

Determining chronic pain data elements as a first step towards improving quality of care and research in chronic pain

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Abstract. *Background:* Chronic pain is a significant clinical problem in the world. There is still no quite effective treatment for this pain due to its complex nature. Timely retrieval of accurate and comprehensive information through organized clinical and epidemiological studies is an essential prerequisite for providing high quality clinical care and more accurate health planning. We aimed to determine minimum set of data needed as a first step in design and development of a chronic pain registry system. *Materials and Methods:* This descriptive-applied study was carried out in three phases; identifying necessary minimum data, preparing a primary minimum dataset, and surveying experts by questionnaire. *Result:* The literature review revealed that, the primary minimum dataset consisted of 51 elements, which were reduced to 41 after applying the experts' opinion. This dataset covered six areas: demographic information (8 elements), initial pain assessment (12 elements), medical history (8 elements), mental health and well-being (6 elements), diagnostic measures (3 elements), and diagnosis and treatment plan (4 elements). *Conclusion:* Determining minimum set of chronic pain data will be an effective step towards integrating and improving information management of patients with chronic pain. It will also allow for proper storage and retrieval of information related to these patients.

Key words: Chronic pain, Registry, Minimum dataset, Pain management

Introduction

Pain is an unpleasant emotional and sensory experience caused by potential or actual tissue damage, which mankind has been trying to control since the beginning of history (1,2). Chronic pain is a pain that lasts longer than expected and may persist for many years even if the underlying cause is removed.

Chronic pain in the long term can lead to economic, psychological and behavioural problems by reducing a person's abilities to perform personal and

social activities such as daily, recreational, and occupational activities (3-5). For this reason, physicians do not view chronic pain as a symptom or even a disease, but as a complex biological, psychological, and social phenomenon (6, 7).

While most diseases, such as diabetes and hypertension, have a well-defined and proven treatment plan, unfortunately, chronic pain does not have any definite and validated treatment plan. Also, specialists in this field are required to use evidence-based activities that include analysis of therapeutic models and

patient's responses to each model in order to ensure the quality of care provided to patients. In the face of such challenges, the complex role of information management through the creation of electronic registry systems is increasingly apparent(8). The ability of registry systems to deliver high-quality and accurate reports, assist in better clinical decision-making, and facilitate research projects depends of the entry of data with predetermined standards (9-11). These predetermined standards are in fact, the minimum datasets in the registry systems that enable proper communication between care providers and health managers by providing the necessary minimum variables (12-14). The use of standard elements along with the same definitions as the minimum dataset results in increased comparability of data, and facilitates the decision-making process. Thus, the minimum dataset, in addition to being considered a standard, can be a valuable resource for continuous evaluation of patient progress and performance (15, 16).

Considering the benefits of designing and determining the necessary minimum dataset on diseases and other health domains, and also taking into account the importance of chronic pain control and monitoring, the main objective of this study was to identify and create the minimum dataset needed for the registration, control and monitoring of patients with chronic pains. Creation of this dataset can be the first step in establishing a chronic pain registry system in Iran (17-18).

Methods and methods

This descriptive-applied study was carried out in three structured phases. In the first phase, a literature review was carried out by conducting a search in databases such as PubMed, Science direct, Clinical key and Google scholar search engine using defined keywords. The keywords used in this search included chronic pain, registries, pain management, and minimum dataset.

In the second phase, a list of necessary minimum datasets was prepared considering the similarities and differences in the datasets. Then, based on the primary list obtained from the literature review phase, a questionnaire was designed by the experts. Validity and reliability of the questionnaire were confirmed in the

pain clinic of Rasoul Akram Hospital. This clinical setting was selected because it was a teaching and research environment with the presence of leading experts who had over 10 years of experience in the field of pain. At first, the face validity of the questionnaire was approved by experts and then, its content validity was assessed by using the proposed method of Lawshe and calculating content validity ratio (CVR) and content validity index (CVI). Reliability of the questionnaire was also determined and accepted by calculating the percentage of experts' agreement.

