


Respect for privacy and confidentiality as a global bioethical principle: Own reasons from a Protestant perspective



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In the development and acceptance of Article 9 of the Universal Declaration on Bioethics and Human Rights (UDBHR or also refer to as 'the Declaration'), the United Nations Educational, Science and Cultural Organisation (UNESCO) did not involve the Protestant faith tradition in the consultation process (other traditions were consulted). This given brings the universality (UNESCO perspective) as well as the acceptability of the Declaration and its principles (democratic perspective) into question. In order to address this issue, it is necessary to involve the Protestant tradition in the discourse by presenting own reasons that support the universal principles in the Declaration (theological perspective). This discourse shows that respect for privacy and confidentiality as universal shared values can be grounded from a theological perspective. Therefore, the appeal of the Declaration to consider this principle seriously in the field of bioethics can be supported by the Protestant religious tradition.

Introduction

In this article, attention will be given to the universal bioethical and human rights principle as formulated in Article 9 of the Universal Declaration on Bioethics and Human Rights (UDBHR) of the United Nations Educational, Science and Cultural Organisation (UNESCO 2006). The article reads as follows:

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law. (n.p.)

Bioethics does not function as an exclusively national phenomenon anymore, but has become a global necessity (Stiennon 2009:170). Within the context of Article 9, this truth may be illustrated briefly with three examples that also indicate the relevance and necessity of studying universal ethical principles: In the first place, the *Bioethics Core Curriculum Section 2* of UNESCO refers to the French president Francois Mitterrand who passed away in 1996. In a book (*The Great Secret* by Gubler & Gonod 2005), published shortly after his death by one of his personal physicians, a substantial amount of information regarding his medical condition is described and illustrated by photos. This book was an overnight international bestseller and raised the question whether global bioethics should not have protected the privacy of the president globally (UNESCO 2011a:44). In the second place, UNESCO refers to the modern reality of people who do not live in an environment in which they were born. Consequently, they find themselves in a strange sociocultural ethos where the language is unknown and where they are particularly vulnerable (UNESCO 2011b:9–11). People who come to mind are emigrant workers, political refugees, asylum seekers and displaced persons who, for several reasons, are unable to explain a health problem or obtain information and, consequently, have to make use of interpreters (Martin 2014:124). In the third place, several biobanks that function globally have come into existence. Africa is not excluded in this respect. In June 2010, the National Institutes of Health (USA) and Wellcome Trust (England) lodged a project called Human Heredity and Health in Africa (H3Africa). Medical information (lifestyle, demographic risk factors, prevalent illnesses and genetic information) is collected in one country and stored and studied in another country (H3Africa Biorepository Program:n.d.). This information could be used against donors by insurance agents, employers or law officers (Shickle 2014:491). Several global ethical issues are closely related to the phenomenon of biobanks, namely informed consent, privacy and confidentiality as well as sharing benefits. Do participants receive protection when their personal information leaves their country?

In light of the above-mentioned global ethical issues (and many others), UNESCO developed and accepted the UDBHR in 2005. The UDBHR was unanimously accepted (without any notated dissentient vote, reserve or qualification) by all member states (IBC 2008:45; Ten Have & Jean 2009:17). The Declaration, with its 15 bioethical principles, is therefore not only the first in the history of bioethics to which almost all the governments in the world, South Africa included, have committed themselves, but it is currently also the only bioethical (political) text to have this status (UNESCO 2005).

The research problem from a UNESCO *democratic and theological* perspective is indicated by Tham (2014:2), a Roman Catholic bioethicist. Regarding the *perspective* of UNESCO, Tham finds a shortcoming in the claim to universality, saying that only one short opportunity was afforded to religions (Islam, Confucianism, Buddhism, Hinduism, Roman Catholicism and Judaism) to make an official contribution to the development of the Declaration (Gallagher 2014:135; IBC 2004:2–4; Ten Have & Jean 2009:31). Further, Tham emphasises that Protestants made no contribution to the development of the UDBHR. Ten Have (2016), previous director of the Division of Ethics of Science and Technology at UNESCO, confirms the dilemma, saying:

It is clear that given the short time frame for drafting the Declaration, the development of the text and the resulting consensus has been vulnerable to criticism since not all relevant actors could be consulted while others did not feel represented by the experts involved. (p. 12)

To be truly credible and representational, support from a selective group of religions cannot exclusively serve as consent to a global bioethics. From a UNESCO perspective, it is important to make the UDBHR (and Art. 9) more representational of religions and thus broaden the claim to universality.

From a *democratic perspective*, however, it is also important to make the Declaration more representational of the religions in a specific state. It has to be kept in mind that the UDBHR describes itself as ‘universal principles based on shared ethical values’ in its Foreword (UNESCO 2006). These principles are also known as ‘common morality’ and form an independent meta-ethical theory. What are shared values? John Rawls (1993; cf. also Wenar 2017), an American political philosopher in the liberal tradition, gives the following answer to the question:

Since justification is addressed to others, it proceeds from what is, or can be, held in common; and so we begin from shared fundamental ideas implicit in the public political culture in the hope of developing from them a political conception that can gain free and reasoned agreement in judgment, this agreement being stable in virtue of its gaining the support of an overlapping consensus of reasonable comprehensive doctrines. (pp. 100–101)

Firstly, Rawls (1993:144) acknowledges that pluralism is a permanent historical reality that cannot be ignored. Each reasonable citizen has their own view about God and life,

right and wrong, good and bad (reasonable comprehensive doctrines). He is convinced, however, that this reasonable pluralism does not wish to impose values upon others, but rather strives after shared values and is built on the viewpoint that diverse ethical traditions share minimum ethical values based on consensus. According to Rawls, this pluralism is known as ‘overlapping consensus’ or ‘political conception’ (Ten Have 2011:25; Wallace 2009:55–68). The reason for using shared values is that they are not grounded in any specific philosophy or religion. They emanates from the ‘political culture’ and have the special value that supporters of diverse ethical theories can agree on bioethical principles as was clearly shown by the acceptance of the Declaration (cf. also Gallagher 2014:135; Ten Have 2011:23).

