articolo

Sezione aperta

Relieving pain and suffering: considerations on palliative care and pain therapy

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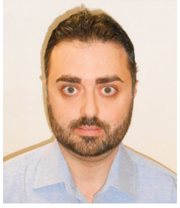

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Throughout history pain and suffering have been interpreted in different ways. In ancient Hippocratic medicine, alleviating suffering was deemed to be among the duties of a doctor. That was a historic period of medicine that preceded the common era and where the healing of patients was not common. Along with the obligation to cure patients, tradition therefore assigned to medicine the fundamental task of sedating pain[1].

An ancient aphorism says: «*Divinum est sedare dolorem*». The absence of sickness is therefore a value, because alleviating suffering is the work of a good god who seeks man's wellbeing[2].

Francis Bacon, a philosopher of the 17th century, also attributes the task of alleviating the patient's pain to the doctor: «*I esteem it the office of a physician not only to restore health, but to mitigate pain and dolors; and not only when such mitigation may conduce to recovery, but when it may serve to make a fair and easy passage. [...] But the physicians contrariwise do make a kind of scruple and religion to stay with the patient after the disease is deplored; whereas in my judgment they ought both to inquire the skill, and to give the attendances, for the facilitating and assuaging of the pains and agonies of death*»[3].

Nonetheless, the idea that alleviating suffering was among the duties of a doctor has not always been universally confirmed throughout history, largely because of a tradition of accepting suffering with forbearance.

From the Judaeo-Christian viewpoint, pain is a historic event that is the consequence of man's guilt and freedom[4]. The human condition, so strongly marred by sin and the ensuing pain, is redeemed by the passion and death of Christ. It is for this reason that suffering was extolled as a moment of achieving inner perfection[5]. This attitude was reinforced by the fact that analgesics available to medical practice at the time were relatively few.

The praising and gratification associated with the idea of suffering seen as an opportunity for inner improvement may be called «*dolorism*» - the praising of pain[6]. This thought has been present to a lesser or greater extent in Christianity for at least two reasons: the desire to imitate the sufferings of Christ and the influence of some philosophical-religious schools of thought like Stoicism, Platonism, some rabbinic approaches, Manichaeism, and Albigensianism. These schools had a dichotomous view of the relationship between body and soul and tended to value the latter to the detriment of the former. They believe that the body was an obstacle to the achievement of the perfection of the soul, and that such perfection could be achieved only by weakening and mortifying the body. Suffering in Christianity was emphasized by the Christian martyrs, by Monasticism in the early years of the Church, and by the already mentioned Albigenses. Until the Second Vatican Council, the praising of pain was rather strongly encouraged in the lifestyle of religious orders and among the faithful[7].

The teachings of the Roman Catholic Church have long since stated that this attitude, albeit legitimate, is not a model to be imposed as a general rule. The use of painkillers is absolutely acceptable as expressed by Pope Pius XII, the *Catechism of the Catholic Church* and the *Declaration on euthanasia*[8].

The praising of pain may have been upheld by Christianity but it is not a duty[9]. Instead actions should aim at enhancing the good of the person. Guidance for Christians as to whether they should fight or responsibly accept their pain is provided by inner maturity and enlightened awareness and prudence on a case by case basis[10].

Some authors strongly point out that the function of fighting pain is inherent in the Christian vocation. The philosophy of the Waldenses decidedly refuses the teaching according to which suffering may have a positive, fortifying and redemptive connotation derived from the contents of some letters of the New Testament. But this vision is opposed by the message in the Gospel expressed through Jesus Christ who healed the sick[11].

Not only Christianity but also the other monotheistic religions (Judaism, Islam)[12] have provided interpretations of the meaning of suffering. The Jewish tradition now sees the fight against pain in a positive light. Luzzatto points out that the best of Jewish tradition did not identify with a sort of vocation to suffering and pain, even though historic circumstances have often compelled it to experience both. According to Luzzatto, pain is not an ideal as in the case of ascesis, nor it is a fundamental aspect of man's relationship with God, which is raised to a higher level. Rather, pain is seen as an unpleasant but unavoidable experience of life that man has the right to fight with means available to him, even though this requires the help of God and above all God's permission and benevolence[13].