Results

After searching the valid databases, 530 articles on pain registries and guidelines were found worldwide of which the duplicate and inaccessible articles were removed. Finally, 27 sources including valid articles and guidelines related to the topic were selected as the main sources of study. The sources were mainly from the United States, Canada, England, Australia, Sweden, Denmark, Norway and Scotland. The highest number of sources with 6 national guidelines in the field of pain relief and management and 3 chronic pain registry systems were related to the United States of America. It is worth mentioning that, the World Health Organization (WHO) has also published an international guideline on the management of non-cancer chronic pain in adults in recent years to illustrate the importance of chronic pain treatment and management.

In the next phase, a total of 51 data elements were identified as the primary elements of the descriptive phase which are listed in tables 1 to 4, presenting frequency of each data elements (19-45).

Then, based on the classification of world's famous registries such as Quebec's Pain Registry, EU's Pain Out System, Swedish Quality Registry for Pain and Canadian Chronic Pain System, the researcher summarized and classified the range of data elements in six domains, including demographic information, initial pain assessment, pain history, mental health and wellbeing, diagnostic measures, and diagnosis and treatment plan. Early corrections were approved by two pain specialists, two information management

Table 1. List of demographic and social data elements

Elements Reference	N(%)	WHO 2008 (19)	SIGN 2013 (20)	Burce et al., 2017(21)	Chou et al., 2016(22)	Giummarra et al., 2014 (23)	Practice parameter 2010(24)	Rosenquist et al., 2018(25)	Nyberg et al., 2011(26)	Choiniere et al., 2017(27)	Zaslansky et al., 2014(28)	Vaegter et al., 2017(29)	Health care guideline 2009(30)	NICE 2018(31)	Paice et al., 2016(32)	MCRH 2020(33)	Mackey et al., 2015(34)	Lacasse et al., 2017(35)	Griffiths et al., 2003(36)	Granan et al., 2019(37)	Caraceni et al., 2002(38)	Jamison et al., 2012(39)	Love et al., 2012(40)	Breivik et al., 2008(41)	Hansen et al., 2010(42)	Milton et al., 2013(43)	Hawker et al., 2011(44)	Dressler et al., 2019(45)	
Gender	17(62.96)	-	-	-	-	✓	-	✓	✓	✓	✓	✓	-	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	-
Age	23(85.18)	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-
Nationality	8(29.62)	✓	-	-	✓	✓	-	-	-	-	✓	-	✓	-	-	-	-	✓	-	-	-	✓	✓	-	-	-	-	-	-
Education level	12(44.44)	✓	-	-	✓	✓	-	✓	✓	✓	-	✓	-	-	-	-	✓	✓	-	✓	✓	✓	-	-	-	-	-	-	-
Religion	9(33.33)	-	-	-	✓	-	-	-	✓	-	-	-	✓	-	✓	-	-	✓	-	✓	✓	✓	✓	-	-	-	-	-	-
Income status	12(44.44)	✓	-	-	-	✓	-	✓	✓	✓	-	✓	-	✓	-	-	✓	✓	-	✓	-	✓	-	-	-	-	-	-	✓
Marital status	7(25.92)	-	-	-	-	-	-	✓	-	✓	-	✓	✓	✓	-	-	-	-	-	✓	-	-	✓	-	-	-	-	-	-
Type of insurance	5(18.51)	-	-	-	-	-	-	-	-	-	-	✓	-	✓	-	-	-	-	-	✓	✓	✓	-	-	-	-	-	-	-
Email/post code	7(25.92)	-	-	-	-	-	-	-	✓	✓	✓	✓	-	-	-	-	✓	-	✓	✓	-	-	-	-	-	-	-	-	-
Weight	5(18.51)	-	-	-	-	✓	-	-	-	-	✓	✓	-	-	-	-	-	✓	-	-	-	-	✓	-	-	-	-	-	-
Height	3(11.11)	-	-	-	-	-	-	-	-	-	-	✓	-	-	-	-	-	✓	-	-	-	-	✓	-	-	-	-	-	-
Address & Contact number	3(11.11)	-	-	-	-	-	-	-	✓	✓	-	✓	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

specialists and one epidemiologist. After the confirmation of face validity by experts, the questionnaire was given to 14 pain specialists who were selected through convenience and snowball sampling to confirm its content validity using Lawshe method. Although the minimum number of experts was calculated to be five based on Lawshe method, more than five experts were selected to compensate for the possible sample drop or non-compilation of the questionnaire in order to increase its reliability. Finally, out of 14 questionnaires distributed among the specialists, 8 were returned to the research team. The specialists involved in this phase were mostly men (87.5%) with the age range of 40-49 years (50%). Also, 62.5% of the specialists were faculty members and 75% of them were full professors. In terms of medical practice, half of them (50%) had more than 20 years of experience in practice and more than 10 years of experience in pain management and control. The specifications of the expert panel are listed in table 5.

