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Complexity of the Patients' Perspective of Living with Atrial Fibrillation

V. Høgh¹, S. Riahi^{1, 2}, C. Delmar²⁻⁵

Kurzfassung: Patientenperspektive bei Vorhofflimmern. Die Perspektive von Patienten ist naturgemäß komplex. Aus diesem Grund erfordert die Untersuchung der Perspektive von Patienten mit Vorhofflimmern, die entscheidend für die Lebensqualität der Betroffenen ist, komplexe Forschungsprozesse.

Das vorliegende Manuskript verwendet qualitative und quantitative Datenquellen, um die Komplexität der Perspektive von Patienten mit Vorhofflimmern zu beschreiben. Es wird hier, bezogen auf ein Patientenjahr mit Vorhofflimmern, dargestellt, wie Scores aus Fragebögen, Scores aus qualitativen Daten aus dem täglichen Leben der Patienten sowie ihrem Familien- und Berufsleben unterstützen können. Diese Synergie wird eindrucksvoll anhand des aufbereiteten Fallbeispiels aufgezeigt. Daten aus Beobachtungen, aus der schwierigen Aufgabe, diverse Körperreaktionen dem Problem Vorhofflimmern zuzuordnen, sowie aus Scores von selbst beantworteten krankheitsspezifischen Fragebögen tragen dazu bei, Informationen darüber zu gewinnen, wie Patienten Einschränkungen bei den täglichen

Aktivitäten besser erkennen können, wie auch Einschränkungen, die durch die Symptome des Vorhofflimmerns erklärbar sind. Bedingt durch die Tatsache, dass Verbindungen und Kommunikation quer durch die verschiedenen Sektoren des Gesundheitssystems fehlen, steigt die Herausforderung für die nötige Unterstützung von Patienten mit Vorhofflimmern ständig.

Schlüsselwörter: Perspektive, Patient, Vorhofflimmern, Lebensqualität; Gesundheit, Verlaufsbeobachtung

Abstract: The patients' perspective is by nature complex. Investigating the patients' perspective, which is important for the quality of care for patients living with atrial fibrillation, therefore calls for complex research processes.

This article aims to illuminate the complexity of the patients' perspective of living with atrial fibrillation by combining qualitative and quantitative data sources and methods.

Related to a one-year patient journey of living with paroxysmal atrial fibrillation it is here illus-

trated how scores from questionnaires can be explored by supporting the scores with qualitative data on information related to the context of the patient's daily life, family life and work life.

The example provided in the article illustrates how the qualitative and quantitative information work as a synergy. Together, information gained from participant observations, on the challenge of recognizing bodily reactions related to AF, and scores from the self-administered disease specific questionnaire can contribute to enrich the details of information on how patients recognise their limitation in daily activity more than relating their limitation to symptoms on AF. Due to lack of connection and communication across organisational sectors in the healthcare system, the challenge of gaining the needed support for a patient living with AF, is further increased. **J Kardiol 2017; 24 (9-10): 212-5.**

Keywords: perspective, patient, atrial fibrillation, lived experience, health status, patient journey

■ Background

Atrial Fibrillation (AF) is a significant and serious health burden associated with an increased risk of stroke and other co-morbidities. With predictions of an expected expanding population of patients, AF is considered an epidemic [1, 2]. In clinical practice, patients with AF might be considered to be non-complex and easy patients when compared to patients living with other serious and immediate life threatening conditions. This may be one of the reasons for patients with AF reporting they are neglected and left alone with their doubts and questions, thereby experiencing marginalisation of their concerns [3-6]. As the patients are alone in experiencing their whole journey, quality of care relies not only on knowledge on AF, but also information on the patient's perspective of living with the disease [7]. The patients' perspective involves concepts as quality of life, self-reported health, and lived experience, and is therefore complex in nature [8]. This complexity is further increased with the population of patients with AF being heterogeneous in relation to age, gender, co-morbidities, and symptom burden [7, 9]. Patient reported outcomes are popular and widely applied for assessing the pa-

tient's perspective. But, the interpretation of results from the variety of assessment tools used can be a challenge [7]. The challenge related to interpretation of results and difficulties in comparing study populations are documented by reports as major methodological weaknesses in terms of low sample size, short-term follow-up, and use of non-validated assessment tools [10-12].