Secondly, the question of legitimacy remains, namely why would the global community (also those with a Protestant religious tradition) give their consent to shared bioethical values? According to Rawls (1993:134), diverse ethical traditions or groups may support shared values, but they do it because of different or own values (or own reasons): ‘In such consensus, the reasonable doctrines endorse the political conceptions, each from its own point of view.’ In this way, shared values are confirmed by own moral grounding. Thus, the shared values are not experienced as imposition by others, but as part of the own religious system.

Thirdly, Rawls (1993:140–144) is of the opinion that if citizens are unable to give reasons from their own religious tradition why they support the bioethical shared values, the shared values would not be valid and the social order would disintegrate (Wenar 2017). From another angle, the philosopher Charles Taylor supports this view of Rawls in his influential work *The politics of recognition* (1994). According to Taylor (1994:34), cultural diversity as a unique human identity is essential to human existence. When the identities of individuals and groups are intentionally denied, ignored or passed over, it leads to alienation and disillusionment. Maggay (2017: 1202–1205) states that one of the reasons why universal values enjoy so little respect in Asian and Arabic countries is ‘the lack of a deep enough philosophical basis for human rights in these cultures’. The lack of participation and absence of own reasons for the universal values of the UDBHR are probably the most important reasons why the Declaration, according to an in-depth study by Langlois (2013:154), has had no or very little impact on the bioethical community in democratic South Africa. The own reasons from the Protestant tradition will strengthen the political acceptability of the shared values in the Declaration and can make a contribution to the discourse on bioethical practices in South Africa. The community of believers as part of civil society in a democracy can have a great influence in the field of global bioethics. In this connection, Ten Have (2016:21–22) refers to the example where the Tongan government secretly gave permission to Autogen – an Australian biotechnological company – to collect genetic material from the Tongan citizens and to store those in a databank with a view to research, in exchange for annual

financial support for research and royalties. When the agreement became known, churches (and pro-democratic groups) rebelled against it. They were of the opinion that no informed permission had been given by the citizens and that it posed a great danger to their privacy and confidentiality. In 2001, the project was dismissed (Burton 2002:443).

This article serves as part of a conversation by and with the broad community with a Protestant tradition and it has a dual purpose. On the one hand, the aim is to bring about stronger representation of the UDBHR in the Protestant community and on the other hand, it endeavours to prevent alienation of the Protestant community from the Declaration by presenting own (theological) reasons to emphasise the validity of the Declaration's principles and, in this way, to strengthen their influence.

The central theoretical statement of this discourse is that sufficient own reasons exist in the Protestant theology to accept Article 9 of the UDBHR and therefore to regard it as part of the calling of the Christian community. What is meant by *Protestant*? The following statement of Matz (2017; see also Pauls & Hutchinson 2008:431; Van Leeuwen 2014:419–420) is relevant to social ethics: 'For Protestants, Scripture is the ultimate authority for faith, life, and doctrine, and this is no less true in the field of social ethics ... Scripture is foundational for Protestant social ethics ...'.

The research to achieve the aim of the article will consist of two phases. In the first phase, with a view to indicate own reasons convincingly, the meaning of Article 9 of UNESCO will be investigated and construed. In the investigation, the focus will be exclusively on official material by UNESCO and commentators that interpret the Declaration with the purpose of construing a 'UNESCO perspective' (Martin 2014:119; Shickle 2014:486). In the second phase, having acquired adequate insight into Article 9, it will be evaluated and grounded theologically.

In order to execute the first phase of the research, the meaning of Article 9 will now be investigated and construed.

Privacy and confidentiality

In order to establish own reasons for accepting Article 9, it is important to examine the meaning of the concepts in Article 9. What does Article 9 protect and in what way does it do it? In the first place, the UDBHR relates human dignity and privacy or confidentiality to each other. Respect for privacy and respect for confidentiality give expression to human dignity (UDBHR, Art. 3). Where these principles are respected, people are treated with human dignity (Stiennon 2009:165; UNESCO 2008:42). From the following statement, it is clear that UNESCO (2011c:10) wanted to formalise these principles: 'Nevertheless, in order to use "dignity" in our lives, some practical principles were established'. In the second place, privacy and confidentiality are the direct outcome of autonomy. Autonomy, according to Article 5 of the UDBHR, deals with the global recognition that the human

being has the right to determine the content of his life himself (Martin 2014:120; Stiennon 2009:165).

What is UNESCO's interpretation of the concept of *privacy*? In their explanation of Article 9, both Stiennon (2009:166) and Martin (2014:120) use the definition of the International Bioethics Committee (IBC) of UNESCO as found in UNESCO's *Explanatory memorandum on the elaboration of the preliminary draft declaration on universal norms on bioethics* of June 2005:

A right to privacy guarantees a control over personal information in many ways. It restricts access to personal and medical information and it provides a claim of non-interference in various private spheres of the individual. Privacy extends beyond data protection, as certain private spheres of the individual that are not manifested in data processing can also be protected by the right to privacy. (p. 9)

The first fundamental distinguishing 'norm' of the right to privacy is the recognition or confirmation that every individual has a personal space and that he or she has an autonomous decision-making right pertaining to that space (Stiennon 2009:168; UNESCO 2008:42). This private space of persons that have the capacity (to make autonomous decisions) are protected or held private by the right of (informed) consent which can be summarised as follows:

Any preventive, diagnostic and therapeutic medical intervention ... [as well as scientific] research ... is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. (Stiennon 2009:165; UNESCO 2006)