By analyzing the results of questionnaires, calculating the CVR by following formula, and considering the mean scores given to each information element, only items with the CVR of 0.75 and the mean of 2 or higher were considered (46-49).

$$CVR = \frac{N_e - n/2}{n/2}$$

In this formula, “ N_e ” represents the number of people who found the selected item necessary, and “ n ” refers to the total number of experts who completed the questionnaire (46-49).

According to the results of table 6 (Additional file), out of 51 surveyed information elements, 41 elements with the CVR of above 0.75 had the necessary conditions to remain in the questionnaire. Also, 10 data elements with the CVR of less than 0.75 were removed from the minimum dataset, which included

Table 2. List of medical history and examination data elements

Elements Reference	N(%)	WHO 2008 (19)	SIGN 2013(20)	Burce et al., 2017(21)	Chou et al., 2016(22)	Giummarra et al., 2014(23)	Practice parameter 2010(24)	Rosenquist et al., 2018(25)	Nyberg et al., 2011(26)	Choiniere et al., 2017(27)	Zaslansky et al., 2014(28)	Vaegter et al., 2017(29)	Health care guideline 2009(30)	NICE 2018 (31)	Paice et al., 2016(23)	MCRH 2020(33)	Mackey et al., 2015(34)	Lacasse et al., 2017(35)	Griffiths et al., 2003(36)	Granan et al., 2019(37)	Caraceni et al., 2002(38)	Jamison et al., 2012(39)	Love et al., 2012(40)	Breivik et al., 2008(41)	Hansen et al., 2010(42)	Milton et al., 2013(43)	Hawker et al., 2011(44)	Dressler et al., 2019(45)	
Consumption habit (opioid, cigarettes, alcohol)	18(66.66)	✓	✓	✓	✓	-	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	-	-	-	-	-	-
Comorbidities	20(74.04)	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-	
Any history of allergy	14(51.85)	✓	✓	✓	✓	-	✓	-	-	-	-	-	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-	
History of mental disorder	20(74.04)	✓	-	-	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	✓	✓	
Family history of chronic pain	5(18.51)	-	-	-	-	-	✓	✓	-	✓	-	-	-	-	-	-	-	-	-	-	-	✓	-	✓	-	-	-	-	
Analgesics	17(62.96)	✓	✓	✓	✓	-	✓	✓	-	✓	✓	-	✓	✓	✓	✓	-	-	✓	-	✓	✓	✓	✓	-	-	-	-	-
Adverse/side effect	19(70.37)	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-	-	
Past treatments & interventions	21(77.77)	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	-	
Current treatments & interventions	21(77.77)	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	-	
Assessment of impact of treatment/ interventions	19(70.37)	✓	✓	✓	✓	✓	✓	-	-	-	✓	-	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	-	
Physical examination	14(51.85)	✓	✓	-	✓	-	✓	✓	-	✓	-	-	✓	✓	✓	✓	-	-	✓	-	✓	✓	-	-	-	-	-	✓	
Assessment result of laboratory & imaging tests	9(33.33)	-	-	-	-	-	✓	✓	-	✓	-	-	✓	-	✓	✓	-	-	-	-	✓	✓	-	-	-	-	-	✓	

