

CONFERENCE

QUALITY OF LIFE AND THE IMPACT OF PAIN ON MALTESE CITIZENS

Date: 18th April 2018 **Venue:** Il-Luzzu Conference Hall (Qawra, Malta)

The conference on the Quality of Life and the Impact of Pain on Maltese Citizens was organized to present and discuss the results of the research results of project carried out by the Malta Health Network (MHN) and No Pain Foundation (NPF). The project was carried out with the support of Voluntary Organisations Projects Scheme (VOPs) managed by the Malta Council for the Voluntary Sector on behalf of the Parliamentary secretary for youths, Sports and Voluntary Organisations (80%) and Co-financing supported by Grünenthal GmbH. Ms Gertrude Buttigieg, Chairperson, MHN and Ms Silvana Fanalista, President, NPF opened the ceremony and welcomed about 50 participants representing several Maltese organisations.

Hon. Clifton Grima (Parliamentary Secretary for Youths, Sports and Voluntary Organisations) gave a brief introduction how voluntary organisations are being supported through Voluntary Organisations Project Scheme (VOPs) and reconfirmed the commitment of the Ministry for Education and Employment to help voluntary organisations especially in research.

Panel 1 A Research Study on the quality of life and the impact of pain on Maltese citizens the burden of chronic pain in the Maltese population

Multi-disciplinary experts from Malta presented the results of the study on the quality of life and the impact of pain on Maltese citizens. .

The session was opened by the Chairperson Professor r. Boaz Samolsky-Dekel (Scientific Director, NPF) who introduced the panel speakers.

Dr Christine Baluci (Public Health Specialist and MHN board member) introduced the audience into the area of pain by discussing the various definitions especially with regards to the duration of pain. According to the International Association for the Study of Pain (IASP), pain is *'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'* . She referred to several European studies concluding that chronic pain should be considered as a major health care problem in Europe that needs to be taken more seriously.

Ms Vanessa Bajada (Esprimi) then explained the methodology used in the research and presented the key results. The main scope of the research was to collect data to provide insight about the extent of chronic pain in Malta and the impact that it has on the day-to-day activities of individuals and their social and economic activities.

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The quantitative survey, carried out in December 2017, used a random sample of 1,100 members of the general public aged 18 and over using a mixed methodology approach whereby the survey was carried out partially online (70% of responses) and partially by telephone/mobile (30 % of responses). The sample was stratified to represent all ages, gender and geographical spread of regions as defined by the National Statistics Office (NSO).

A focus group was carried out in February 2018 using a small sample of the study population identified as suffering from chronic pain in the quantitative part of the survey. The aim of this focus group was to understand:

- the personal experience of pain
- the management of pain and
- the support systems used by people suffering chronic pain

Results show that twenty-two per cent (21%) of those interviewed reported moderate to severe pain lasting for the last 3 months or more. It was reported that, the first point of contact of patients reporting pain is most commonly the general practitioner and pain specialists are consulted only to a minor extent. It was shown that physical pain interferes with several types of daily activities and leads to significant impact on absence from work. Most of the people experiencing pain claimed that they are not receiving any form of medication and 46% received even no treatment at all.

Ms Bajada then gave a brief overview of the results from the focus groups where patients shared their individual stories.

'I feel that the pain is affecting my life extremely as I want to be active and I cannot. Before there wasn't an event I would miss (Male – Age 68)

In most cases, respondents felt that their immediate families were a good source of support with the issues they were facing. But later in the discussions it was also mentioned that due to the aging population the family may give less support in the future.

Dr Mario Grixti (Specialist in Palliative Medicine and in Family Medicine) highlighted the fact that the general practitioner is very often the first point of contact for patients with chronic pain (70% of patients) whereas less than 8% opt for direct consultation with pain specialist. Thus, general practitioners remain the gate keepers for this issue within the current health care system in Malta. the survey showed that 47% of pain sufferers do not receive any treatment at all. Dr. Grixti concluded that this research provides clear evidence to support sustainable investment in structured primary care pathways to manage chronic pain within the community. A multidisciplinary team is needed, including GP's specialized in the use of diverse pain medications within structured pain

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protocols and referral pathways. He further emphasized the importance of integrating NGO's in the 'no pain advocacy' work.

Mr Christopher Vella (Bioethicist and MHN Hon Secretary) explained that ethical issues are usually discussed only at the beginning and end of life stages. However, living with chronic pain is a very important issue where individual, financial and professional limitations must be taken into consideration. Education is needed both for the society at large and also for professionals at all stages of the pain course. The Maltese Consensus Paper, launched at the 2017 Societal Impact of Pain (SIP) Symposium held in Malta, has shown that Malta is a good example of patient empowerment and action to actively involve policy makers.

'Reading the transcripts of the focus groups hits hard, and should serve to reinvigorate our commitment towards having a just policy which can easily be attainable.'
(Christopher Vella)

Professor Julian Mamo (Specialist in Public Health and Family Medicine) urged caution when interpreting the results of this survey due to potential bias especially in the sample selection; not all contacted persons volunteered to participate in the survey. Nevertheless, very important information emerged from this study. Results have shown that 21% of the respondents reported chronic pain (moderate, severe and very severe pain of at least 3 months duration). Of these, more than 40% report living with pain for more than 2 years. One out of four patients are not satisfied with the treatment they have received.