Abandoning the notion of pain as something that is praiseworthy has led to some positive consequences: appreciating the value of palliative care; legitimating the search for a better quality of life, namely the positive search for anything that may improve quality of life with equilibrium and a sense of proportion and without falling into extremes; and finally, paying attention to the psychosocial components of suffering.

Reflections on suffering are also present in Eastern philosophies. Buddhism, for instance, has considered a great deal on the nature of suffering.

Frank Ostaseki, a spiritual master of Zen Buddhism, states that in treating the dying person, compassion is just as important as a sound management of pain or effective control of symptoms. Death, which in our society is seen above all as a clinical fact is, in reality, a moment of great psychological, emotional and spiritual value. The people who surround us in our last days of life are of great importance[14].

Hence suffering, often mixed with feelings of fear and depression that cause disharmony in cognitive and operational skills, is to be fought. This fight is legitimate and, to the extent to which this is in line with the wishes of the patient, is a duty[15].

This does not rule out that people may individually attribute meaning, a function and some usefulness to suffering. Aeschylus, the Greek tragedian, used to say that man learns through pain. However, irrespective of whether pain may be turned into good, this should not lead, in our opinion, to a masochistic idolatry of pain, nor should we give in to the idea that we are to be passive in the presence of pain. Acceptance of pain is not at odds with the cultural and ethical legitimacy that is to be acknowledged to the medical actions taken to dominate it[16].

Medical science and health organizations are facing the new challenge today of helping people to die with dignity[17]. Palliative care is a confirmation of the dignity of the person by focusing on the person rather than on the diagnostic-treatment aspects of the disease[18].

It must be noted that many aspects of palliative care are applied earlier on in the course of disease treatment long before they arrive to terminal stages (they are in this sense *palliative simultaneous care*).

According to the World Health Organization palliative care is the active and global treatment of patients whose disease do not respond to cure[19]. It has set up a program under which a panel of experts has developed guidelines for a simple and rational approach to the treatment of pain known as *the three step analgesic ladder*[20]. The approach envisages the use of a combination of opioids, non-opioids and adjuvants, administered according to the individual needs of the patient. The first step envisages the administration of analgesic drugs for mild or moderate pain. In these cases it is best not to use opioids but non-steroidal anti-inflammatory drugs that may or may not be associated with adjuvants.

If this treatment fails then you move to the second step: the patient is treated with a combination of non-opioids plus a weak opioid.

The third step envisages the use of strong opioids such as morphine, methadone, fentanyl and levorphanol that are more effective in the case of severe pain, and which may or may not be combined with non-opioids and adjuvants[21].

Palliative care is a confirmation of the dignity of the person by focusing on the person rather than on the diagnostic-treatment aspects of the disease

Palliative care and pain therapy obviously do not fully coincide: palliative care is aimed at improving the quality of life of patients who have a poor prognosis in the short term, while pain therapy is applied to patients who are not necessarily close to death but who suffer from chronic pain, to patients giving birth, after surgery and during invasive diagnostic procedures. Hence, while in the latter case we speak about pain proper, in the former case it is more appropriate to speak about suffering: we might deem that pain affects the body in its neuro-patho-physiological dimension, whereas suffering affects the whole person globally[22]. This distinction has not always been explicit and was introduced only recently in Italian regulatory texts.

Palliative care usually concerns patients suffering from oncological diseases, but it also involves progressive diseases that affect the cardiovascular system, the breathing apparatus and the nervous system, as well as AIDS patients[23].

In general, in terminal illnesses the most important symptom is pain, and pain relief is a primary concern in ethical care. Indeed, in terminal treatment pain does not have any real function and so controlling it in all its aspects becomes a priority goal[24].

Pain is a very common symptom of many disorders and an important alarm bell that signals the risk of losing psychophysical integrity. When the body loses its «sentinel» function in chronic disorders, pain is the red light indicating the presence of a disease or organic lesion of the body that hence requires treatment. At the same time, pain itself becomes the «disease» and cause of useless and humiliating suffering[25].

A life entirely without pain is not possible and should not be invoked because our very survival would be seriously jeopardized if the pain «signal» were to be absent. But many degenerative diseases and tumours are accompanied by persistent pain that has no biological function, and is merely an end in itself; it is absolutely superfluous and inflicts a heavy punishment on a person who among other things knows that he/she does not have long to live[26].

