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ORIGINAL ARTICLE

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The role of religious beliefs for the acceptance of xenotransplantation. Exploring dimensions of xenotransplantation in the field of hospital chaplaincy*

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Abstract

Background: The Changsha Communiqué (2008) calls for a greater account to be taken of the ethical aspects of xenotransplantation as well as of public perception. This also applies to the field of hospital chaplaincy. So far, there has been no empirical exploration of the assessment and acceptance of xenotransplantation by pastoral workers in German-speaking countries. In view of the prospect of clinical trials, in-depth research is both sensible and necessary, since both xeno- and allotransplantation can have far-reaching consequences for patients, their relatives, and the social environment. In addition to the tasks of health monitoring, questions of the individual handling with and integration of a xenotransplant must also be considered. They can affect one's own identity and self-image and thus also affect religious dimensions. Hence, they make a comprehensive range of accompaniment necessary.

Methods: This paper presents the first explorative results of a Dialogue Board with Christian, Jewish, and Muslim hospital chaplains. It explores pastoral challenges of xenotransplantation for the German-speaking countries, in particular (a) self-image and tasks of hospital pastoral care, (b) religious aspects of transplantation, and (c) religious aspects of xenotransplantation as anticipated by the hospital pastors.

Results: Depending on their religious background, hospital chaplains see different pastoral challenges when xenotransplantation reaches clinical stage. In particular, the effects on the identity and religious self-image of those affected must be taken into account. Three desiderata or recommendations for action emerged from the Dialogue Board: (a) initial, advanced and further training for hospital pastoral workers, (b) contact points for patients, and (c) interreligious cooperation and a joint statement. All participants of the Dialogue Board emphasized the chances of xenotransplantation and expressed their hope that xenogenic transplants could save patients or improve the quality of their life substantially.

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Conclusions: Xenotransplantation can affect the identity work of patients and relatives also in religious terms. In order to provide better pastoral and psychosocial support for these persons within the framework of the hospital, it is important to reflect on such challenges at an early stage and to develop concepts for pastoral further training and pastoral care in xenotransplantation.

KEYWORDS

Christianity, Dialogue Board, hospital chaplaincy, Islam, Judaism, pastoral care, theology, xenotransplantation

1 | INTRODUCTION

At the end of 2018, research into the transplantation of animal cells, tissues, and organs attracted broad media attention. Munich scientists had succeeded in transplanting a baboon with a genetically modified pig's heart, which it lived with for six and a half months.[1] This was a considerable success compared to earlier xenotransplantations. It now seems more realistic that in a few years genetically modified animal organs, in this case pig hearts, will be transplanted to humans, while clinical trials with islet cells are already under way. Therefore, the prospective examination of these new medical possibilities also appears to be more urgent for all those who could accompany and care for patients and their relatives in the future.

The Changsha Communiqué (2008) of the First WHO Global Consultation on Regulatory Requirements for Xenotransplantation Clinical Trials in its principles calls for a greater account of the ethical aspects of xenotransplantation as well as of public perception. "Because of these wider community risks, xenotransplantation clinical trials and procedures need to be effectively regulated. There should be no xenotransplantation in the absence of effective regulation by the government of the country. Regulation should have a legal basis with powers to ban unregulated procedures and enforce compliance with regulatory requirements. The regulatory system should be transparent, must include scientific and ethical assessment and should involve the public."[2] This also applies to the field of hospital chaplaincy. While there are empirical studies on the assessment and acceptance of xenotransplantation,[3,4] there is no empirical exploration of the assessment of pastoral workers in German-speaking countries. In the face of prospective clinical trials, in-depth research is both sensible and necessary.

