

“Nursing ICT” Methodological Approach to Analyse Patients’ Needs and Expectations

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Abstract: Many European healthcare systems face extensive changes as traditional forms of medical treatment cannot be financed anymore. Structures erode and gaps emerge. eHealth is said to be the solution appropriate to the needs of patients and healthcare professionals. But, although a broad variety of promising eHealth applications can be found, a deeper understanding of reasons for success and failure is missing. Based on the fundamental presumption that illness means more than a physical defect, especially in the case of chronic illness this paper argues that developers of eHealth solutions have to understand patients’ needs and expectations. Requirements engineering for eHealth solutions thus has to take not only rational arguments into account but has to obey emotional as well as social facts. In this paper, we present a methodological approach to analyse patients’ needs and expectations using psychological and sociological theories. Interviews with patients are used to illustrate the theoretical findings.

1 Introduction

Nowadays, it is pretty difficult to imagine a situation in daily life not influenced by information and communication technology (ICT). ICT has become an integral part of everyday life and has caused several waves of innovation that have had a tremendous impact on our lives. The Internet has become the major integration platform that allows to access and to integrate any kind of information that is electronically available.

This also comes true for the healthcare system. Healthcare organizations use innovative information technologies in order to optimize business processes. Online health information and virtual communities are examples for the way how patients and their relatives use ICT in order to manage their disease. Studies show that health information seeking via Internet has become a normal activity [EPK02]. Doctors and other healthcare professionals state that patients have changed their attitudes towards them, especially, that they have started discussing about therapy and medication. A lot of patients have become members of online groups, e.g. forums and chats, and find support in these virtual groups. With respect to ICT used as a therapeutic means the majority of the solutions are home care applications. Examples are electronic health records, integrated clinical signs monitoring and medication reminders.

A next step is the mobilisation of information and communication technology. The combination of minimized hardware and wireless data transfer allows the development of mobile applications enabling a flexible support of the user regardless of location and surrounding infrastructure. According to telecommunication companies future life will be more flexible and convenient. Services or service spaces will accompany the user regardless of location and time. People will live in a surrounding that facilitates everyday life. Still, vision and reality differ a lot. It is pretty difficult to find convincing solutions. Nowadays, the majority of mobile applications are used for fun and entertainment, only.

With respect to healthcare one can find a lot of promises. Most of them focus on patients being enabled to live a normal life again as a mobile eHealth application secures their well-being regardless of time and location. A well-known example for this is the so-called heart-handly that automatically calls the ambulance in case of emergency. Applications like this might be helpful for the individual to a certain degree. But they do not bring significant changes in medical care. Applications like the heart-handly are nothing more than an extension lead of a doctor or hospital. In order to support changing structures and interaction in healthcare and to fill gaps, ICT has to become more complex and more “human”.

The problem is that nobody really asks for patients’ needs and expectations. Besides technical and functional requirements social and emotional requirements that deal with the meaning of illness have to be fulfilled, e.g. medical confidentiality and professionalism, not to mention trust, confidence and consolation. These requirements result from characteristics of health and disease. Sick people have special needs. They are not like customers that buy a product or service, as the illness touches their body and soul. Nursing is not just a job and health is not a product that can be bought. Although a broad variety of promising eHealth applications can be found, a deeper understanding of reasons for success and failure does not exist. Furthermore, it is even impossible to judge the benefit and importance of successful solutions.

The aim of this paper is to define patients’ needs and to discuss consequences for the development and developers of “nursing” ICT. The question is how ICT can be designed and used in a way that it is more than an instrument that allows long-distance care. If ICT is to become more than such an instrument – as the discussion about eHealth suggests - ICT has to get a new and more sophisticated significance.