A practical example would be that before any medical examination and undressing, a person must consent to such actions and, likewise, receive the assurance that nobody else may see him or her or hear the discussion concerned (UNESCO 2008:42). Persons without the capacity (to make an autonomous decision), for example children are not excluded from the right to privacy and confidentiality. Article 7 of the UDBHR states clearly a substitute (person or instance) has the right and obligation to protect the privacy of persons without the capacity to consent by means of surrogate consent (UNESCO 2006). The UDBHR (UNESCO 2006) clearly states the participatory responsibility of children (persons without the capacity to consent) in Article 7b: 'However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent'. UNESCO's point of departure is, given the specific living conditions of the child (or any other person with the incapacity to consent), that the young individual has to be involved in the decision regarding medical and research intervention that might enter the private space (UNESCO 2006). That would imply that parents cannot decide on their own if their daughters may visit a gynaecologist to ask for a prescription for a contraceptive or to request an abortion (Martin 2014:127–128; UNESCO 2011b:23–27). Respect for privacy also implies that the aspects of autonomy and consent continue to be applicable. It means that the individual retains total authority and say over personal space and spaces which comprises that

an individual can withdraw him- or herself from medical intervention or research at any time without giving reasons. Article 6 of the UDBHR (UNESCO 2006) states clearly, 'The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice'.

The second fundamental distinguishing guideline on the right to privacy is the recognition that within their personal space, every individual also has multiple spaces to which their right to autonomous decision-making pertains (see definition above). Article 9 of the UDBHR restricts the scope of the consent. This is deduced from the principle that regulates privacy, confidentiality and information (UNESCO 2006):

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used ... for purposes other than those for which it was collected or consented to ... (n.p.)

From this explanation, it is clear that consent can or has to be clearly aimed at a specific goal ('should not be used or disclosed for purposes other than'). Consent is very specifically applicable to certain spaces within the larger space and does not open up the total personal space (UNESCO 2008:42). A visit to an ophthalmologist does not open up the space for a gynaecological examination.

What does UNESCO understand by the concept of *confidentiality*? In their discussion of this concept, both Stiennon (2009:166) and Martin (2014:120) (again) make use of the definition as found in the explanatory memorandum (see above) of the IBC quoted by UNESCO (2005):

Confidentiality refers to a special and often fiduciary relationship, such as that between researcher and research subject, or doctor and patient, and provides that the shared information shall remain secret, confidential and shall not be disclosed to third persons, unless a strictly defined, compelling interest justifies disclosure under domestic law. (p. 9)

The first basic norm (or 'principle' in the language of the UDBHR) of the concept of *confidentiality* is that the person is and remains the lawful and autonomous owner of all information that has been moved from the private space (UNESCO 2011c:10). This ownership is quite clear from the following statement by UNESCO 2008:42): 'Individuals "own" their information: it is essential to their personal integrity'. It means that it is the duty of the physician or researcher to make the following information known to the person involved: firstly, all information obtained through observation, laboratory and other paraclinical examinations; secondly, the diagnosis and possible therapeutic solutions, including the advantages and disadvantages of each; and thirdly, the prognosis. This should be done spontaneously in an adequate and complete manner, without any delay. Patients have the right of access to their files (UNESCO 2011c:9–11). It also means a person has the right not to know and may request not to be informed about a certain situation.

After death, a person also has the right to privacy and confidentiality (Martin 2014:135–136).

The second basic guideline is that if a person or persons want to share information with others outside the relational situation, he, she or they have to obtain consent to or exemption from specific confidentiality. Article 9 states clearly, 'Information should not be used or disclosed for purposes other than those for which it was collected or consented to ...' (UNESCO 2006). From this, it is clear that consent consists of two phases. In a 'first consent' opportunity, information that has a specific purpose is entrusted to a very clear demarcated space. If someone wants to move this information from the first space for which consent has been given (whatever the reason might be), a 'second consent' opportunity is necessary (UNESCO 2008:43). Confidentiality includes all physical and psychological medical information as well as genetic data (Stiennon 2009:167; UNESCO 2008:42). UNESCO's *International Declaration on Human Genetic Data* (2003) provides the following explanation: '... all medical data, including genetic data and proteomic data, regardless of their apparent information content, should be treated with the same high standards of confidentiality'. Persons without the capacity (to make an autonomous decision), for example children, are not excluded from the right to confidentiality. Article 7 states clearly that a substitute has the right and the obligation to protect the confidentiality of persons without capacity by means of surrogate consent (UNESCO 2008:43). As with the right to privacy, the UDBHR enforces consideration of the principle of participatory responsibility of children (Martin 2014:127–128; UNESCO 2011b:23–27). Without such consent, information has to remain a secret (UNESCO 2008:42). Before any confidentiality can be breached, the consent of the patient or the substitute has to be obtained which will render the breach of confidentiality ethical (UNESCO 2008:43).

UNESCO also recognises that the principle is not absolute in all respects and that exceptions are possible. The golden rule is that before any confidentiality may be breached, the consent of the patient or substitute has to be received (UNESCO 2008:43). Article 9 regulates that confidentiality should be respected to 'the greatest extent possible' (UNESCO 2006). It means that in exceptional cases it is allowed that the right to confidentiality could be infringed. These exceptions are described as follows in Article 27 of the UDBHR (UNESCO 2006):

If the application of the principles of this Declaration is to be limited, it should be by law, including laws in the interests of public safety, for the investigation, detection and prosecution of criminal offences, for the protection of public health or for the protection of the rights and freedoms of others. Any such law needs to be consistent with international human rights law.

