19 Nevertheless, the participant found the information useful when seeing his or her general practitioner
20 discussing the attacks as the letter documented the individual history from Philadelphia. Thus, the discharge
21 letter has similarities with the mandatory discharge letter; most participants found that the discharge letter
22 was more comfortable to read, more comprehensive and communicated directly to the individual patients.

23
24 A sense of feeling secure

25 The second theme was the participants' experience, how the discharge letter, by being personal created a
26 higher level of security for the patients and parents after being discharged from Philadelphia. The content of
27 the discharge letter enabled the patient to remember what had happened and ensured that the patient could
28 easily understand, for example, what had occurred during their admission and secured the doses of
29 medication they need to treat their epilepsy.

30 The discharge letter gave a deeper understanding of one of the parents regarding her son. The parent had
31 received confirmation from the discharge letter that it is okay that her teenage son can walk in town or
32 cycle through the woods alone. This created a feeling of secureness as well as certainty for the family that
33 they do not have to be nervous about general epileptic attacks as what the son experiences are
34 myokloniers, which are harmless.

1 The letter described the individual patient's diagnosis and generated more understanding and knowledge
2 regarding epilepsy. The diagnosis thus became easier to perceive as the parents have received all the
3 information about the family member.

4 "It is my impression that it is personal as it is specifically about my son, with everything about him, motor
5 skills, disease, learning abilities, and his attention level. It is clear down to the smallest detail, and also in
6 regarding his social relations when admitted to Philadelphia"(Participant 1, parent)
7

8 Another participant, a parent mentioned the discharge letter as helping her feeling secure when her
9 daughter had an attack. Instead of being afraid every time she had an attack, she could alleviate her
10 family's concerns with her newly documented knowledge from the letter that it was not dangerous in itself
11 to experience such a small seizure.
12

13 The discharge letter and the care from the nurses made the relation to the participants individual and gave
14 them a feeling of feeling secure when home.
15

16 *"...so, for example, my contact person was mentioned and the telephone number and things like that...."*

17 (Participant 8, patient)
18

19 Subsequently, the discharge letter being personal creates a concrete change in the life world of the patient
20 and parents when they are at home. The participants were informed in the discharge letter which form of
21 epilepsy they have, not merely that they have epilepsy is an example.
22

23 In the interviews, it was argued that it was a fear for parents when their child would become a teenager
24 and how epilepsy would influence the changes in the child. The parents expressed that the personal
25 discharge letter would be helpful here as the child would not be treated in the paediatric department but as
26 an adult.
27

28 Discussion

29 Principal findings

30 This study identified possibilities and barriers when using a personal discharge letter. The overall finding
31 was that the participants experienced the personal discharge letter to be useful in their everyday life when
32 discharged from hospital. Moreover, questions were raised about being discharged as a patient or a parent
33

1 to a child with epilepsy. Barriers such as time, communication and understanding of the letter were
2 recognised.

3 As noted in the introduction, the purpose of this study was to explore the experience of patients and
4 parents discharged from Philadelphia with a personal letter. The results support the existing literature about
5 discharge from hospital in general (14, 15) however, literature describing the personalised discharge letter
6 is challenging to find.

7
8
9 It was written about me

10 Generally, the personal discharge letter had an impact on the participants in the transition between the
11 patients' admission to the hospital and discharges to their homes.

12 The findings showed an interesting tendency in the move from having "individual" to "personal"
13 approach in the discharge letter. When the participants received personal information, they experienced a
14 change in how they experienced their admission. Wedlund et al write that care and treatment to people
15 with epilepsy should be individually designed (14).

16 In particular the participants who were parents felt that the individual letter may be helpful. The discharge
17 letter enables the patients or the parents to make the transition into everyday life with the best and most
18 up-to-date information about themselves and their current condition as a patient with epilepsy. However,
19 findings in this study point out that although every patient is different, their experience with the discharge
20 letter is almost the same. Consequently, the discharge letter becomes the participants' passport to the
21 outside world when encountering the workplace, the general practitioner or the children's school.

22 The personal discharge letter helped the participants to identify themselves and their medical condition in
23 the written word and thus understand how it is affecting them. Findings from the literature show how
24 other areas of healthcare benefit from a personalised discharge letter(16, 17). However, the participants
25 described that it was of importance that they were involved in decisions regarding their treatment – also at
26 home. Healthcare Management, such as shared decision making – to include and involve the patient in
27 their treatment and care can support this (18, 19).

28
29 `A sense of feeling secure

30 Feeling secure was a theme expressed by most of the participants in the study. According to Mollon,
31 feeling safe is an emotional state where the patients experience that the care they receive contributed to a
32 sense of security (20) Epilepsy is a condition which makes the patients and parents particular vulnerable
33 (3). It is described in the literature how the sense of feeling secure enhances the discharge from hospital
34 (20, 21). Patients with epilepsy are often not informed adequately about their condition and may find

1 themselves prone to stigma and shame, which was also mentioned by the participants. Often, they are
2 missing out of the forwarded information due to cognitive disabilities prone to epilepsy (15, 16). In this
3 study, the participants expressed that being seen as individuals and reading one's own story in the letter
4 was of importance, which lead to a sense of feeling secure. Studies support the finding and emphasise that
5 patient contact, both written and oral, should be personal in order to insure, that the patient has understood
6 the communication forwarded (15).

7 Patients need to feel secure during admission to hospital; however, feeling secure when being discharged
8 was frequently mentioned by the participants (22). Epilepsy may affect the patient's ability to be fully
9 present aware, and they fear they have missed important information during admission to hospital (20).
10 This was expressed both by adult patients and by parents to children with epilepsy as well as fearing they
11 may have misunderstood or missed information.