2 New Interaction in Healthcare

Most of the European healthcare systems face extensive changes. Politicians, healthcare professionals and patient organisations state that the established systems are not sufficient anymore. They speak of the breakdown of systems and structures. As a consequence traditional forms of interaction and cooperation between doctors and patients change. Above all, this comes true in the sector of chronic diseases. An analysis of the situation shows three central problems:

- Rise of chronic diseases: Most of the healthcare programmes are set up for acute diseases. With respect to actual statistics, only 20 percent of diseases are acute, whereas the majority of patients suffer from chronic diseases [He05, Wo05]. The treatment of those persons, who are chronically or long-time ill, requires a close partnership between the patient and all healthcare providers, very often until the end of one's life. As people get older and the modern medicine gets better, people will live longer although suffering from a chronic disease. The costs for this will be enormous. *In order to reduce costs the frequency of doctor patient interaction need to be downsized without a deterioration of the quality of care.*
- Lack of compliance: Compliance is defined as the willingness to follow a doctor's advice [SS79]. The level of non-compliance is very high. Reasons for this are numerous. Patients are often confronted with complex instructions difficult to understand. Doctors often do not have enough time to explain things in a way that laymen can follow. Furthermore, it is difficult to integrate new activities into everyday life. Although patients are willing to change their life they are not able to do so as too many things need to be changed. Finally, many people dispel their illness. They try to forget it and reject obtrusive signs of being ill, e.g. taking medicine. *In order to improve compliance new forms of interaction and education are needed.*
- Reforms: The rise of chronic diseases and the lack of compliance have lead to a cost explosion. Even today most of the national healthcare systems already have enormous deficits. In many countries the conditions in hospitals are horrible. Doctors in Germany go on strike as they do not accept the discrepancy between amount of work and payment. Patients have to wait months until they get a certain treatment and have to pay more on their own. Politicians and policy makers want patients to become customers that use medical services. They try to optimize business processes in healthcare by adopting medical structures to the structures of service sectors. *Due to reforms of healthcare systems patients have to care more for their own without endangering their well-being.*

To sum up, health professionals and patients are confronted with a situation where changes are overwhelming. The traditional forms of healthcare disappear. Being a doctor is more and more a job in the services and being a patient today requires self-responsibility to a very high degree [Ro05]. This development is dangerous as nursing is not just a job and health is not a product that can be bought. Although the established ways of interaction and cooperation are partly outdated we cannot abolish them without compensation. If information and communication structures break the whole system is at risk. Bridges, links and middlemen are needed to handle the emerging gaps in the interaction structures.

Here, information technologies come into play. Many people think that ICT can fill the gaps and even may substitute doctors. For example, instead of going twice a month to the doctor, the visits are reduced to one per quarter. In the meanwhile, correspondence is realized via emails and chats with a medical communication centre.

Undoubtedly, it is possible to integrate ICT into interaction and cooperation structures. The question is how and where to integrate it. What are the characteristics of the patient doctor relationship? Which interactions between doctors and patients are essential? Which are obsolete? How to judge them? From our point of view, there is only one starting point that might serve as criterion: patients' needs and expectations. Before we change structures and processes we must understand what patients really need, what they expect from the doctors, what they can do on their own and where they need help. Then we will be able to develop and implement ICT that is really useful.

3 Patients' Needs – Doctors' Tasks

In this section, we focus on patients' needs and expectations. Firstly, we shortly describe related work, i.e. research done in information and medical science. Secondly, we introduce classical psychological theories about needs and expectations. Thirdly, we conceptualize patients' needs as one side of a social relationship, whereas the doctor is the essential complement of the patient in their interactive partnership. Finally, we will bring together the psychological and social perspective and take them as starting point for defining patients' needs.

3.1 Status Quo

The usage of information and communication technology to improve the management of chronic disease is discussed both in information and medical science. Although we find a lot of theoretical and empirical works the spectrum of them is very narrow and it is difficult to get statements about patients' needs. Research topics in information science are online health information and telemedicine.

Online health information research focuses on the way patients use online applications and how this influences the care process. It is often said, that patients are not able to tell the good from the bad of online health information. According to Ferguson and colleagues [Fe00] this is not true. Ferguson argues that the term “patient” in the sense of an invalid, a sufferer or victim is no longer appropriate. Instead, terms like “customer” or “client” should be used. With this he tries to strengthen the position of patients and pleads for a better service. In order to define patients’ needs Ferguson has analysed preferred applications and websites. According to his research search-engines, e-mail, online support, virtual groups and medical guidance are the favourites. We may assume that the first and the latter show the need for knowledge in order to manage a disease, whereas e-mail, online support and virtual groups can be interpreted as the need for community and the wish to share one’s feelings with others who are in the same situation. Another important aspect is the fact, that not only patients but relatives use these options, too. This presumably shows the social dimension of chronic disease, whereas the disease affects the whole family. Still, these explanations are not reliable.