Possible examples are found where a country uses legislation to enforce reporting the following: sexual transgressions against children, a patient threatening to use violence against somebody or someone purposefully transmitting a disease like HIV through sexual contact (Stiennon 2009:168;

UNESCO 2008:43). However, Martin (2014:121) shows that the interest and well-being of the community may not be used as an argument to justify unlawful infringement of the right to privacy and confidentiality. Article 3.2 of the UDBHR motivates this truth as follows: 'The interests and welfare of the individual should have priority over the sole interest of science or society' (UNESCO 2006). It means the respect for privacy and confidentiality of the person has greater weight than the interests of the community and science.

What is the implication of Article 9 as universal bioethical principle and human right? The article states clearly that the right to privacy and confidentiality has to be respected (UNESCO 2006). The concept of *respect* has the meaning of 'protection' within the framework of the Declaration and Article 9 (Martin 2014:126; UNESCO 2008:42). These meanings are confirmed by one of the objectives of the UDBHR, namely 'to promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law ...' (Art. 2c) (UNESCO 2006). This protection can take place by means of legislation, policy, instruments in the field of bioethics (Art. 2), ethics committees (Art. 19) and education in bioethics (Art. 23) (Stiennon 2009:167; UNESCO 2006). Martin (2014:126) shows further that the respect for privacy and confidentiality, which is described in Article 9, has the purpose of protecting the health interests of the person. This purpose is expressed in Article 4 of the UDBHR (UNESCO 2006) which is verbalised as follows:

In applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants and other affected individuals should be maximised and any possible harm to such individuals should be minimized.

The *Bioethics Core Curriculum Section 1* (UNESCO 2008) has the following explanation:

Patients are less likely to trust health care providers and confide in them if they think that the health care providers will not keep the information confidential. This can have serious consequences for the patients' health and well-being and sometimes for the health of others (e.g. family members). (p. 42)

Stiennon (2009:167) is of the opinion that the right to privacy and confidentiality, according to the UDBHR, wants to protect the person in the health care, medical research and technological environment. This interpretation links up with the scope and aims of the UDBHR. Article 1 describes the scope of the Declaration, saying it 'addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings' (UNESCO 2006). Aims set out in Article 2(d) are:

[...] to recognize the importance of freedom of scientific research ... while stressing the need for such research and developments to occur within the framework of ethical principles set out in this Declaration and to respect human dignity, human rights and fundamental freedoms. (UNESCO 2006)

These guidelines refer to both the subject and the object in the context of medical care, medical research and theological procedures (UNESCO 2006).

Subsequently, a Christian ethical grounding for the universal right to privacy and confidentiality will be discussed.

Own reasons

Hermeneutical point of departure

It is, however, not only important from a UNESCO and democratic perspective to offer own reasons for a shared value, but it is also necessary to indicate own reasons from a *theological perspective*. According to Hollinger (2008:64) and Rusthoven (2014:250), contrary to the theory of shared values, God is the ground, the norm and the authority of all ethics.

The human rights authority and ethicist in the Protestant tradition, Vorster (2015), links the Bible and shared values when he states that the second commandment (Ex 20:4–6) lays down knowledge of and living from the Bible as a duty and then continues, saying

Hiermee word ten diepste 'n belangrike fundering vir Christelike morele handelinge gelê. Uiteindelik bied die geskrewe Woord die beginsels vir die etiek en is dit ook die toetssteen van alle etiese kodes en handelinge. [*With this, at the very base, an important foundation for Christian moral actions is laid. Ultimately, the written Word provides the principles of ethics and it is also the touchstone for all ethical codes and acts.*] (p. 109, [author's translation])

According to Higginson (1995:98), the concept of '*privacy*' or '*confidentiality*' is nowadays regarded an acknowledged axiom and reality necessitates the urgency of developing a Christian theory. In this regard, Vorster (2004:233–234) uses the concept of *privacy* (and *confidentiality*) in his discussion of the bioethical issue of HIV and human rights, but without evaluating the concept critically. The same is true of the Protestant ethicist Douma (1997:115–117, 127), who describes the right to privacy and confidentiality ethically as good in his book on medical ethics, but without supplying any theological grounds for his evaluation.

The Christian testing and grounding (presentation of own reasons) of shared bioethical values is a new development in Protestant ethics and has been introduced by the publication of two books, namely *Covenantal Biomedical Ethics for Contemporary Medicine: An Alternative to Principles-Based Ethics* by Rusthoven (2014) and *The New Testament and Bioethics: Theology and Basic Bioethics Principles* by Macaleer (2014). Macaleer (2014:24–30) shows clearly that up to the publication of these two books, no Protestant ethicist has given probing attention to theoretical grounding of modern global bioethical principles. His book treats the Protestant theological grounding of four universal bioethical principles by Beauchamp and Childress (autonomy, beneficence, maleficence and justice). Macaleer (2014) comments on these principles, saying,

As outlined by Beauchamp and Childress, these principles are based on what they call the common morality. Thus, the principles have no specific theological foundation; this book attempts to give those principles a Scriptural foundation. (pp. ix–x)

According to Rusthoven (2014:201–203), Protestant ethics must ‘explore the normativity of the principles of principlism’ or shared bioethical values, because they do not flow from a Christian or Protestant life- and worldview. ‘A Christian ethical approach should start with the main question, and that is the question of the theological foundation for human rights and the responsibilities they impose on man’, Vorster (2004:22–24) writes. The same is true of the universal principles of the UDBHR for which no theological grounding exists. With reference to this truth, the view of Stott (2006:197) is offered, namely that a theological grounding gives moral authority and strength to universal principles (Lorenzen 2009:298) and that it is of special value to the Christian medical doctor, researcher and politician, because a Christian grounding forms the religious motivation and impetus for the execution of a human right as shared value. A grounding forms part of ‘I believe in’ (Waldron 2010:233–234) and can help that human rights and universal bioethical principles live in the heart of the Christian (Vorster 2004:24).