'Follow up on pain is essential and not always easy'
(Prof J Mamo)

Panel 2, Comparative with European Data on chronic pain and the impact of pain on person, family & society

In panel 2 a discussion on a comparison with European Data on chronic pain and the impact of pain on the individual, family & society was presented. The Chairperson, Prof Ray Galea (Vice Chairperson MHN) introduced the international speaker who represented the European Societal Impact of Pain (SIP) platform. Professor Bart Morlion (President of the European Pain Federation EFIC and Director of the Leuven Centre for Algology) through a recorded video message reminded the audience to the successful SIP 2017 Symposium held in Malta under the Maltese EU Presidency 2017 and

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congratulated the Maltese partners for keeping alive the legacy of the Symposium through this project.

Joop Van Griensven (President Pain Alliance Europe, PAE) presented results from the PAE survey in 2017 which surveyed 3940 respondents including Maltese respondents. More than 70% of pain patients required more than one year to get a diagnosis while 78% reported that their treatment was not as good as they expected. He emphasized the importance that Healthcare Systems work together.

Professor Boaz Samolsky-Dekel (Scientific Director, NPF) presented the results of a survey of 46,394 adults from 15 European countries where 19% suffered from chronic pain, of which 40% complained that pain was inadequately managed. Pain affects work and work efficiency, and often reduces quality and quantity of life. Prof Samolsky-Dekel concluded that chronic pain conditions can be a substantial socio-economic burden and should therefore be a priority for policy makers. He explained the 'referral issue' to the audience - management of chronic pain is complex; it requires specific pain treatments with accompanying psychological and physical support. Referral of patients to the correct specialists is essential in the process of pain management and continuity of care as these can affect clinical outcomes and costs. Inappropriate referral induces misuse of healthcare facilities, time and resources wasting, and increase in personal, societal and economic burden. The Maltese pain research data provides evidence that pain patients are not adequately referred to a specialist. He requests that the general practitioner should participate and collaborate with specialists in providing continuity of care. Prof Samolsky-Dekel reported that in Italy since 2010 there the state law (38/2010), which provided free access to palliative care and, or pain therapy to all citizens in need. Although the implementation of the law is still ongoing, this is a great example how the state can provide the regulatory framework to improve management of pain. He concludes that stratified-based referral-selection of chronic pain patients, based on prognosis/risk elements can target the right treatments to the right chronic pain patient.

Dr Gudula Petersen (Governmental Affairs & Patient Centricity, Grünenthal GmbH) congratulated the Maltese research group for this important pain study. Robust data is essential to convince policy makers to support improvement of pain management. She presented the European Societal Impact of Pain (SIP) platform which is a multi-stakeholder initiative with more than 300 endorsing organisations including several Maltese organisations. SIP was set up in 2009 by Grünenthal and European Pain Federation EFIC to ensure access to adequate pain treatment for all citizens and to unite all organisations and societies advocating better pain care to jointly address, define and foster pain policies. Partners include Pain Alliance Europe and Active Citizenship Network which represent patients and citizens on this platform. SIP has just been selected by the European Commission as one of only three thematic networks for 2018. This is a fantastic opportunity to directly influence the European Commission's approach to health policy especially with regards to pain. Another focus of the SIP activities in 2018 is to build national SIP platforms based on the experiences of the pain advocacy work in Brussels.

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*'SIP Malta is a great best practice of a national initiative
how to follow our recommended strategy'
(Dr Gudula Petersen)*

The achievements of the national SIP platforms will be shared in 2019 and SIP Malta is highly welcome to present its results there.

Mrs. Mary Vella, Chairperson Association for Rheumatoid Arthritis, Malta (ARAM) & member of SIP Malta, described emotionally her personal journey as a pain patient especially the time taken for a correct diagnosis. She explained how this led to a change in her life and that of her family. However she spoke of how she turned this challenge into an opportunity and set up the ARAM support group which is now very active in patient education, awareness and advocacy.

Another emotional story was told by Mr. Mario Xuereb (NPF member), who cares for his wife, a severe pain sufferer.

*'People do not remember her anymore ...she is a
complete other person now.'* (Mr Mario Xuereb)

In the final **Panel 3, Key policy proposals to address the impact of pain on Maltese citizens**

Discussion on the proposed policy measures Ms Sina Bugeja (CEO Special Projects Ministry for Health and ARAM representative) promoted a more holistic approach.

*'It is our business to improve quality of life of patients.
(Ms Sina Bugeja)*

Dr John M Cachia (Commissioner for Mental Health, Malta) raised the issue of chronic diseases like chronic pain and recommended to focus on solutions. Dr Cachia sees parallels to other diseases like mental health and joint initiatives may benefit to more than one disease.

Hon Claudette Buttigieg (Maltese member of parliament and Deputy Speaker) said 'pain is reality' and clear evidence of this was presented by the Maltese pain research results. She encouraged those present to make use of their right to set the agenda of politicians – and pain is currently not on the [Hier eingeben]

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health agenda in Malta. Politicians need to listen to the patients to take care of health care systems instead of just managing health systems from their ivory towers. Early diagnosis and treatment of pain patients is needed as impressively demonstrated by Mary Vella when she explained her disease journey.

During the discussion that ensued, the audience debated the major gaps in pain management in Malta and ways to improve such. Currently a multidisciplinary team is missing and patient focus instead of professional focus is urgently needed. Stigma makes the condition of the patients even worse. Breaking the silos and building bridges between the various professionals involved, patients and carers is clearly needed. Disciplines like physiotherapy, Occupational therapy and pharmacists can help a lot if the right protocol is set up.

Gertrude Buttigieg closed the meeting with the words *'We need to keep the momentum ongoing. Let us define our next steps and call for action now!'*

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