The majority of research done in telemedicine investigates the functionalities of home monitoring and home telecare systems. Case studies and field tests are used as proof of concept or to show cost efficiency of the applications [CLB03, FG02]. Typical applications include the management of diabetes, hypertension and chronic heart failure. Although many studies mention communication functionalities only technical aspects are investigated on depths, e.g. how often a person uses the data-transfer and how good the quality of mobile phone pictures is. Psychological and social aspects are not discussed. The focus is put on the hard facts of illness. Telemedicine systems provide a tool for specialists. They facilitate continuous data monitoring of distant patients. The early identification of adverse trends in clinical signs can either avoid hospital readmission or reduce the length of a hospital stay. Still, we do not know if telemedicine really meets the needs of patients. An evidence for improved healthcare is not available.

In medical science the use of ICT is mainly discussed in connection with self-management and disease management programmes. A lot of studies describe the possibilities of self-management programs, compare them to traditional care and enlist means to motivate patients to participate [GT97]. Examples range from instructions about the consequences of an illness to financial incentives. Although we gain a good insight into successful measurements we miss explanations why these measurements are successful.

To summarize, neither information nor medical science answers the question what patients need. Although a broad variety of promising solutions can be found, a deeper understanding of reasons for success and failure does not exist. Furthermore, it is even impossible to judge the benefit and importance of successful solutions. Do they really help patients? Do they improve life? Until now, we are not able to answer these questions. In our opinion, the reason for this is that the methodological integration of the patients’ perspective is missing. Therefore, our approach starts from psychological and sociological theories that conceptualize needs and expectations.

3.2 In Search of Patients' Needs

Needs are investigated in different areas, e.g. psychology and economy. A classical theory is Maslow's theory of human motivation and the hierarchy of needs [Ma54]. The picture below shows the building blocks of the hierarchy. Basic needs are psychological needs, e.g. food, warmth, home. Safety needs include need for protection and security, whereas the need for belonging and love addresses emotional and social aspects. The fourth level is a psychological aspect, the need for esteem. Without respect and admiration people become depressed. Finally, people have to be creative and to express themselves in order to have a good life.

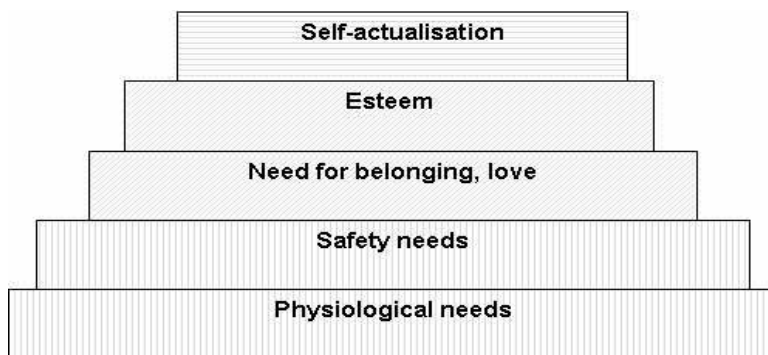


Figure 1: Maslow's hierarchy of needs

With respect to patients' needs it is useful to distinguish three instead of five levels. The first level encompasses physiological and safety needs. These needs are met by the classical healthcare, i.e. treating physical complaints. The second level deals with the social dimension as patients need to be part of a group or society. Illness should not lead to isolation. Esteem and self-actualization are difficult to transfer as they touch on a new aspect whereas the patient plays an active role. Examples for this can be found in the Internet where experienced patients take the role of an expert and give advice to new patients.

Another more business oriented approach [Ha02] distinguishes between individual and collective needs and between primary and secondary needs. While individual needs are restricted to the single person collective needs result from societal life. According to this theory, the need for healthcare is a condition for sustaining society. Thus, healthcare should not be reduced to an individual problem. The whole society is responsible for this. Another important aspect is the difference between primary and secondary needs. From this we learn that most of the needs are products of civilisation. To aim for education, wellness, wealth and transportation is a consequence of socialisation. Even longing for being well is partly a learned attitude. The explanation for this is that being well is no absolute term. Especially, in the case of chronic diseases the health status has to be qualified according to the particular course of disease.