Stratton (2011:628) is of the opinion that the Bible as a source of faith is extremely lacking in information on the concept of privacy and therefore he thinks that a biblical theory on privacy would be dubious and forced. Regarding the concept of confidentiality, also Helm (1995:248–249) is of the opinion that few explicit facts are available in the Bible. Macaleer (2014:10, 14, 212) indicates that the concepts of *privacy* and *confidentiality* as formulated human rights are not explicitly found in the Bible, as 21st century bioethical concepts were not part of biblical thought (Verhey 2011:96), but that this fact does not make an ethical foundation impossible. As an introduction to his in-depth discussion of informed consent with a view to research, the well-known Protestant ethicist J.F. Childress (2002) makes the following statement:

Which Protestant beliefs lend support to standards of self-determination (autonomy) and voluntary, informed consent/refusal in clinical care and research? Methodologically, Protestants have tended to downplay tradition in favor of direct appeals to scripture, and they have found in, or developed from, scripture several key themes. (pp. 187-189)

Several Protestant theologians such as Macaleer (2014), Douma (1997:41), Vorster (2003:240) and the Catholic bioethicist Cahill (2013:69), support a thematic treatment of Scripture in ethical evaluation. The ethical founding of the concepts of *privacy* and *confidentiality* will be undertaken by using the themes of the universal God, the hidden God and the revealing God.

The universal God

In discussing the universal God, the *Kingdom of God* is taken as the point of departure. God is the ‘Creator King of heaven and earth’ (Is 44:2, 6, 24), and his *present* rule over *everything and everyone* (church and world) is an eternal reign, which encompasses past, present and future (Cahill 2013:101–102; Col 1:13, 16; 1 Cor 15:27; Lk 1:32–34; Mt 28:18; Ps 103:19, 22; 145:10).

In the second place, the Kingdom of God has to be seen in relation to creation and anthropology. The King did not only create the heavens and the earth, but he also created the *human being* as his viceroy (Gn 1:26–28) with a view of the human being ruling on behalf of God (Morphew 2015: 930). Furthermore, the human being as viceroy was also created in the *image of God*, which means the human being was clothed with great power and glory to rule as viceroy of creation (Heb 2:5–8; Ps 8). In the Kingdom of God, *human dignity* is derived from the fact that the human being is created in the image of God. Being in the image of God brings the human being particularly close to God (König 2001:100–101; Vorster 2004:91–92). In this hierarchy of existence, God axiomatically forms the highest form of existence and dignity, and therefore he is praised in Revelations 4:11 as the ‘worthy’ (see also Heb 3:3; Higginson 1995:98). If God is absolute worthiness and the human being is his image, then the human being in the kingdom possesses derived, but absolute worthiness (Mt 6:26; 2 Pt 1:4). ‘If God can become a man, how great can man be?’ Morphew (2015: loc. 675) argues tellingly. Not only is the human connected to the image of God, but also to human freedom. Reformed bioethicists agree that the human being is a free creature, *because God is free* (Childress 2002:192; VanDrunen 2009:43). Barth (1976) founds the freedom of God on concepts such as ‘I am the Lord (Is 45), I am the Lord your God’ (Is 41, 43, 51) and the words of Jesus ‘I am’ (Jn 8) with the following description:

This mode is characterized by the fact that it is absolutely God’s own, in no sense dictated to Him from outside and conditioned by no higher necessity than that of His own choosing and deciding, willing and doing. (p. 301–302)

Because the human being is the image of the living God (Gn 9:6; 1 Tm 3:15) and therefore has human dignity and is a free creature, life in general as well as human life and freedom in particular must be respected (1 Pt 2:17; Frame 2008:685; Nullens 2013:62–63). Respect indicates the obligation that not even the least physical or psychological harm or disadvantage should be inflicted on human life (Ex 20:13, 21:18–3; Mt 5:22; 10; Rm 13:8–10; Childress 2002:192; De Bruyn 1993:134). Therefore, the human being is under the obligation to refrain from causing even the least form of harm to human life (1 Th 5:22; Küng 2010: 2349, 2415).

In the third place, the rule of God must be understood in the context of *fall into sin* (Gn 3) which is the reason that possible evil against people is still present and will continue to be. The basic message of Genesis 1–2 is that God created everything and it was good, but the world fell into the hands of sin and evil in an indescribable way. In this regard, Genesis 3 points out that the human being sinned against God, Genesis 4 underlines the reality of evil against the fellow human being while Genesis 6 indicates the violent nature of sin (Gn 6:11–12). The point in this creation narrative is indeed to confess the terrible reality of unloving evil: people violate each other’s physical and psychological integrity (Ac 21:32; Am 1:13; 1 Cor 8:12; McGrath 1995:32; Mk 5:5; Mt 24:49, 27:30; Sentamu 1995:835–854). The reality of evil and disease calls for

protection and healing (Jr 17:14; Ps 6;) – something God promises that is a reality now and in the future (Mt 4:2; Hurding 1995:431).