Table 3. List of Pain data elements

Elements Reference	N(%)	WHO 2008(19)	SIGN 2013(20)	Burce et al., 2017(21)	Chou et al., 2016(22)	Giummarra et al., 2014(23)	Practice parameter 2010(24)	Rosenquist et al., 2018(25)	Nyberg et al., 2011(26)	Choiniere et al., 2017(27)	Zaslansky et al., 2014(28)	Vaegter et al., 2017(29)	Health care guideline 2009(30)	NICE 2018 (31)	Paice et al., 2016(32)	MCRH 2020(33)	Mackey et al., 2015(34)	Lacasse et al., 2017(35)	Griffiths et al., 2003(36)	Granan et al., 2019(37)	Caraceni et al., 2002(38)	Jamison et al., 2012(39)	Love et al., 2012(40)	Brevik et al., 2008(41)	Hansen et al., 2010(42)	Milton et al., 2013(43)	Hawker et al., 2011(44)	Dressler et al., 2019(45)	
Location	22(81.48)	✓	✓	-	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	-	-	✓	-	✓	✓	✓	✓	✓	✓	-	-	✓	✓	✓
Pain intensity	23(85.18)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓	✓	✓	-	-	✓	✓	✓
quality of pain	11(40.74)	-	-	✓	✓	-	-	-	-	-	-	-	✓	-	✓	-	✓	-	✓	-	✓	✓	✓	✓	-	-	✓	-	✓
Onset of pain	23(85.18)	-	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	-	✓	✓	✓	-	-	-	-	-	✓
Pain duration	13(48.14)	✓	✓	✓	-	-	✓	-	-	-	-	-	✓	✓	✓	-	✓	-	✓	✓	✓	✓	✓	-	-	-	-	-	-
Kind of pain	12(44.44)	✓	✓	-	-	-	-	✓	-	✓	-	-	✓	-	-	✓	✓	-	✓	-	✓	✓	✓	✓	-	-	-	-	-
The spread pain to other organs	9(33.33)	-	-	-	-	-	✓	✓	✓	✓	-	✓	✓	✓	-	✓	✓	-	-	-	-	-	-	-	-	-	-	-	-
Suspected etiology	12(44.44)	✓	-	✓	-	✓	-	-	-	✓	-	-	-	✓	✓	✓	✓	-	✓	-	✓	✓	✓	-	-	-	-	-	-
Assessment of pain with VRS, NRS,...	13(48.14)	✓	✓	-	✓	-	-	-	-	-	-	-	✓	-	-	-	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	-	-
Frequency in the past 6 months	5(18.51)	-	-	✓	-	-	-	✓	-	✓	-	✓	-	-	-	-	-	✓	-	-	-	-	-	-	-	-	-	-	-
Frequency in the past 7 day	6(22.22)	-	-	✓	-	-	-	✓	-	✓	-	-	-	-	-	-	-	✓	-	✓	✓	-	-	-	-	-	-	-	-
Pain relievers & exacerbating factors	12(44.44)	-	-	✓	✓	-	✓	✓	-	✓	-	-	✓	-	✓	✓	✓	-	-	✓	✓	-	✓	-	-	-	-	-	-
Intensity of pain during movement	8(29.62)	✓	-	-	✓	-	-	-	-	-	-	-	-	-	✓	-	✓	-	✓	✓	-	-	✓	-	-	-	✓	-	-
Diagnosis	18(66.66)	-	✓	-	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	✓	✓	✓	✓	✓	-	-	✓	-	-
Treatment plans & interventions	22(81.48)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	-	-
Next visit date	7(25.92)	-	-	-	-	-	-	✓	✓	✓	-	-	-	-	✓	-	✓	-	-	✓	-	-	✓	-	-	-	-	-	-
Total health status	11(40.74)	-	-	-	-	-	-	-	✓	✓	✓	✓	-	-	-	-	✓	-	✓	✓	-	-	✓	✓	-	-	✓	✓	-