12 The participants who were parents felt insecure about having a child with epilepsy (23). In particular, the
13 children's transition into teenage years when they were no longer attached to the paediatric department
14 was a concern (23). Teenagers with epilepsy experience loneliness in the transition into adulthood if they
15 are not being informed adequately about their situation (28). The personal discharge letter will support the
16 teenager when meeting authorities without parental guidance.

17 .
18 This study refers to how obstacles e.g. sorting out medication when being discharged. The personal
19 discharge letter helped the participant obtaining an overview of the specific medication. However, it was
20 expressed it could be difficult for them to administer the medicine at home. At an individual level more
21 guidance during the transition between hospital and home may have been needed e.g. the possibility of a
22 telephone or video contact to the hospital (19, 24) or a visit from the district nurse from the municipality.

23
24 Factors, such as the nurse's skills and knowledge of the individual patient could influence the discharge
25 letter. The time issue was mentioned by several of the participants as they had appreciated the time spent
26 reading through the letter with the nurse, e.g. correcting errors. It became evident that a mutual
27 understanding and the non-complex use of language when reading and writing the discharge letter was
28 essential for the participant's everyday life when home. The use of a personal discharge letter could be
29 supported by a patient and a family-centred approach, e.g. family nursing, which involves both parents
30 and relatives (19). In caring for vulnerable patients and relatives, e.g. patients with epilepsy, it is
31 recognised that empathetic and reflective listening may influence the experience of being discharged from
32 hospital and reduce the number of re-admissions and errors (25, 26).

33 In summary, the discharge letter eased the transition from hospital to everyday life and thus improved
34 quality of life for the participants. The participants were empowered in their everyday lives through the

1 co-creation of the letter. (27). Moreover, attention to patients discharged from the hospital reduces re-
2 admission and costs (28).

3
4 The discharge letter becomes a patient-centred tool where communication and understanding between
5 nurses and patients and parents are essential. Subsequently, the discharge letter could help to bridge the
6 gap to patients with health illiteracy, as the patient co-creates the oral and written information with the
7 nurse to safeguard the patient's individual and personal situation (21, 29). An impact on the patient's self-
8 efficacy and quality of life after discharge from the hospital may be seen here. A further implementation
9 of the discharge letter may lead to nurses working on the discharge letter while the patient is in the
10 hospital – and not before the discharge, where time might be scarce (28).

11 In healthcare there is a demand for high quality and a patient-centred approach (11, 30). The personalised
12 discharge letter is an example of how a discharge letter can support patients with diagnosis such as
13 epilepsy in their transition from hospital to home. Further, careful planning and follow up on the hospital
14 admission may enhance the discharge positively for the patients and family (18)

15
16 The main strength of this study is the use of a validated qualitative and scientifically robust methodology
17 to explore how the patients and parents from Philadelphia experienced discharged from hospital with a
18 personal letter. This could not have been achieved using a quantitative study. A limitation of the study
19 could be that the study only explores the user experience from the patients' and parents' side. It could,
20 have been interesting to explore the healthcare professionals' perspective. Furthermore, the inclusion of
21 patients and parents of children with epilepsy with co-morbid illnesses may have given another insight
22 into the phenomenon. Despite these limitations, this research study reveals insight into future research.
23 This could be conducted in a follow-up study.

24 25 Conclusion

26 Our study found that the discharge letter enables the patients and parents to make the transition into
27 everyday life with the best and most up-to-date information about themselves and their children as well as
28 their immediate condition as a patient with epilepsy. The letter becomes a passport to the outside world
29 when encountering the general practitioner, the or authorities in general.

30 This study has produced new information and knowledge which will enable Philadelphia to continue
31 personally designed care and treatment when discharging patients from the hospital. The letter becomes a
32 patient-centred tool proving that enhanced communication and understanding between nurses and patients
33 is vital throughout admission and discharge. Findings from this study may be transferrable to other
34 hospitals to heighten the patient's self-efficacy and quality of life after being discharged from the hospital.

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Conflict of interest

The authors state that there was no conflict of interest in connection with this article.

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Table 1. The Personal Discharge Letter - an example

<p>The Personal Discharge Letter</p> <p>Personal security number: Name: Admission to Ward Contact persons: Diagnoses: Aim for admission: Interdisciplinary discharge conference date: Patients' own experience of the admission: Current attack situation: I have achieved the following from my admission according to my aims: I have worked on the following with my contact person: You may continue working with: Psychologist: Occupational therapist: Physiotherapist: You have been taught in: (an example) The cognitive model, anxiety, perfectionism, Self-esteem, stress, sleep. Ambulatory meetings: You will be called in to speak to Dr..... in approximately 3 month's time. Your contact person will call you at home in approximately 14 days after discharge.</p> <p>Best wishes the Psychotherapeutic team</p>

Table 2. Giorgi's analysis

1. Sense of the whole	All transcripts were read and re-read to get a sense of the whole experience of the participants.
2. Discrimination of meaning units	After becoming familiarised with all the transcripts, a thorough reading took place in which the significant meaning of the differences of the phenomena in the transcripts were taken out. These were labelled as meaning units.
3. Transformation of meaning units	Reflection was used by the author group to convert the participant's statements with respect to their experiences into understandable language. This was done by considering each unit and then combining with others.
4. Specific description	This step involved a more specific description of the phenomena.

of the phenomenon

5. General description
of the phenomenon

The final step was to synthesize and put the meaningful units into themes. The essential structure, the core understanding of the phenomena is clarified.