In the fourth place, against the background that God rules over the whole world, the reality of sin and the obligation to protect human integrity, God also started a universal justice system which includes global ethics. Through this system, the world is able to take care of and protect each other as *modus* of God's rule. According to VanDrunen (2009:33), God's relation with the world forms the background for understanding global bioethics. The Bible reveals the development of a universal justice system that has the purpose of governing the diverse and broken human existence after the fall into sin. König (2010:113–114) and Van Wyk (1998:176) show that Genesis 1–11 deals with universal human history and should be interpreted as follows: first, God is universally involved (*or in a covenant*) with humankind or all living creatures from the beginning (Gn 9:16); and second, the section deals with matters that are common to humankind. The way of God's involvement and communion is explained by VanDrunen (2009):

Genesis 4:15 and 9:6 are particularly relevant. In both of these texts, God ordained a system of human justice not as the sole possession of those who believed in him but as the common possession of the human race. (pp. 31–33)

Genesis 4 and 9 indicate that God will provide earthly authority in the form of universal codes with the purpose to protect the human being and the creation against evil, and to promote well-being (Vorster 2007:108). In this sense, the world is made up of people who are brothers and sisters of each other (Am 1:9). They should have the common goal to promote peace and stability by means of a universal system of law and justice (Is 32:17; Ja 3:18; Ps 85:11; Van Wyk 1991:259) in a diverse and secular world (Jr 29:4–7; Rm 12:18). Because God is good to all people (Mt 5:44–46; Ps 145:9), the human being has the commission to do good to all people (Gl 6:10) and thereby promoting the common good (Douma 1990:54). One form of common good is the global right to privacy and confidentiality. Attention will subsequently be given to this matter.

In light of the theme of the universal God, the existence of the UDBHR may be supported as a form of universal legal system with which the ruling God wants to protect the human being in a broken world. The universal God provides the foundation of the human dignity and freedom of all people. Therefore, the mutual relationship between human dignity, autonomy, privacy and confidentiality in the UDBHR may be defended (Douma 1997:127; Helm 1995:248; Wagner 2011:192).

The hidden God

According to Van den Brink and Van der Kooi (2012:163), the theme of the hidden God has become very important in the postmodern world. Muers (2004:183, 209–210) is convinced that the founding and importance of the concept of *privacy*

arises from 'the mystery that God is in Godself, without which the "mystery" of a person is not fully understood' and suggests the following: 'My final suggestion is that ... the mystery of the immanent Trinity may be a focus for theological reflection on privacy' (cf. also Cooper 1977:29–30).

Already in the 4th century, Eunomius (AD 400) reasoned on the basis of the concept of the *simplicity* of God that there is nothing in or of God about which the human being does not know everything and that cannot be understood by the human intellect (Berkhof 1985:29, 42). Nevertheless, this point of departure has not been widely followed in theology. The concept of the *mystery* or *hiddenness* of God is not a strange idea in reformational theology and has been supported since Augustine (*'Deus semper maior'*). To talk about God and the Trinity is talking about a mystery, Van Wyk (2015:92) writes. The consensus since the Early Church, Middle Ages and the Reformation up to modern times has been that God is hidden or incomprehensible by his very nature, but knowable through his features. In church history, Luther paid particular attention to the theme of the hidden God (Berkhof 1985:59). During the Reformation, he distinguished between the hidden God (*Deus absconditus*) and the revealed God (*Deus revelatus*). According to Weber (1984:405), Luther used the distinction to explain that the revealed God is the hidden God that entered human existence. Although Calvin gave less attention to the hidden aspect of God, he recognised that the nature of God is hidden in his *Institution* (Calvin 2008):

Those, therefore, who, in considering this question, propose to inquire what the essence of God is (*quid sit Deus*), only delude us with frigid speculations, – it being much more our interest to know what kind of being God is (*qualis sit*), and what things are agreeable to his nature. (826, 1137:1.2.2; 1.5.9)

According to Weber (1984:410–406), the conclusion from this statement is that Calvin recognises the mystery of God.

Karl Barth (1976:179–206) has an impressive discussion and acknowledgement of the hiddenness of God. The hiddenness of God is forcefully confirmed by Isaiah 45:15 (also see Berkhof 1985:58) and is put forward by Paul when he indicates that God dwells in inaccessible light (1 Tm 6:16) which means that certain features of God cannot be accessed, known or seen now. In the Old Testament, notwithstanding a special request, Moses is not allowed to see God frontally, but only from behind as he passes by (Ex 33:13–23; Van den Brink & Van der Kooi 2012:163). In his discussion of the right to privacy, Chodos (2012) explains the passage as follows:

The classical expression of this idea of the self is found in the Hebrew Bible's notion that no one can see God's face and live (Exodus 19, 33). It is of course curious that God speaks to Moses but does not allow Moses to see God's face, that hearing God's voice is a good thing but that seeing God's face leads to immediate death. This is because the voice is produced linearly and in context and does not reveal the full nature of the speaker. But to see the speaker face-to-face is to see God's whole being and its limits and to peer into the window of the soul and the mystery at the core – and that is unavailable. (p. 16)

From the discussion up to now, it is clear that God has a private sphere (dwelling) which a human being cannot enter, and a 'private face' which a human cannot see.

Hiddenness finds expression in the features of the incomprehensibility and 'unseenability' of God. The incomprehensibility of God is raised by the following exclamation of Job (36:26): 'How great is God – beyond our understanding! The number of his years is past finding out' (cf. also Job 11:7, 26:14; Ps 139:6, 17, 145:3). The incomprehensibility of God implies that the human being does not have access to the private thoughts and mental world of God, and therefore he or she will not (always) understand his actions and the course of the world (Is 40:28; Rm 11:33–34; Grudem 2007:150; Heyns 1981:62). The human does not have full knowledge of God (Grudem 2007:189) and God alone can be fully known by God (Berkhof 1985:57). Paul recognises the hiddenness of God – that there are things that no human being knows about, and points out that only the Spirit fully knows the hidden things about God (1 Cor 2:11). A trinitarian mystery therefore exists in the sense that nobody knows the Son except the Father, and nobody knows the Father except the Son (Mt 11:27). We know who God is, but we do not yet fully know who God is. The human being knows God only in part (1 Cor 13:12; Van den Brink & Van der Kooi 2012:162; Van Wyk 2015:92–93). Deuteronomy 29:29 reads, 'The secret things belong to the Lord our God, but the things revealed belong to us and to our children forever, that we may follow all the words of this law'.