It is therefore professionally ethical to alleviate pain because while it is true that pain has the biological function of being an alarm bell that signals that something is wrong, it is likewise true that pain in and of itself has a harmful impact on the person.

Terminal patients have a wide array of symptoms that have the characteristics of being multiple, chronic, severe and above all subjective[27]. The symptomatology may include an endless list of disorders, besides pain. Just to mention the most frequent ones, they include: shortness of breath and in particular difficult or laboured breathing (dyspnea); digestion problems like dry mouth or being thirsty, distortion of the sense of taste (dysgeusia), mucositis of the oral cavity, nausea and vomit, dysphagia (difficulty in swallowing) and loss of appetite (which may be accompanied by anorexia-cachexia, constipation that may even lead to intestinal occlusion) and dysuria (difficulty in urinating), or incontinence (both urinary and faecal); oedema and bed sores; asthenia; depression, anxiety, insomnia and confusion; incontrollable itching; etc.[28].

It is worth recalling that suffering in and of itself does not exist, what exist is the patient who is suffering, with all the social and human problems that patients have to face[29]. Suffering involves the sick person at several levels: there is the psychological pain of feeling that one has deeply changed; social pain caused the changes that occur in one's most significant relationships; and existential pain, namely the need to find meaning to such radical changes in one's life. Hence any approach that does not take into account the complexity of a terminal patient's needs is largely insufficient[30].

Hospices were set up with the intention of humanizing death[31], a goal of the palliative care movement. Experience gained with these facilities has demonstrated that it is possible in general to control pain and other discomforting symptoms, allowing the patient to remain aware and in active cooperation and dialogue with family members and with the team of care givers[32].

The hospice has a care-oriented philosophy that has remained consistent over the years: the basic tenets are the provision of individual care, human contact and an interdisciplinary approach[33].

The hospice movement began in England where, in 1967, Cicely Saunders (1918-2005) founded St. Christopher's Hospice, the first modern health facility for terminal patients. The word hospice derives from the Latin *hospitium* that embodies the ancient concept of hospitality as a divine right of the guest and a divine duty of the host.

St. Christopher's Hospice[34], is still a point of reference for the whole community of caregivers working in this particular field of medicine.

In Italy, where palliative care has received momentum above all from the work done by Vittorio Ventafridda and by the Fondazione Floriani in Milan during the 1980s, the first hospice to begin operation was the *Domus Salutis* in Brescia (1987); then came the first public hospice at the Istituto Geriatrico Pio Albergo Trivulzio in Milan (1991)[35], and later on the hospice in Aviano in the Province of Pordenone (1996). In 1995 the Italian Palliative Care Society prepared a document laying down the minimum organizational, structural and technological requirements that hospices were to comply with. Since then there has been a growing awareness of the need to devote attention and resources to terminal patients, and indeed provision was made to have at least one hospice per Region.

The hospices are located within hospital facilities or in the community and may be managed directly by the health institutions or by non profit volunteer associations that enter into a specific agreement with the health institutions. Care is free of charge, but access to the facility is obtained through the hospital departments or from the home upon request by the general practitioner. In general each patient has an individual room with the possibility of a carer staying overnight. The room is equipped with all the facilities the patient may require and also the furniture can be rearranged to suit the patient's wishes. There are no limits to visiting hours so that the patients' relatives may visit at any time[36].

Elisabeth Kubler-Ross is the author of a ground-breaking book in which she describes the stages of terminal diseases.

This author identified some typical stages in the mood of terminal patients when informed about their impending death[37]. The first reaction is *denial*: the patient panics and tries to push away reality pretending that nothing has changed in his life. Denial is followed by *anger*: the sick person with sadness, depression and more often anger, wonders about her fate comparing her position with that of other healthy persons. She suppresses in her mind all plans for the future that are now unachievable. Then there is *bargaining*: the patient tries to postpone the inevitable by bargaining with God, with the physicians, with his family, and with himself. What normally follows is *depression*: the body warns that the end is at hand and the dying person often sinks into silence and listlessness. Finally *acceptance*: this coincides with the achievement of inner peace and with the relinquishing of fighting back, and acquiescence sets in. The sequence of these stages is not always precisely the same. Indeed many patients slip back into a previous stage or they experience several stages simultaneously. In any case, the patients' moods are influenced by what they know about death[38].