Table 4. List of psychological and activities of daily living data elements

Elements Reference	N(%)	WHO 2008(19)	SIGN 2013(20)	Burce et al., 2017(21)	Chou et al., 2016(22)	Giummarra et al., 2014(23)	Practice parameter 2010(24)	Rosenquist et al., 2018(25)	Nyberg et al., 2011(26)	Choiniere et al., 2017(27)	Zaslansky et al., 2014(28)	Vaegter et al., 2017(29)	Health care guideline 2009(30)	NICE 2018 (31)	Paice et al., 2016(32)	MCRH 2020(33)	Mackey et al., 2015(34)	Lacasse et al., 2017(35)	Griffiths et al., 2003(36)	Granan et al., 2019(37)	Caraceni et al., 2002(38)	Jamison et al., 2012(39)	Love et al., 2012(40)	Brevik et al., 2008(41)	Hansen et al., 2010(42)	Milton et al., 2013(43)	Hawker et al., 2011(44)	Dressler et al., 2019(45)	
Tendency to catastrophize in the face of pain	18(66.66)	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	-	-	✓	✓	✓	✓	✓	-	-	✓	-	-	-	-	-
Pain interference on daily activities	26(96.29)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓
Impact of pain on occupational tasks	22(81.48)	✓	✓	-	-	✓	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓
Impact of pain on ability to participate in social activities	25(92.59)	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓
Impact of pain on sleep	20(74.04)	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	-	-	-	-
Impact of pain on mood, anxiety depression,....	24(88.88)	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	-
Patient satisfaction with treatment	15(55.55)	-	✓	-	-	✓	✓	✓	✓	✓	-	✓	-	✓	✓	-	✓	-	✓	✓	✓	✓	✓	-	-	-	-	-	-
Risk of opioid abuse/misuse	7(25.92)	✓	✓	-	✓	-	-	-	-	-	-	-	✓	-	✓	✓	-	-	-	-	-	✓	-	-	-	-	-	-	-

religion, nationality, income status, type of insurance, email, height, frequency of pain in the past 6 months, assessment of patient's willingness to use addictive drugs, assessment of patient's attitude towards pain, and assessment of patient's overall health. Then, the total content validity index was calculated by the following formula with an acceptable value of 0.9(46, 47).

The reliability of the questionnaire was determined by calculating the percentage of experts' agreement, which is called: "Expert Percent Agreement (EPA)"(50). For this purpose, the questionnaire was

distributed among pain specialists who were divided into two groups of specialists with more than 5 years of experience and those with less than 5 years of experience. Then, the percentages of their agreement were calculated by examining the agreement and disagreement of the two groups in regard to adding an information element in the questionnaire. The EPA in regard to demographic dataset, pain assessment data, health and well-being dataset, diagnostic measures dataset, and diagnosis and treatment plan dataset was 100% and in regard to the medical history dataset, it was 95% that indicated a high level of agreement.

$$CVR = \frac{\sum CVR}{\text{RetaindNumbers}} = \frac{31}{41} = 0.9$$

Finally, the minimum dataset needed to control chronic pain were grouped into six main groups as shown in Figure 1, with details of each group being compared.

Discussion

Systematic collection and analysis of chronic pain control and management data through the establishment of a registry system can have positive effects on health planning, treatment and prevention. Since the success of registry systems depends on the quality of stored data, identifying and determining the necessary minimum data elements to meet the needs of registry users are among the first steps in designing and creating a chronic pain registry system. The necessary minimum dataset is, in fact, a standard that facilitates data exchange and comparability at a different individual (patient), organizational (care provider) and national and international levels (society).

In 1995, the Swedish Rehabilitation Association was first to set up and developed a national qualitative registry system with the aim of rehabilitating patients with chronic musculoskeletal pain and assessing the impact of rehabilitation programs through the study of patient-reported outcomes. The system assessed the impact of rehabilitation programs and compared patients in different rehabilitation clinics through a standard set of data collected before the rehabilitation, a few days after the rehabilitation, and one year later. The minimum required data in this set were divided into two main groups of demographic information (age, sex, income status, education level, type of insurance coverage) and clinical information (severity of pain, mental and behavioural status, physical disability, and life satisfaction). The classification systems of the International Classification of Functioning, Disability and Health (ICF) were also used to provide diagnostic codes for disability and pain, respectively(26). Collection of chronic pain data in Sweden, Norway, Denmark, Canada and the United States aimed at establishing national and

international chronic pain registry systems to provide quality and accurate care to patients, evaluate the quality of services provided, and facilitate clinical projects.