Scripture also emphasises that God is unseen (Ex 33:20; Jn 1:18; 1 Tm 1:17, 6:16). In this way, the Bible states that God is indeed far above the powers of human sensory observation. There are features of God that cannot be observed (now), and it means that the human being cannot see or know everything about God now (Grudem 2007:189). We do not see God face-to-face, but one day we will see him face-to-face (Mt 5:8; Berkhof 1985:109; Heyns 1981:63). Although the revelation of God is not a full revelation of God, it is still the revelation of God himself (Jr 9:23–24), and no tension exists between the hidden and revealed God in the sense that they differ from each other (Berkhof 1985:43; Grudem 2007:152). The result of the inaccessibility, incomprehensibility and unseenability of God is set out well by Grudem (2007):

To say this, does not imply or require that we know everything of God ... When I say that I have three sons, that statement is entirely true, even though I do not know everything about my sons, nor even about myself. So it is in our knowledge of God: we have true knowledge of God from Scripture, even though we do not have exhaustive knowledge. (pp. 150–51)

The confession of the incomprehensibility and unseenability of God has a positive ethical meaning for the life of the human being (Grudem 2007:150). According to Heyns (1992:57–58), the revelation does not only foreground the being God of God, but also the being human of the human. The revelation as a truth of God and about God is at the same time also a truth about human beings and a question to the human being. In God, the privacy or hiddenness of the human being is

confirmed (Chodos 2012:16). If God reveals to us that he also has features of hiddenness, incomprehensibility and unseenability, it is the obligation of the human as image of God to respect the hidden aspects of other people. Cooper (1977) writes the following in this regard:

Further, the true end of man is God, and therefore, the individual person's life before God is of paramount concern to other men. Persons are mysteries, and the mysteries are to be honored and reverently cultivated. (pp. 20–32)

Already the fact that God clothed the human being, guarantees the moral law that not everybody needs to know or see everything (Gn 3:7). When Hezekiah uncovers everything in his house before strangers, it is negatively judged (2 Ki 20:14–19). Jesus also recognises that some aspects of being a human being will remain hidden (Mt 6:4; Helm 1995). According to Braulik (1998:208), the right to privacy can be grounded in Deuteronomy 24:10–11. Morphew (2015: 438–440) links up with this view, saying, 'There were special laws guarding its dignity and preventing the humiliation of people in their own homes (Deuteronomy 24.10–11). This signifies a right to privacy'. Here it is clearly stated that a home is a private sphere that may not be entered without permission. It is even said in the Bible that the believer's life together with Christ is hidden in God (Col 3:3; Cooper 1977:29).

Some theologians, for example H. Tristram Engelhardt, question the concept of *privacy* in light of the fact that God is omnipresent and omniscient (Muers 2004:183, 209–210). However, it must be remarked that God does not only expect people to respect each other's privacy, but that even he respects the privacy of the human being (Falls-Corbitt & McClain 1992:369–386). Although the Bible recognises the omnipresence and omniscience of God (Ps 139), it does not mean that God does not, for example, respect human intimacy. God is not always present in the same manner. He chooses or decides when and how he wants to be present. It means he is free as far as space is concerned. According to König (2012:296–302), this viewpoint is derived from the fact that God is sometimes close to people and at other times far from people (Ex 33:1–5, 44:24–25, 73:27–28); He even forsakes people (Ps 22:2–3). God is also not in the grave (Ps 88:11–13). The fact that the Bible speaks of the different dwellings of God, shows that God is not always present in the same way and sometimes he is not present.

In light of the theme of the hidden God, the concept of *privacy as a human right*, as found in the UDBHR, can be defended by Protestant ethics. As the image of the hidden God, the human being also has hidden spaces that cannot be known or entered by another human being (Grisez 1993:551). Where freedom and hiddenness of the human are connected to each other, a strong case can be made out for privacy to be protected by consent (also through a substitute). Although the idea of multiple spaces is not found in Scripture, it is acceptable in the context of the hidden God as well as the fact that God lives (in a house with different rooms) in inaccessible light.

The revealing God

In this section, brief attention will be given to the concept of *confidentiality*. 'Scripture warrants confidentiality up to a point', Frame (1988:45) contends. Theologically, Helm (1995:248) and Douma (1997:115) judge that the concepts of privacy and confidentiality can be distinguished, but not separated from each other – an assumption that is clear from Exodus 3. Against the background of the hiddenness of God, it must be pointed out that God did not remain hidden in all respects. God has revealed him to the human being. God communicates information to the human being (Heb 1:1; Jn 14:21–22; Mt 11:27; Rv 1:1). The important fact is the hidden God himself decides what the content, place, time and manner of revelation will be (Heyns 1981:4). In this regard, one can refer to the revelation of God to Moses (Ex. 3). Theologians in general are convinced that this section treats two matters, namely the hiddenness of God (Ex 3:4) and his hiddenness in relation to his revelation of himself (Ex 3:14). In the narrative, the hidden God reveals the fact that he is the God of Abraham, Isaac and Jacob (Ex 3:6). However, this information is not sufficient to Moses. He requires more or other information from the hidden God, namely what his name is (3:13). God answers, 'I am who I am' (Ex 3:14). The latter information is not a name, but in the context of Exodus 3 – it is an indication of what God is going to do. According to Barth (1976:61, 302) as well as Van den Brink and Van der Kooi (2012:122, 163), Exodus 3 particularly emphasises the sovereignty of God to decide what information he wants to communicate. The freedom of God is confirmed by the fact that he refuses to give the specific information asked for and he himself decides about the nature of the information. God cannot be manipulated or forced to reveal the information because it has been requested. The same idea is found in Exodus 33:18–23. This Old Testament example is confirmed in the New Testament when Christ expects his disciples in Matthew 17:9 to keep certain information confidential for a certain time. An authoritative fact in the section is that it is implied that the disciples has the consent of Christ to make the information known at the right time (Rutecki & Geib 1991:11).