A holistic view on humans, understood as "humans are like all others, like some others, and like no other" is important when considering the patients' perspective. Humans are like all others, because all humans are in the world with their lived bodies. All human beings thereby contain universal biological components and patterns of existence [8, 13-15]. Humans share typical human patterns in specific life situations of living with a disease, as AF. Some patients receive the same treatment, have the same co-morbid conditions and symptoms, and live a daily life with AF. Therefore, humans are like some others. Nevertheless, despite typical human and biological patterns in the specific human's situation, a human's subjective lived experience will never reoccur in the exact same form, even for the same human being. The human uniqueness therefore implies that humans are like no others. The patients' perspective illustrated here is therefore complex and demands the use of a holistic view. Access to the patients' perspective therefore requires complex research processes. Based on experiences gained undertaking a research project on the patients' perspective of living with AF [8], the aim of this article is to exemplify the benefits of combining both qualitative and quantitative data and methods in order to understand the complexity of the patients' perspective of living with AF.

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Aim

To illuminate the complexity of the patients' perspective of living with AF by combining qualitative and quantitative data sources and methods.

Method

This article is based on an already published research project [8], designed as a case study [16] and with data sources, published in three separate papers [17–19]. The paper published in 2014, illustrates how the concept of quality of life appears to be taken for granted in the context of patients living with AF [18]. Based on a text analysis of 53 scientific research papers, we emphasised the need for defining and providing arguments when applying the concept of quality of life for a scientific purpose. The cross sectional study using data reporting health status from 42,598 individuals in the Danish Diet, Cancer, and Health cohort, illustrated how physical components of health status is lower when being diagnosed with AF and/or atrial flutter for both men and women, when comparing with participants without the diagnosis [17]. In contrast, we found no systematically significant difference on mental components of health status between the two groups. Based on these results questions remained in relation to: why and how the physical components of health status were affected by AF and how to explain the unexpected results of no systematic difference for mental components score of health status between the two groups. Therefore, we designed a study to illuminate how AF can impact on a person's daily life, family life and work life at an individual level [19]. One of the researchers followed a 55-year-old man in his one-year patient journey after being diagnosed with paroxysmal AF. The patient will be referred to as 'he' and the researcher as 'she' in the following.

The researcher followed the patient during his five outpatient visits, two radio frequency ablations in the hospital, and 38 visits in general practice for check-ups on International Normalised Ratio (INR) related to his anticoagulant treatment. Accordingly, the researcher conducted several home visits where she also talked to his wife and son. Approximately six months into the study, the researcher also gained access to visit him at his work. Data sources for the study consisted of: Participant observa-

tions; Generic and disease-specific self-administered questionnaires – Short Form 36 [20], Atrial Fibrillation Effect on QualiTY-of-life – AFEQT [21], and AF-QOL-18 [22, 23]; Letters received from hospital; his medical records both from the hospital and from general practice. The patient filled in the three questionnaires five times during the one-year journey. Qualitative data were analysed inspired by a phenomenological inspired approach of meaning condensation [24, 25]. The results from questionnaires underwent inspection for exceptional patterns. Narrative weaving – a technique developed within mixed methods [26] – was used in order to integrate quantitative and qualitative data sources.