Suffering caused by an illness is a severe and at times dramatic test bench where promises that life held, the good reasons to live, and spirituality are put to the test. But if a dying person is helped not to leave anything unfinished, he spontaneously reaches the point where death is accepted[39].

In the fight against pain and suffering the *right to die with dignity* emerges: the right to die with dignity means that any situation that prevents a person from dying serenely is to be prevented. The dying are entitled to receiving treatment, to being accompanied in their last moments of life, and not be submitted to burdensome treatment only with the aim of postponing for a short time the moment of death[40].

NOTE

[1] Consulta di Bioetica, «Consulta di Bioetica sulle cure palliative e l'eutanasia», *Bioetica*, 2 (2000), 350-354. See also F. Toscani, «Cure palliative: una nuova etica della medicina?», in M. Mori (edited by), *La bioetica. Questioni morali e politiche per il futuro dell'uomo,* Bibliotechne, Milano 1990, 221-224.

[2] M. Caporale, «La cultura del dolore nell'evoluzione del rapporto medico-paziente. Da Ippocrate agli ospedali senza dolore», *L'Arco di Giano*, 41 (2004), 115-124.

[3] F. Bacon, *The advancement of learning* (1605).

[4] A summary overview on the topic of suffering in the Bible is offered by M. Gagliardi, «Il senso teologico della sofferenza», *Studia bioethica*, 1-2 (2010), 47-63.

[5] S. Leone, *Bioetica, fede e cultura*, Armando, Roma 1995, 169-179.

[6] See G. Zaninetta, «Dolorismo e dolore», *Rivista italiana di cure palliative*, 3 (2011), 47-48.

[7] S. Leone, *Oltre il dolore*, Oftes, Palermo 1992, 61-68. For an overview of the idea and meaning of pain in history, starting from primitive civilizations through to the present day, see P. Procacci, M. Maresca «Il dolore nella storia», *Quaderni di cure palliative*, 2 (1993), 105-108.

[8] S. Cipressa, *Bioetica per amare la vita*, Dehoniane, Bologna 2010, 148-151.

[9] S. Spinsanti, «Il diritto di non soffrire», *Janus*, 1 (2001), 51-59.

[10] S. Leone, *Nati per soffrire?*, Città Nuova, Roma 2007, 92-96.

[11] F. Becchino, «Eutanasia o medicina palliativa?», in P. Ricca (edited by), *Eutanasia: la legge olandese e commenti*, Claudiana, Torino 2002, 61-65.

[12] M. Picozzi, L. Violoni, P. Cattorini, *Il significato della sofferenza. Tre religioni monoteiste interpretano l'esperienza della malattia*, Franco Angeli, Milano 2004. See also M. Desmet, «Il ruolo della religione, della teologia e della filosofia nello sviluppo e nella pratica delle cure palliative», in S. Privitera (edited by), *Vivere bene nonostante tutto. Le cure palliative in Europa e in Italia*, Istituto Siciliano di Bioetica, Acireale 1999, 53-62.

[13] A. Luzzatto, «L'uomo a fronte delle sofferenze nella tradizione ebraica», in E. Agazzi, *Schmerz in Wissenschaft, Kunst und Literatur,* Guido Pressler Verlag, Huertgenwald 2000, 194-201.

[14] F. Ostaseski, *Being a compassionate companion*, Zen Hospice Project, San Francisco 2003. Frank Ostaseski is the founder, director and teacher of the Zen Hospice Project in San Francisco, the first and largest Buddhist hospice in the United States.

[15] G. Perico, *Problemi di etica sanitaria*, Ancora, Milano 1992, 173.

[16] F. D'Agostino, *Parole di bioetica,* Giappichelli, Torino 2004, 54.

[17] M. Furlan, A. Bernardi, R. Pegoraro, *Etica delle professioni sanitarie,* Piccin, Padova 2009, 533-546. The same approach is taken by H. M. Chochinov, *Dignity therapy. Final words for final days*, Oxford University Press, New York 2011.

[18] A. Turriziani, «Cure palliative», in E. Sgreccia, A. Tarantino (edited by), *Enciclopedia di bioetica e scienza giuridica,* Edizioni Scientifiche Italiane, Napoli 2010, 776-782.