To sum up, we can formulate the following assumptions:

- Basic or primary needs versus secondary needs: The majority of needs are not physiologically but socially and culturally based. Only addressing the physiological part of illness means neglecting important aspects.
- Individual and collective task: Being well should not be reduced to an individual task as it is a collective need. Thus, society has to care for a functioning healthcare system and for the single person, whereas the individual must adopt self-management as a life long task.
- Quality of life: Ill people still have the need for belonging and love. Isolation has to be avoided and integration is necessary.
- Identity: Being ill should not lead to passiveness. People have to be creative in order to hold on their identity. Essentials of this are communication processes, as communication is central for human life.
- Social construct: Being well and being ill are no absolute terms. Both are socially constructed, i.e. society defines what being ill means.
- Relativity: The level of health is related to the individual course of disease. A person suffering from asthma has other criteria for being well than a person suffering from hypertension. Furthermore, a person who has never been ill before will act in another way than a person who has been suffering for years.

Needs are more or less wishes. They express the gap between desirable and real conditions. Nevertheless, one cannot judge the possibility of fulfilment. Needs are appropriate or not due to individual characteristics. Thus, taking needs as a basis for defining requirements on ICT is too vague. In order to come to more obliging statements we discuss expectations in the next section.

3.3 Great Expectations

Expectations are assumptions based upon social norms. Thus, human life is not as chaotic as it sometimes seems. A great part of it is ruled by norms. Norms regulate human action as they guarantee that people are likely to act in a commonly accepted way. Besides single norms roles are of great importance for social life. Roles define how the occupant of a social position has to act. As a result, if we know the role of an individual, we are able to guess his or her predispositions to act.

In healthcare we find two central roles: the role of the patient and the role of the doctor. A sick person becomes a patient by getting in touch with a doctor. Parsons [Pa51] described this relationship as the nucleus of the healthcare system. He theorized illness as a dysfunctional deviance that jeopardises society. People suffering from a disease are not able to work or to fulfil normal tasks and need to be reintegrated. In order to manage this situation and to facilitate the reintegration, the doctor-patient relationship consists of two complementary roles.

The sick role is a transitional state of a temporary nature only. It legitimates the absence and abides the normal level of human respect. According to Parsons, four norms govern the sick role: First, individuals are not responsible for their illness; second, sick people are excused from normal obligations until they are well; third, illness is undesirable; and fourth, sick persons should seek professional help. They will get it from people occupying the doctor role.

The doctor role legitimates actions that touch the private sphere. Socialisation and role expectations guarantee that persons taking the role of a doctor act in accordance with the high responsibility they have for the single person and the whole society. The same comes true for the patient who will obey the doctor in order to gain a functional state again. Thus, the sick and the doctor role build a stable network of obligations and responsibilities based upon social mechanisms such as professionalism and role expectations. Parsons focuses on these more functional aspects where the doctor restores the dysfunctional state of the patient.

Parsons has been criticised for different reasons. The main critic centres upon his functional perspective. From a more holistic perspective, patients are more than an ill body. They are sufferers. Therefore, doctors should be able to take the role of an understanding therapist, too. Furthermore the relationship between patient and doctors is not only service-based but trust-based (see fig2). Trust is necessary as the patient doctor relationship is very asymmetric. The patient can neither constrain nor control the doctor. He is inferior to him. Nevertheless, trust is possible as the doctor role is of high moral standing. Patients have good reasons to accept inferiority and dependence as misbehaviour will be sanctioned by society [La00].