Figure 1. Display overall scores from AFEQT, global score from AF-QOL, physical component and mental component scores (PCS and MCS) from SF-36v2. Time on the x-axis and score on the y-axis. All scales range from 0–100, with a score of 100 being the best. © V. Høgh

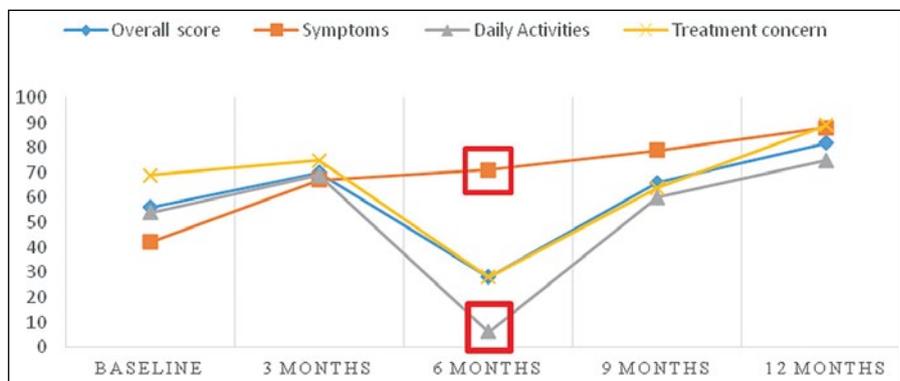


Figure 2. Display scores from subscales of AFEQT at five point in time of the one-year patient journey. Time on the x-axis and score on the y-axis. All scales range from 0–100, with a score of 100 being the best. © V. Høgh



Figure 3. Display scores from subscales of AF-QOL at five point in time of the one-year patient journey. Time on the x-axis and score on the y-axis. All scales range from 0–100, with a score of 100 being the best. © V. Høgh

■ Results

Illustrating the impact on the patient's daily life, family life and work life, the results from the qualitative analysis revealed four central themes: 'balancing responsibility', 'navigating the system', 'adjusting to the situation' and 'recognizing bodily reactions'. Lack of communication between sectors (hospital and general practice) left the patient alone with the responsibility for his journey, which increased his challenge of navigating the healthcare system. Adjusting to life with the condition of AF happened over time. Lack of acknowledgement of his own perspective on the situation when going to the general practitioner complaining on not being able to run and bike, resulted in blaming himself for showing up. Moreover, it was difficult for him to link his body's reactions to symptoms from AF. Further descriptions of the four central themes are provided in the published paper [19]. The results from the three questionnaires are displayed graphically in Figure 1. Specific results from the subscale scores from AFEQT and AF-QOL are displayed graphically in Figure 2 and Figure 3, respectively. The benefits of combining both qualitative and quantitative data sources are illustrated in the following examples.

Presentation of a Central Theme from the Qualitative Data Analysis

The central theme of 'Recognizing bodily reactions' illustrates the challenge for a patient to pose experience and knowledge to point on his body's reactions and symptoms due to AF. Despite gradually adjusting to life with AF, it was troublesome for the patient to recognize his own body's reactions. He just felt tired, but was it because of his AF, his 10-kilo weight gain or the flu? He found it hard to tell. He realised that he could use his sports watch with a basic heart-rate monitor to get an idea, but he was still in doubt. The expectation from healthcare professionals about knowing when and how to react in case of a new event of AF combined with the lack of connection and communication between sectors and the healthcare professionals in the hospital and in general practice increased the challenge of recognizing his bodily reactions.

Presentation of Exceptional Patterns from Questionnaires

Looking at the score results from the questionnaires displayed in Figure 1, it can be seen that across the one year three of the summary scores AF-QOL, SF-36 MCS and SF-36 PCS, did not have much of exceptional variation. In contrast, the overall score for AFEQT at six months is interesting. As displayed in Figure 2, the specific subscale scores for AFEQT reporting 'Daily Activities' are responsible for this low overall score at the stage of six months in the study and not the scale expressing 'Symptoms' as would have been expected to capture his physical limitation due to AF. As displayed in Figure 3, the patient's physical limitation was not captured from the AF-QOL. In contrast to the results from AFEQT, the scores in the subscale for 'Physical dimension' in AF-QOL were surprisingly high and progressed throughout the study.