[19] As is well known, WHO intends health as a state of complete physical, mental and social well-being and not merely as the absence of disease or infirmity. This definition contains the premise for recognizing the need to improve quality of life where there is no cure.

[20] Htt://pwww.who.int/cancer/palliative/painladder/en

[21] Developments in pain therapy in its various forms are bound to make some ethical dilemmas less dramatic. See M. Aramini, *Introduzione alla bioetica,* Giuffrè, Milano 2009, 142-143. Controlling symptoms is obviously not restricted only to the administration of analgesics. For more thorough information refer to: D. Amadori, O. Corli, F. De Conno, M. Maltoni, F. Zucco (edited by), *Libro italiano di cure palliative,* Poletto, Vermezzo 2007. Promising signals, but also strong ethical challenges, come also from neurostimulation and neuromodulation applications used in pain therapy. See L. Borghi, «Profili bioetici della neurostimolazione», *Medicina e morale,* 6 (2004), 1203-1214.

[22] See also M. Caporale, «La cultura del dolore nell'evoluzione del rapporto medico-paziente. Da Ippocrate agli ospedali senza dolore», *L'Arco di Giano,* 41 (2004), 115-124.

[23] With regard to terminal patients with AIDS, see A. G. Spagnolo, «Obbligazioni etiche di fronte al malato di AIDS in fase terminale», in E. Sgreccia, A. G. Spagnolo, M. L. Di Pietro (edited by), *L'assistenza al morente: aspetti socio-culturali, medico-assistenziali e pastorali,* Vita e pensiero, Milano 1994, 487-494.

[24] C. Viafora, *Introduzione alla bioetica*, Franco Angeli, Milano 2006, 355-373.

[25] D. Gioffrè, *Il dolore non necessario*, Bollati Boringhieri, Torino 2004. G. Amato, «La discrezionalità del medico nella prescrizione di sostanze stupefacenti», *Cassazione penale,* 1 (2001), 327-330. Id., «Ancora sulla somministrazione di sostanze stupefacenti da parte del medico», *Cassazione penale,* 6 (2005), 2101-2106. A. Pessina, *Bioetica. L'uomo sperimentale,* Bruno Mondadori, Milano 1999, 156.

[26] D. Gioffrè (edited by), *Il dolore superfluo*, Erickson, Trento 2008.

[27] M. Lombardi Ricci, *Malati di vita. L'uomo contemporaneo, la malattia e la morte*, Istituto Siciliano di Bioetica, Acireale 1999, 80.

[28] See C. Zavaroni, «Il modello assistenziale olistico nelle cure palliative», in M. Bonetti, M. T. Ruffatto (edited by), *Il dolore narrato. La comunicazione con il malato neoplastico grave*, Centro Scientifico Editore, Torino 2001, 135-171.

[29] E. De Martino, «La terapia del dolore», in D. M. Toraldo (edited by), *Il dolore nelle malattie croniche. La prospettiva cristiana*, Martano, Lecce 1998, 35-42.

[30] A. Turriziani, «Dignità del vivere e del morire», in A. Bagnato, A. Brambilla, A. Trombetta (edited by), *Dignità del vivere e del morire*, Pontificia Università Lateranense, Roma 2002, 41-49.

[31] M. Aramini, *L'eutanasia. Commento giuridico-etico della nuova legge olandese*, Giuffrè, Milano 2003, 160. M. Aramini, *Introduzione alla bioetica*, Giuffrè, Milano 2009, 457. P. Scarcella, F. P. Calamo Specchia, «Il problema del malato terminale nella società attuale», *Medicina e morale,* 1 (1987), 69-87.

[32] L. Alici, F. D'Agostino, F. Santeusanio, *La dignità degli ultimi giorni*, San Paolo, Cinisello Balsamo 1998, 27.

[33] M. Petrini, *La cura alla fine della vita*, Aracne, Roma 2004, 157.