Since both xeno- and allotransplantation can have far-reaching consequences for patients, their relatives, and the social environment, in addition to the tasks of health monitoring, questions of personal contact and integration must also be considered. They can affect one's own identity and self-image and thus also affect religious dimensions. Hence, they make a comprehensive range of accompaniment necessary.[5-7]

2 | EXPLORING THE "PASTORAL CHALLENGES OF XENOTRANSPLANTATION"—AN INTERRELIGIOUS DIALOGUE BOARD

This article presents results of an initial qualitative exploration with experts focussing on pastoral counselling and hospital chaplaincy in the German-speaking context. Against this background, an expert forum in the form of a Dialogue Board took place in October 2018, at which hospital pastoral workers from a Christian, Jewish, and Muslim background exchanged views on the challenges of xenotransplantation and, based on their practical experience, drew up scenarios for accompanying xenotransplant patients and their relatives, identified possible difficulties, explored potentials, and developed initial, partly religion-specific, partly common pastoral perspectives.

Among the participating experts, who came from Germany and Austria, were four full-time pastoral workers, three Catholic, and one Protestant. In addition, one Jewish and two Muslim pastoral workers took part, who do voluntary work by looking after the needs of patients. On the basis of an introduction to the research status of xenotransplantation, the participants discussed the following topics: hospital pastoral care in general (a), religious aspects of transplantation (b), and in particular of xenotransplantation (c). Based on this, desiderata and recommendations for action for pastoral care in hospitals were identified and developed (d). The article presents the central discussions and results.

2.1 | Self-image and tasks of hospital pastoral care

In the three major monotheistic religions, it is part of their established practice to take care of the sick.[8-12] In the 20th century, special pastoral care has been developed in hospitals in German-speaking countries. This so-called hospital pastoral care is usually provided by professional pastoral workers on behalf of the respective religious community. The integration into the medical-care team varies from hospital to hospital. For some years now, a Jewish and Islamic pastoral care or accompaniment of patients has been developed gradually, which is largely based on voluntary work.

The first unit focused on individual ideas, experiences, and expectations around hospital care including the respective ideals of hospital pastoral workers. Key questions were "What are my ideals of hospital pastoral care?," "What is my role as a pastoral care worker?," "What are specific challenges and contexts of pastoral care in hospitals?," "What are the needs and desires of the patients I accompany?" In discussions between the experts, it became clear that the main task of pastoral care in hospitals is to provide open, empathetic, and empowering attention to patients and their relatives as well as to clinic staff. Especially, the Jewish and Islamic sides also do a lot of educational work. They explain to the patients and their families the meaning of religious rules and show that the already existentially demanding situation of a hospital stay must not be additionally burdened by the fact that, for example, they are not able to comply with food and prayer regulations. Among all professional groups in hospital, the particular strength of pastoral care is to support people in an exceptional situation through simple presence, conversations or rites and to bring other perspectives into the stressful everyday life of the hospital. Pastoral care thereby helps patients to come to themselves by discovering resources in their respective life stories and making these fruitful. In this sense, hospital pastoral care accompanies identity work under the condition of special vulnerability. In this way, it can support patients in making authentic decisions, for example, with regard to the acceptance or rejection of a treatment plan, and therefore,— if necessary—promote the patients' maturity in order to reach a thought-through, developed, and autonomous understanding of themselves as religious individuals.

The perspective of pastoral care can help especially when it is not clear what patients need in addition to adequate medical and nursing care in everyday hospital life. Sometimes patients simply wish that someone endures with them the situation of powerlessness—a need which can also be found among relatives, doctors, and caregivers. In terms of pastoral psychology, the attitude required in such cases is called containing. A person neither seeks to perform the decisive act nor waits passively for the outcome of the development, but opens him- or herself up to what happens and allows for changes through an attitude of awareness.

2.2 | Religious aspects of transplantation

Serious illnesses can often plunge people and their relatives into deep crises. In such cases, a comprehensive psychosocial care can help in which not only medical nurses, psychologists, and social workers but also hospital pastoral workers are involved. This often results in implicit references to religious and pastoral aspects, such as religious images and metaphors. We, therefore, asked for general experiences from the accompaniment of transplantation patients and the specific religious dimensions. In supporting the patients during such crises, the affiliation of patients or hospital pastoral workers to a particular religion or denomination plays hardly any role. Rather, the respective hospital pastoral workers provide comfort and assistance and also represent the dimension of transcendence. Experience shows that patients usually ask themselves similar questions, such as the meaning of the disease, and struggle with why the disease affects them.