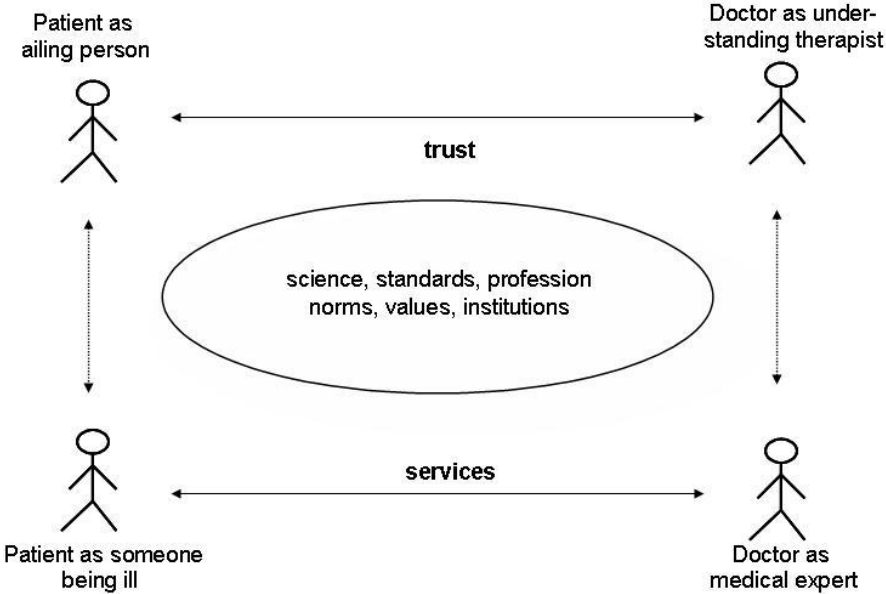


Figure 2: Patient doctor relationship

The following assumptions can be derived from the theories discussed above:

- Networks and groups are binding forces: The interaction between patient and doctor is ruled by social norms. Patients know what they can expect from a doctor. Their hopes and fears are related to long-time established and commonly accepted social conventions.
- Roles are basis for interpretation: It makes no sense thinking about the patient without considering the role of the doctor. Patients' expectations are oriented towards the doctor and his abilities and vice versa. The meaning of illness depends on the way how patient and doctor interact.
- Trust based upon high moral standing: The patient doctor relationship is a very trustful relationship. The foundation for this is the high moral standing of the doctor.

To sum up, patients' expectations should be conceptualized as a social and interactive phenomenon. They base upon a stable network of obligations and rights between patient and doctor. The high moral standing of the doctor is backed by society. Under these conditions trust is possible although patients are in a high-risk situation, where mistakes harm their body and soul. Thus, requirement analysis should start from a middle or macro level and not from the micro level, i.e. the individual. Decisive factors are a) the importance of groups and social networks, b) the meaning and significance of illness, and c) the high moral standard of the role of the doctor. Every factor may be the core of a strategy for systematically transferring patients' needs to ICT functionality. The next step is to translate the abstract terms of moral, network and meaning into practical requirements on e-Health applications.

4 Requirements on eHealth

In this section, we introduce requirements on eHealth applications that can be derived from the needs and expectations discussed above. We comment on ICT functionalities that might meet these requirements, too. Furthermore, we will consider their empirical evidence according to findings of expert interviews and workshops¹ [He04].

In order to define requirements we first arranged a brainstorming with a group of five ICT experts. It was important, that four of them had a sociological or medical background and that they had a lot of experience in user centred system development. The work we did was like a translation from one language to another. As a result we had a list of requirements on eHealth (see table 1) that we discussed with health professionals specialized in psychosomatic illnesses and cardiology.

¹ Interviews and workshops are part of a mobile health project for obese adults and children that began in 2003. The clinicians are specialised in psychosomatics, cardiology, paediatrics and diet. This year, the fieldwork starts. Besides the fieldwork a survey with patients suffering from cardiovascular diseases will be conducted.

In a next step we talked with a group of seven patients suffering from obesity about our findings. Three of the participating patients were persons who had been treated in a clinic half a year ago. The others were treated at that time. We started with the following questions: “Which problems did you have after leaving the clinic?” and “After leaving the clinic which problems might occur?” respectively. According to the patients the most critical aspect was losing the social relationships that had been established while staying in the clinic. Besides contacts with health professionals the interaction with other patients was crucial. The second point was passivity. During the treatment patients were forced to be active and they got the impression that they could do something for their wellbeing. Being home again they were confronted with everyday life and fell back in the former passiveness. Finally, the moral instance of the doctor or therapist was missing. Patients explained that they tried to remember the warnings of the dietician in order to motivate themselves but that this was not enough. Furthermore, patients missed the trustful atmosphere.

We not only argued about requirements but tried to imagine ICT functionalities and asked the patients what might have helped them. It is important to note that we did not comment on the application we had in mind but only mentioned information technology in general. Some of the answers were very clear, e.g. “timer to eat more slowly” or “diary to review the day”. It was not too difficult to transfer answers like these to ICT functionalities. The problem was to find solutions for vague answers such as “getting the feeling that somebody is there” or “being motivated”. Still we succeeded in some cases. Examples are a feedback mechanism in order to give people the feeling that somebody is there, a reminder to stimulate action and a counter to motivate to do exercises.