Quebec Pain Registry System in Canada is one of the most successful chronic pain registries in the world due to its rich and high-quality data. It also has been able to meet all three management, clinical and research goals of registry systems simultaneously. The main feature of this system is that it pays considerable attention to the data it collects to the extent that, it provides researchers with a very clear understanding of chronic pain and thus contributes to the high quality of research. Also in 2007, the system was introduced as a strategic initiative in the area of chronic pain management. An example of the quality of its data can be the recording of the code for chronic pain diagnosis and intervention based on a unique network(27). Most chronic pain registry systems in the world (except for the Oslo chronic pain registry system) use ICD versions 9 and 10, while they do not provide appropriate diagnostic code for chronic pain syndrome as a disease. On the other hand, the codes presented by the International Association for the Study of Pain (IASP) are so complex that they are practically non-functional (27, 37).

The Danish multicenter clinical pain registry system, which was developed in 2015 by the Danish University of North and the University of Odense, has similar minimum dataset to that identified in this study, but with little difference in classification. This dataset also consists of 6 main sections, including demographic data, social data, pain characteristics, psychological factors, daily living activities, and other information elements(29).

In the United States, the chronic pain registry system was developed in 2016 by the medical department of Stanford University and the clinical informatics center in collaboration with the national health organization to monitor the progress of chronic pain status and the impact of interventions. This registry system emphasizes on the follow-up of patient information as the key components of clinical practice. This system's minimum dataset is similar to the one identified in this study with a difference that, it includes the data of children with chronic pain. When the patient who has chronic pain is a child, the system collects data from both the child and his/her caregiver or care provider(34).

Table 5. Demographic information about respondents on the dataset of chronic pain registry

Profile		frequency	percentage
gender	female	1	12.5 %
	male	7	87.5 %
	total	8	100 %
age	30-39	1	12.5 %
	40-49	4	50 %
	>50	3	37.5 %
	total	8	100 %
Being Faculty Member	Yes	5	62.5 %
	no	3	37.5 %
	Total	8	100 %
Science ranking	Professor	6	75 %
	Fellowship Assistant	2	25 %
	total	8	100 %
Years of Experience	<10	1	12.5 %
	10-20	3	37.5 %
	>20	4	50 %
	Total	8	100 %
History of pain medicine	<5	3	37.5 %
	5-9	1	12.5 %
	>10	4	50 %
	Total	8	100 %

Table 6. CVR values, Mean Judgments and Results of Acceptance or Rejection of data elements from the Primary Questionnaire of Chronic Pain Registry

Row	Data elements	CVR	Numerical Mean of Judgments	Accept/Reject
1	gender	1	3	accept
2	age	0.75	2.87	accept
3	National code	0.75	2.87	accept
4	Educational level	0.75	2.87	accept
5	Employment status	0.75	2.87	accept
6	Religion	0	2.37	reject
7	Income status	0.25	2.62	reject
8	Nationality/Race	0.25	2.62	reject
9	Marital status	0.75	2.75	accept
10	Type of insurance	0.25-	2	reject
11	Email	0.75-	1.62	reject
12	weight	0.75	2.87	accept
13	Height	0.25	2.62	reject
14	Address & contact number	0.75	2.87	accept
15	Pain location	1	3	accept
16	Pain intensity	1	3	accept
17	Quality of pain	1	3	accept
18	assessment of pain with NRS , VAS , VRS	1	3	accept
19	Onset of pain	1	3	accept
20	Pain duration	1	3	accept

Row	Data elements	CVR	Numerical Mean of Judgments	Accept/Reject
21	Kind of pain(neuropathic, ...)	1	3	accept
22	The spread pain to other organs	1	3	accept
23	Suspected etiology	1	3	accept
24	Exacerbating & relievers factors	1	3	accept
25	Intensity of pain during activity & resting	1	3	accept
26	Frequency in the past 6 months	0.5	2.62	reject
27	Frequency in the past 7 days	1	3	accept
28	Physical examination	1	3	accept
29	Assessment result of laboratory & imaging tests	1	3	accept
30	Consumption habits(cigarettes, alcohol, illicit drugs)	1	3	accept
31	comorbidities	1	3	accept
32	Any history of allergy	0.75	2.87	accept
33	History of mental disorder	1	3	accept
34	Is it degree family history of chronic pain	0.75	2.87	accept
35	analgesics	1	3	accept
36	Adverse/side effect	1	3	accept
37	Risk of opioid abuse/misuse	0.5	2.75	reject
38	Past and current treatments/interventions	1	3	accept
39	Assessment of impact of treatment interventions	0.75	2.87	accept
40	Patient satisfaction with treatment	0.75	2.87	accept
41	Tendency to catastrophize in the face of pain	0.5	2.75	reject
42	Pain interference on daily activities	0.75	2.87	accept
43	Impact of pain on occupational tasks	0.75	2.87	accept
44	Impact of pain on ability to participate in social activities	0.75	2.87	accept
45	Impact of pain on sleep	1	3	accept
46	Impact of pain on mood, anxiety, depression	0.75	2.87	accept
47	Total health status	0.5	2.75	reject
48	Differential diagnosis	1	3	accept
49	Diagnosis	1	3	accept
50	Treatment plans	1	3	accept
51	The next visit date	0.75	2.87	accept