In such encounters and conversations, explicit religious references can also be made. Some patients draw strength from prayers and religious rituals, or re-examine their faith because of their illness. It is possible that patients struggle with God, feel left alone by Him and are disappointed by Him. In the context of the Dialogue Board, a practicing Catholic cancer patient was reported who drew strength from the sacrament of the Eucharist during her illness. Yet, after a relapse, this ritual had suddenly lost its power for her. In such conflicts with one's own faith, various religious images and patterns of interpretation can become virulent. Depending on the religious-cultural origin and individual religiosity, the illness can be interpreted differently, for example, as God's punishment or as a test. Muslim hospital pastoral workers, for example, reported from their experience that the Koran's promise that no soul would have to endure more suffering than it could bear was perceived as relieving.

According to the experts, problems arise when Muslim and Jewish patients cannot observe religious regulations and ritual acts due to inpatient treatment in hospitals. The following aspects, as the discussion showed, were significant in the experience of the hospital pastoral workers: Many Muslim patients suffered from the fact that they could not perform ritual washings due to the conditions of the hospital stay. The pastors made clear that in the case of illness this religious duty does not bind and that the washings could be carried out symbolically with the help of a stone. This elaboration possesses a special authority if given by Muslim hospital pastoral workers, that is, if coming from an internal perspective. As far as Jewish dietary laws are concerned, it helps patients to point out that they apply only to food ingested through the mouth, but not to artificial feeding by means of a stomach tube. This explanation has a relieving effect. A further conflict may arise from the duty, which is more firmly anchored in Muslim and Jewish than Western Christian circles, that relatives and loved ones should visit the sick. The family environment can be beneficial and supportive in the recovery process, but can also be overstraining and burdensome at times. In such cases, hospital pastoral workers, who are familiar with the respective religious and cultural traditions, can act as mediators. At the same time, it could prove advantageous that hospital chaplains, even if they belong to the same culture, are not part of the immediate social environment. The fact that they come, so to speak, from outside makes it easier for some patients to open up.

According to the pastoral workers, pastoral care in hospitals plays a specific mediating role in everyday hospital life. It can mediate between the patient, his living conditions and the general religious norms under the perspective of its life-serving dimension and thereby take the fact of the illness as an existential exceptional situation into account. At the same time, pastoral care in hospitals can question existing religious norms with regard to their "lifability" and has insofar a self-critical potential for its own religious traditions.

2.3 | Religious aspects of xenotransplantation

Prospective considerations were made concerning the application of xenotransplantation. We, therefore, asked about possible religious implications, associations, and images. Key questions referred to the image of God as Creator, to ritual purity, to the sanctity of life, to the relation of body and soul, and to coping with death.

2.3.1 | Effects on identity and self-image as well as anthropological aspects

According to the unanimous opinion of the participants in the Dialogue Board, xenotransplantation can fundamentally affect people's self-image. For this reason, the possible consequences for one's self-image must be considered before a decision is made in favor of a xenotransplant. Furthermore, it cannot be ruled out that irritations and doubts about one's own identity may also occur in the weeks and years following the transplantation. The scenario of a transplantation of nerve tissue was therefore discussed particularly critically, as it could fundamentally reshape a person's identity and self-image.

The discussion about xenotransplantation can touch on central theological-anthropological aspects; for example, the question how man is to be understood: for example, as creature, as body-soul-unity, as image of God. The interpretation of man with the help of such images makes a central thought in all religions, namely the special value of life, visible in anthropological categories and therefore requires a special sensitivity in a holistic view of transplant medicine.