■ Discussion

The issue of capturing the limitation in physical activity due to AF in the subscale of 'Daily Activities' instead of the subscale

of 'Symptoms' is in line with the central theme of 'Recognizing Bodily Reactions'. From the qualitative data, we know that the first ablation was conducted two months after entering the study. At six months, the patient was awaiting his second ablation. Between his first and second ablation the struggles with running and biking were worse than ever before. We also know from his medical journal, that the patient developed both AF and atrial flutter in the period between his first and second ablation. The questionnaire scores can thereby inform about the patient's overall perception of health status over time and can be related to other studies investigating health status in patients living with AF considering age, gender and co-morbidity. Integrating the knowledge gained from following the patient's journey and scores from questionnaires can then elaborate both on his overall impression and the context related to his one-year journey. Without knowledge of the context it is difficult to interpret the scores from questionnaires, and relying solely upon description of lived experiences gained from participant observations we cannot display his overall impression of health status. The patients' reported health status, as well as individual variation in lived experiences, is important for accessing his perspective of living with AF [7]. Integrating the qualitative and quantitative data sources can thereby enrich the level of details on the results.

The limitation on interpretation of results from questionnaires was illustrated in our cross sectional study on the 42,598 individuals from the Diet, Cancer and Health Study [17], because the study reveals no information on the specific context related to the results of self-reported health status. From this example, we illustrate that the AFEQT is more sensitive than the AF-QOL and the SF-36 for capturing the impact from AF regarding his physical limitation on the patient's life. From the qualitative data, we know that the patient reported, he found it hard to complete the questionnaires because his physical ability was constantly changing. Some days he was able to run 5 kilometres whilst having difficulties with climbing the stairs to second floor returning home. This issue is likely to illustrate how variable and dynamic health status can be. This is essential to keep in mind when interpreting results from standardised health status questionnaires. Regarding recognition of bodily reaction, it was hard for the patient to specify if it was his AF causing troubles. He just felt tired. He needed skills to relate his physical limitation to symptoms on AF. As illustrated, his search for support in relation to his physical limitations was impeded by the poor communication and connection between organisational sector boundaries – in the hospital and in general practice. In hospital, the healthcare professionals would ask him what he was told by his general practitioner, and in general practice, the general practice nurse would ask what they told him in the hospital. Fortunately, the patient recognised how important his small orange card with the results from his blood samples on INR could help him in the process of being in a patient journey across organisational sector boundaries. With the limited link between sectors, this card represented the link, even though he felt too much responsibility for his own journey. He still felt left alone.

The challenge relating to the journey across organisational sector boundaries is not a new one. Since 1975 it has been reported that there is room for improvement in the discharge

process from hospital to general practice [27]. Even though there has been significant improvement, it remains a challenge for healthcare professionals to collaborate across organisational sector boundaries [28]. The task of collaborating across organisational sector boundaries is thus challenged by institutional conditions in the society, which are supporting working with own sector and not across sectors [29]. Lack of dialogue and lack of knowledge on one another's clinical practice in the respective sectors can turn the collaboration related to discharge from hospital into a battlefield. For the future treatment and care of patients living with AF and development of a comprehensive patient education program, it is important to place the overall responsibility for the patient journey. Accordingly, to be responsible as a healthcare professional in order to support the patient to achieve the needed knowledge in the process of living with AF, human dignity and respect are important values for supporting the patient's autonomy and self-management. Likewise, providing the patient with a reflective support and standard information adjusted to the patient's specific situation – provides the health care system with a patient centred and holistic approach across organisational sector boundaries. This process may need involvement from the government level and the health care authorities.

Conclusion

The example provided illustrates how qualitative information gained from participant observations, on the challenge of recognising bodily reactions related to AF and scores from the self-administered AFEQT disease specific questionnaire together can contribute to enrich the details of information, and work as a synergy. This synergy is specified from this article by illuminating how qualitative descriptions on patients recognising their limitation in daily activity more than relating their limitation to what can be considered a symptom due to AF, are connected to scores from questionnaires. The qualitative and quantitative information can thereby work as a synergy. Lack of connection and communication across organisational sector boundaries in the healthcare system, increases the patient's challenge of gaining the needed support with responsibility and self-management when living with AF.

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Conflict of Interest

The authors declare that they have no conflicts of interest.

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