Comparing the findings of this study with the chronic pain registries of other countries shows a significant similarity in the minimum datasets of these registries. So it seems that the management and evaluation of chronic pain are similar in all countries, and all-known chronic pain registries consider approximately the same datasets in order to provide high-quality care. Therefore, we can conclude that, since the minimum dataset of our registry system is based on data obtained from a comprehensive review of clinical literature and guidelines, it highly corresponds with the datasets of chronic pain registry systems in the leading countries.

Conclusion

Due to the complex nature of pain, patients with chronic pain often suffer for many years, and in many cases, they are faced with many psychological, behavioural, social and economic problems that challenge not only them but also those around them(5). Thus, long-term management of chronic pain information through the creation of integrated and comprehensive dataset is inevitable in managing and improving the quality of treatment. The findings of the present study showed that determining a minimum set

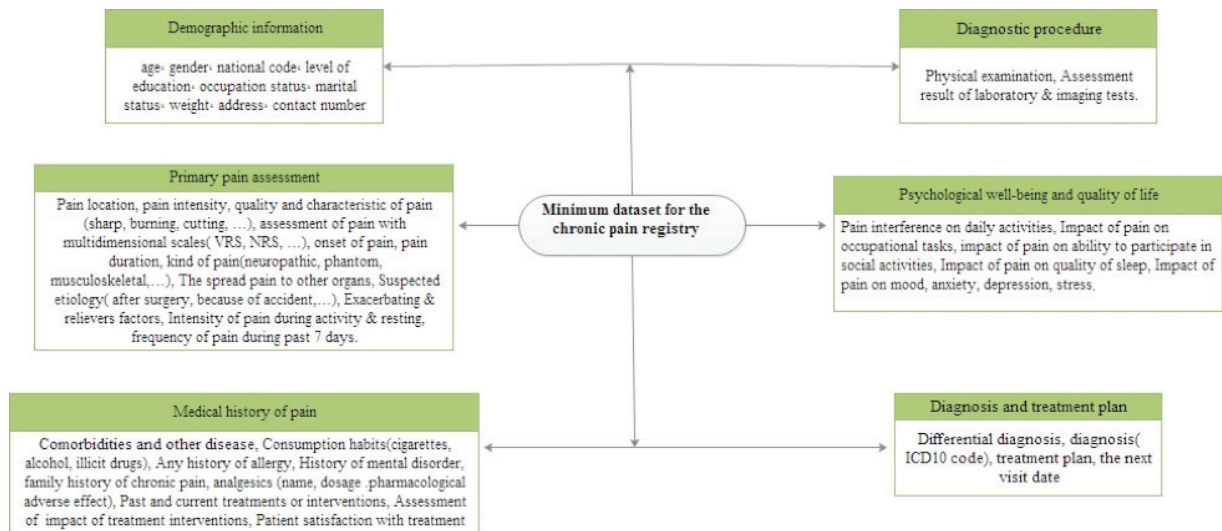


Figure 1. Minimum dataset for the chronic pain registry

of chronic pain data by experts in this field is an effective step towards integrating the information of these patients in Iran and improving the quality of care for patients with chronic pain. It is hoped that by defining the minimum set of data and designing a chronic pain registry system suitable for Iranian social and health contexts, it would be possible to store and retrieve accurate and standard data related to these patients and thus, improve services delivered to them.

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