In the three monotheistic religions, the central idea of the sanctity of life is a pivotal point of reference for understanding man.[9,11,13] Its interpretation, however, is manifold. While especially in Judaism and Islam the duty to preserve life is emphasized, on the Christian side also the disproportionate prolongation of the dying process by medical measures was problematized. Allowing to die could be the more coherent decision for the individual in his concrete situation and thus represent a responsible option. In this regard, criteria of the good life and death are to be discussed, in which direct experiences of the patient such as pain and suffering can play a role as well as the concrete perspective of medical feasibility.

In general, a technical understanding of the human being was viewed critically. If failing organs are only interpreted as a weakness and as a component that can be replaced at will without considering the biographical reference, the physical as well as the body-soul integrity could be overshadowed.

Another topic in the discussion was the question whether, in view of the idea of God's likeness of man, a xenogenic organ could be perceived as a flaw. No final answer was given to this question. Instead, it was discussed whether God's likeness could be conceived of physically at all.

2.3.2 | Emotional reaction

A xenotransplantation, according to the prospective considerations, could also represent a considerable emotional burden. The concerns expressed by the pastoral workers covered three areas. The first thoughts revolved around the phenomenon of disgust. One participant reported on a conversation with a transplant patient about xenotransplantation in the run-up to the conference. Under no circumstances could he have imagined receiving a pig organ. The special feature of this disgust is that it is an "inner disgust". The pig organ as a foreign body is located inside the patient's body. This makes it impossible to physically distance oneself from it. This could result in a disgust for oneself that cannot be physically relieved.

In Jewish and Muslim view, the pig is regarded as an impure animal, which can clearly impair the acceptance of porcine organs. Although the medical use of pig organs can be legitimized by religious law in Islam and Judaism, the pastors suspected that many recipients might feel disgust and revulsion. Using other species than pigs as donor animal could possibly ease the situation. Yet, beyond these special religious reservations, cultural scripts about pigs as inferior living beings are also generally widespread and effective in the western world, so that here too possible disgust reactions are suspected.

The feeling of disgust has an internal or self-reference. It expresses itself in the attitude to one's own body and to one's own identity. At the level of social reference, disgust can be expressed in the desire for discretion on the one hand and a sense of shame on the other. With regard to the former, it is conceivable that xenotransplanted persons hide their own xenotransplantation as far as possible from their environment. Concealing such an important event does not have a beneficial effect on the recovery process and under certain circumstances leads to a mental inauspiciousness.

In addition, a xenotransplantation could also evoke the feeling of shame. The Jewish and Muslim hospital pastoral workers suspect considerable problems in this respect, which must be dealt with psychosocially, religiously, and pastorally prior to a possible transplantation in order to strengthen the acceptance of the received organ by the patients and their relatives. Effective preventive as well as educational work must focus on both the patient and his or her social environment. It must address the conditions of acceptability of a xenotransplantation as well as the necessary identity work with the patient in his social context. This process can be accompanied by ambivalence, because positive and negative aspects can become simultaneously relevant for patients and their relatives at the same time.

Two further feelings were mentioned which are in a tense relationship to each other. One emotion could be compassion for the animals from which the donor organs originate. A second feeling could be the relief of the xenotransplant recipients that no one "had to die for them". This kind of burdensome experience is reported in cases of allogeneic transplantations. It is important for a successful transplant treatment that patients, and their relatives are able to express

and process such feelings before and after the operation. Only then receiving a xenogenic organ can be brought into a reconciled and authentic self-relationship.

2.4 | Aims and recommendations

Three desiderata or recommendations for action emerged from the Dialogue Board. They were developed through group work processes, where each group contained members of at least two different religions and denominations. Guiding questions had been which requirements, wishes, and proposals the hospital pastoral care workers had, in order to be prospectively able to accompany xenotransplantation patients and their families. The recommendations are therefore based on the long-standing and well-founded practical experience of the dialogue partners. At the same time, the proposals presented in the following are also supported by research-based concepts, in particular from pastoral theology and theological ethics.