[34] A. Turriziani, «Cure palliative», in E. Sgreccia, A. Tarantino (edited by), *Enciclopedia di bioetica e scienza giuridica*, Edizioni Scientifiche Italiane, Napoli 2010, 776-782. An interesting essay on the origins of hospices, written by the founder of the hospice movement, is C. Saunders, *Watch with me: inspiration for a life in hospice care*, Mortal Press, Sheffield (UK) 2003. An outdated biography of Cicely Saunders is that written by S. Du Boulay, *Cicely Saunders: the founder of the modern hospice movement*, Society for Promoting Christian Knowledge, London 2007. See also M. Martini, «Cicely Saunders: una vita, tre professioni», *Janus* 26 (2003), 129-132. F. Toscani, «La nascita e l'affermazione della medicina palliativa», *Salute e territorio,* 134 (2002), 320-322. For a description of the activities of the St. Christopher Hospice, see P. Verspieren, *Eutanasia? Dall'accanimento terapeutico all'accompagnamento ai morenti*, Paoline, Cinisello Balsamo 1985, 85-98.

[35] A. Viganò, F. Cruciatti, E. Balducci, «Aspetti socio-culturali ed organizzativi del primo hospice pubblico italiano: interpretazione ed adattamento del hospice movement anglosassone», in E. Sgreccia, A. G. Spagnolo, M. L. Di Pietro (edited by), *L'assistenza al morente: aspetti socio-culturali, medico-assistenziali e pastorali*, Vita e pensiero, Milano 1994, 477-479.

[36] R. Ditaranto, «Hospice», *Aggiornamenti sociali*, 9-10 (2010), 625-628. For more inofrmation about hospices see also R. Barcaro, *Eutanasia. Un problema paradigmatico della bioetica*, Franco Angeli, Milano 1998, 110-115.

[37] E. Kubler-Ross, *On death and dying*, Simon & Schuster/Touchstone, New York 1969. This analysis is taken up by various authors. Among them: C. Viafora, *Introduzione alla bioetica*, Franco Angeli, Milano 2006, 355-373. G. Davanzo, *Etica sanitaria,* Ancora, Milano 1991, 236-237. M. Petrini, «L'assistenza al morente: orientamenti e prospettive», *Medicina e morale,* 2 (1985), 365-388. G. Cosmacini, G. Gaudenzi, R. Satolli, *Dizionario di storia della salute*, Einaudi, Torino 1996, 167-170. G. Russo, «Il malato terminale (cap. XXX)», in G. Russo (edited by), *Bioetica medica per medici e professionisti della sanità*, Elledici, Leumann (TO) 2009, 370-382. S. Leone, *Bioetica, fede e cultura,* Armando, Roma 1995, 154-156. P. Lisi, R. Floridia, N. Martinelli et al., *La dignità nel morire: intervento sociale, bioetica, cura del fine vita*, La meridiana, Molfetta 2010, 49-64. Kubler-Ross herself speaks about death also in other books: E. Kubler-Ross, *Questions and answers on death and dying,* Simon & Schuster/Touchstone, New York 1972. Id., *Death is of vital importance*, Station Hill Press, Barrytown 1995.

[38] C. Iandolo, *L'etica al letto del malato. Per la formazione etica del personale infermieristico,* Armando, Roma 1990, 296-297. See also M. Leoni, *L'assistenza psico-sociale nella malattia inguaribile*, Cittadella, Assisi 1992. C. Borreani, «La condizione psicologica del paziente», Salute e territorio, 150 (2005), 183-185.

[39] Among the books that reflect on the topic of death, the following are pointed out M. De Hennezel, *Mourir le yeux ouvert*, Albin Michel, Paris 2005, where the author, a psychologist and psychotherapist who has worked for years at the Montsouris Institute for palliative care for terminal patients in Paris, develops a deep reflection on death and on dying, a formidable message of hope, compassion and love starting from the moving experience of the death of her friend, the philosopher Yvan Amar. See also M. De Hennezel Marie, *La mort intime*, Robert Laffont, Paris 1995. S. Fassino, «Aspetti specifici del supporto psicologico nella relazione medico-paziente terminale», *Medicina e morale,* 5 (1997), 923-937. M. Galgani, *Sto con te. Accompagnare sé stessi e gli altri verso la fine della vita*, L'età dell'acquario, Torino 2010.

[40] M. Petrini, *La cura alla fine della vita*, Aracne, Roma 2004, 188-191. For other thoughts on end-of-life topics see I. Cavicchi, P. Coda, S. Natoli et al., *Le parole ultime. Dialogo sui problemi del fine vita,* Dedalo, Bari 2011.