It is possible to distinguish two groups of functionalities. The first group consists of functionalities that correspond to favourite Internet and telecare applications, e.g. discussion boards. Our approach helps to explain why these applications are successful: They satisfy the need for networks and for being part of a group. The same comes true for standards, rules and control mechanisms. They give a feeling of security and thus stabilize patients’ expectations, although to a lesser degree than the role of a doctor does.

Besides these well-known functionalities the second group includes innovative ideas (see table 1, entries written in italics). One of them is interaction. Most of the actual applications tend to control the patient and to free him or her from obligations. According to the need for self-actualisation this approach is false as it conceptualises the patient as a passive subject. ICT should force patients to be active, to think and to decide. Furthermore, change and surprise are important. Exhaustive system design seems to be outdated. Instead, little creative components should be combined by chance in order to give the feeling that the system is “alive”. We discussed this topic with paediatrics and they put emphasize on this aspect. In order to interest children eHealth applications should be surprising. Systematically and well-arranged content is boring, even if it is of a great variety. The experts said that less would be more. It would be enough to offer only one or two exercises per week, if they were changed regularly.

Rule-based communication supports the discourse between health professional and patient as parts of the interaction are ruled by the application. A fundamental prerequisite is that this kind of communication is based upon and integrated into a social relationship in order to avoid an Eliza effect.

Related topics are individualisation and customisation. Both are prominent topics in ICT research. The aim is to adapt content and services to the context of a person. According to our findings the particular course of disease might as well as the structure of everyday life help to define the context. Patients said that contextualisation did not need to be automatic. It would be enough to offer information and service bundles for critical situations, e.g. “feeling alone” or “being under stress”. The selection would be realized actively by the patients. This confirms the need for activity as discussed before.

	Need, expectation	Requirements	ICT functionality
Network	Health is physiologically and socially based.	The treatment of patients should be holistic.	Open framework architecture
	Healthcare is a collective task.	Publicity, enlightenment, education and discourse should be possible	Medical guidance systems, eLearning
	Illness should not lead to isolation.	Integration strategies are needed.	Discussion boards, online groups
Meaning	Illness should not lead to passiveness.	Patients should play an active role	<i>Interactive applications</i>
	Illness and health are social constructs.	Initiating a public debate about eHealth.	Discussion boards
	The level of health relates to the corresponding course of disease.	Patients need individualised and customized applications.	<i>Context-sensitivity, structure of everyday life as guideline</i>
Moral	Patients’ expectations are oriented towards the doctor and his abilities.	An equivalent of doctor is needed.	<i>Rule-based communication</i>
	Patients know what they can expect from a doctor.	People need to know what they can expect from their counterpart.	Standards, rules, control
	The high moral standard of the doctor is the foundation of trust.	A moral instance is needed.	<i>Trustworthy proxy agent</i>

Table 1: Network – meaning - moral

In order to test the practicability of the functionalities we developed a prototype according to the above. A preliminary result is that interaction and change are decisive. The moral aspect and its relevance for establishing a trustful relationship are of great importance, too. In our project it was easy to create a good atmosphere as we took a clinic and its health professionals as a starting point. We used them as “anchor” for the eHealth application. By this, moral and trust were transferred to the application. From our point of view such an anchor in everyday life is necessary in order to reembed [Gi84] eHealth in real life and thus close the gap between the e- and the real world.

5 Conclusion

The starting point of this paper was the missing methodological integration of patients' needs and expectations. We have shown that psychological and sociological theories are surprisingly useful. Firstly, they help judging why and to what degree ICT applications meet the needs of patients. Secondly, we are able to define requirements that have not been taken into account before. The reason for this is that they address a completely different type of medical ICT: ICT that is interactive and changes according to the patient. The real challenge is that neither health care professionals nor ICT experts have the slightest idea how to do so. Thus, the aim is to develop a "thick description" [Ge73] of patients' lives by getting very close to them. As a consequence the work of ICT developers will change. They must get in touch with patients - and with illness.

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