2.4.1 | Initial, advanced, and further training for hospital pastoral workers

Even though xenotransplantation has a lot in common with the current practice of allotransplantation, it also has specific aspects. Therefore, it is recommended to develop a specific further education offer for hospital pastoral workers who will be active in this field. It should be holistic and include the following areas in particular.

First of all, it should impart relevant basic medical knowledge in the field of rapidly developing xenotransplantation.

Additionally, this should be embedded in a comprehensive psychosocial and spiritual approach. It is precisely because xenotransplantation can address a variety of emotional and affective aspects that these should also be taken into account in the accompaniment. It is an important task of pastoral accompaniment, which can hardly be carried out by the other occupational groups in the hospital due to time reasons, to endure burdening feelings such as disappointment, anger, grief, or powerlessness or to offer the patient a space at all and to give the security to be able to allow these feelings and to give them an expression. Furthermore, it can be a matter of locating such emotions in life history and developing their specific meaning on the basis of the respective life themes of the patient. Hopes and healing resources should also be discussed.

The holistic approach also includes looking at relatives and the wider social environment, because the support of family and friends is an important resource for the patients to deal with their situation and to make a coherent decision. With regard to the long-term success of a xenotransplantation, the social acceptance conditions play a considerable role.

The situation of the donor animal should be a further component of further training. For it cannot be ruled out that relevant questions may arise in pastoral accompaniment. Pastoral workers should be able to give competent information, take a stand and discuss animal ethical aspects in such conversations. Furthermore, the status of the animal is to be discussed theologically on a fundamental level, for instance as a fellow creature with its own value or as a farm animal, whereby in this respect the different ways of use as food and as organ supplier are to be considered again.

Ultimately, it would be advisable if hospital pastoral workers were familiar with the complexity of xenotransplantation and at the same time develop their own position and attitude in order to be able to accompany patients, relatives, and hospital staff in an appropriately person-centered manner.

2.4.2 | Contact points for patients

With the decision for a xenotransplantation begins a lifelong dealing with the new organ or tissue. Therefore, the further accompaniment of the patient and his relatives is to be understood as a long-term process. Experience with allotransplantations has already shown that doubts may arise afterward for a variety of reasons and that psychological stress or disorders may arise. Further medical aftercare, observation, and treatment can also develop into stress situations. Last but not least, it is difficult to predict how the social acceptance and especially the reactions in the personal environment of the patients will develop, so that here, too, a need for support may arise. For this reason, a long-term contact point for xenotransplant patients (and, if necessary, for their relatives) seems to make prospective sense.

In addition to professional pastoral care for xenotransplant patients, open self-help groups are a suitable place to work on experiences with xenotransplantation. Churches and religious communities could initiate such groups if necessary or support them institutionally and financially.

2.4.3 | Interreligious cooperation and joint statement

In the social context of Western and Central Europe, the sole consideration of Christianity no longer seems appropriate. Different religious orientations and ways of life meet in the clinic. Within the framework of the Dialogue Board, discussion potentials, and points of contact for pastors from different Christian denominations and religions emerged. In addition to the opportunities for increased interreligious cooperation, joint statements by different religious communities were also identified as helpful for the work of pastoral care in hospitals. Among the participants, the wish was expressed to continue the discussion and to think prospectively how the pastoral accompaniment of patients with a xenogenic organ and their relatives could be arranged.

In addition to mentioning the tasks and challenges for the support of potential xenotransplant patients and their relatives, all participants of the Dialogue Board emphasized the chances of

xenotransplantation and expressed their hope that xenogenic transplants could save patients or improve the quality of their life substantially.

3 | OUTLOOK

The Dialogue Board offered a first occasion for mutual exchange and formulated some cornerstones to be further discussed in theological research and pastoral practice. The continuation and further development of this format of an expert discussion represent an important building block for the development of a pastoral care concept for dealing with xenotransplantation. From a comprehensive understanding of therapy and health it follows that, in addition to biomedical progress, psychosocial, and pastoral dimensions should also be taken into account. The closer xenotransplantation comes from bench to bedside, the more attention and support practice-oriented research requires.

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