As with privacy, the confession of the revealing God also has ethical implications, and the revelation, likewise, foregrounds not only the being God of God, but also the being human of the human. The revelation as the truth of God and about God is at the same time also the truth about people and a question to the human being. God himself decides what information will be made known to the human being and thus the principle of confidentiality in the conception of God is confirmed. The human being as the image of God also has a right to confidentiality which means the human being him- or herself can decide what information may leave the privacy of his or her being as a human. The depiction of God with regard to the right to confidentiality takes place in interpersonal relations.

In the Bible, interpersonal relations are called a 'covenant' (Mt 2:14; Stott 2006:380). In this sense, Rusthoven (2014:247)

is correct when he defines relations in the bioethical environment as a covenant (Heyns 1985:16). In Proverbs 11:12–13, confidentiality and trustworthiness in human relationships are connected to each other as covenantal acts which implies that being trustworthy in a relationship means to protect each other's information (Helm 1995:248; Rutecki & Geib 1991:11). In several places in the Bible, mention is made of secret information between people. In this regard, one can refer to Joseph and Esther who both did not want their identity to be made known (Es 2:20; Gn 42–45). It is also written that Jesus talked privately to his disciples (Lk 10:23; Mk 9:28, 13:3; Mt 24:3), and one might refer to a secret or confidential information between God and the human being (Rm 14:22). In a relationship where trust is found between people, personal information is regarded with respect by treating it as a secret as far as possible. However, where trust is lacking, people go about gossiping and let out personal information about other people (Pr 20:19). According to Proverbs 25:9–10 (21st Century King James Version of the Holy Bible – KJ21), trustworthiness means exactly that information communicated confidentially must not be made public without consent: 'Debate thy cause with thy neighbor himself, and disclose not a secret to another, lest he that heareth it put thee to shame, and thine infamy turn not away.'

In Psalm 41, an example is found where friend and enemy show no confidentiality in a bioethical sense. The poet tells that he has been sick and weak (vv. 2–4). In this condition, he explains that his intimate friend and his enemy came to see him – curious about his sick condition. They collected information about him, especially about his emotional condition, and communicated this private information to everyone outside his home (vv. 6–7). The poet feels this breach of confidentiality is an infringement of the covenant between people (vv. 9–10; Cooper 1977:28).

The Bible warns against slanderous behaviour in human relations (Pr 18:8, 26:22). Paul warns against 'whispering' (2 Cor 12:20 – KJ21) of information to each other without the knowledge or consent of others. The departure point in human relations is that one should have the love that 'protects' (1 Cor 13:7 – New International Version [NIV]) or 'covers' personal information between people (1 Pt 4:8 – KJ21). The reason why information must be treated confidentially, apart from autonomous decision-making as a right, is that according to Proverbs 25:9–10, confidentiality protects the human being against harm. In Jeremiah 36:19–20, information is also treated confidentially to protect Jeremiah against adversity. Information can be dangerous swords (Ps 55:21) and a burning fire that tear people apart (Pr 16:27–28). To go around slandering and to ignore confidentiality can even be life-threatening (Lv 19:16–18).

Confidentiality is, however, not an absolute ethical principle and may be set aside under certain circumstances (Wagner 2011:162). Thus, in Leviticus 13, with a view of protecting confidentiality as far as possible, it is said only a priest has to conduct an investigation to ascertain whether a disease can be transmitted. Probably, only the priest and the immediate

family would know about a non-transmitted disease. If the priest diagnoses a transmitted disease that will be dangerous to the neighbour, he has to make it known to the society by isolating the person (Lv 13:45–46). In this regard, Rutecki and Geib (1991) remark the following:

Even though their separation would alert others in the community that something was wrong (i.e., a breaking of strict confidentiality), the ethical framework presented in Leviticus 13 suggests that this practice of limited confidentiality was justified by the higher good of protecting a neighbor's life. This principle of protection of neighbor is also taught in the Wisdom Literature (Prov 24:11–12). (p. 12)

Christian love is aimed at protecting the neighbour against harm (Rm 13:10).

In light of the theme of the revealing God, the acceptance of the UDBHR of confidentiality as a universal principle can be ethically justified. As the image of the revealing God, the human being has the right to confidentiality. Like God, the human being remains the owner of and can make autonomous decisions about all personal information. It is clear that interpersonal relations should be characterised by trustworthiness and confidentiality. The breach of confidentiality is detrimental to the trust between people and may have an adverse effect on people. The UDBHR is also supported with regard to the fact that the rights to privacy and confidentiality are not absolute rights and may be set aside under certain circumstances.

Conclusion

In the development and acceptance of Article 9 of the UDBHR, UNESCO did not involve the Protestant faith tradition in the consultation process (other traditions were indeed consulted). This given brings the universality (UNESCO perspective) as well as the acceptability of the Declaration and its principles (democratic perspective), into question. In order to address this issue, it is necessary to involve the Protestant tradition in the discourse by presenting own reasons that support the universal principles in the Declaration (theological perspective). This discourse has shown that respect for privacy and confidentiality as universally shared values can be grounded from a theological perspective. Therefore, the appeal of the Declaration to consider this principle seriously in the field of bioethics can be supported by the Protestant religious tradition. Van Leeuwen (2014), who evaluates the UDBHR briefly from a Protestant paradigm, may be wholeheartedly supported when he puts forward the following argument:

From the small overview of Protestantism above, it is possible to deduce the main points of concordance with the UNESCO Universal Declaration on Bioethics and Human Rights. The first ten articles of the declaration are in accordance with the recognition of personal, individual conscience and responsibility and with the communal aspects of Protestant religion and its emphasis on justice and being equal in the eye of God. (pp. 425–426)

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