Shared-decision process in people with chronic disease: Integrating the biological, social and lived experiences is a key responsibility of nurses

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Introduction

Shared decision-making (SDM) is a collaborative process through which patients and their providers make healthcare decisions together, based on the best scientific evidence available, the health professional's experience as well as the patient's values and preferences (Chewning et al., 2012). This key feature of person-centred care is advocated broadly, as critical for successful disease management in chronic diseases (de Wit, 2017; Ekman et al., 2011; McCormack et al., 2015; Voshaar, Nota, van de Laar, & van den Bemt, 2015). Despite this, its implementation continues to be delayed.

When making decisions on their own health, patients value not only clinical/biological outcomes but also, and often to a greater extent, the way they feel the disease impacts their life. The trend to capture patient perspectives using patient-reported outcome measures (PROMs), as an attempt to serve person-centred care, is still growing (Fautrel et al., 2018; Harding, Wait, & Scrutton, 2015). However, when it comes to treatment decisions in real-world practice, the primary target is defined by the physician in charge and is often limited to the biological process of the disease. Patients' personal goals come into management plans only when the medical treatment seems to fail or, in the best of circumstances, they are considered for adjunctive treatment options.

Nursing is characterised by evidence-based practice and SDM with the patient and takes place in the context of a multidisciplinary team care (Bech et al., 2019). Therefore, nurses should have a pivotal role in assessing and managing the impact of disease and promoting SDM (Bala et al., 2018; Salisbury et al., 2018; Ventura, 2016).

This paper discusses how nurses can contribute to patient-centred care in chronic diseases through the use of PROMs and coordination of the patient's representation in treatment decisions. Inspired by data from observational studies we have recently conducted with patients with rheumatoid arthritis, an archetype of many chronic diseases (Shaul, 2010), the paper proposes a strategy to address both clinical treatment targets and personal goals in chronic diseases using SDM in the multi-professional team context.

1. Disease control is not equivalent to abrogation of disease impact

Many chronic conditions, such as rheumatic diseases, are characterised by a deregulated immune system that primarily affects a specific organ (Chen et al., 2017; Schultze & Rosenstiel, 2018) and can severely affect all areas of life, including physical, social and psychological well-being (Santos et al., 2018; Taylor, Moore, Vasilescu, Alvir, & Tarallo, 2016). Developments in the pharmacological treatments over the last two decades have revolutionised the management of many of these conditions, effectively reducing the inflammatory process and keeping it rather low or in remission. It has also reduced the risk for complications associated with chronic inflammation (Dinarello, 2010; Kiely & Nikiphorou, 2018).

Paradoxically, these unprecedented pharmacological developments are not always mirrored by patients' overall perception of well-being (Fautrel et al., 2018; Gruffydd-Jones, 2019; Taylor et al., 2016; Torres-González et al., 2014). The control of the disease process does not necessarily mean control of the impact that the disease (and its treatment) has on patients' lives. To maximise long-term outcomes and quality of life (QoL), people with chronic diseases need to develop self-management skills, the ability to manage the symptoms and treatment regimes, and deal with the physical and psychosocial consequences as well as lifestyle changes inherent to living with a chronic condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Huber et al., 2011).

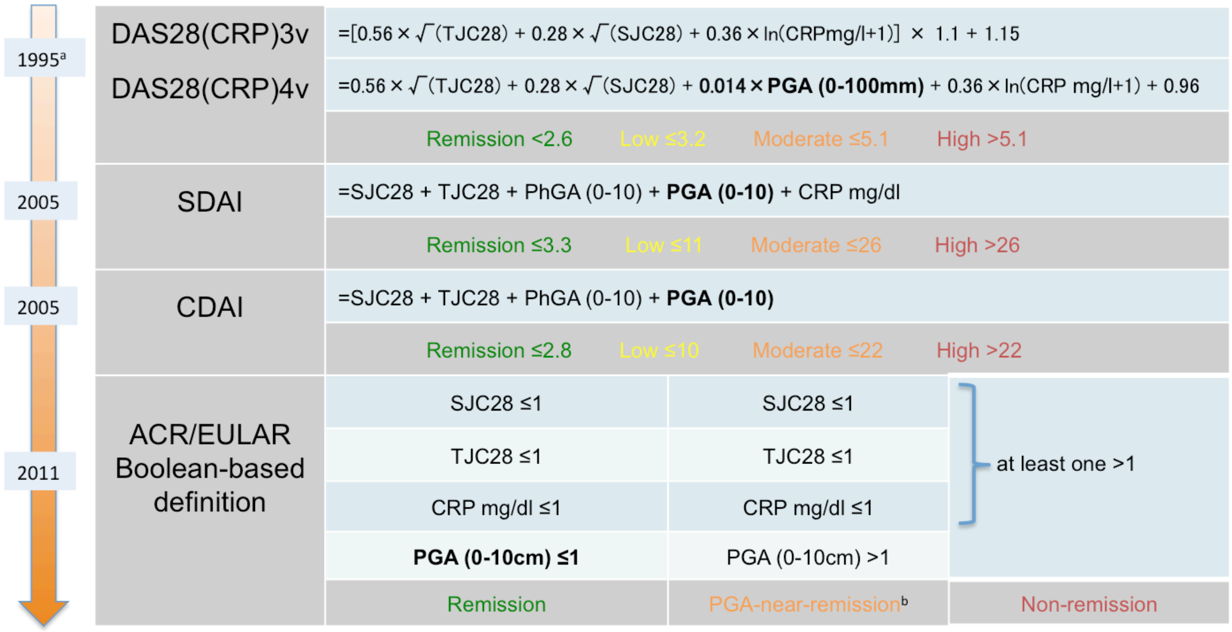
Our recent research has highlighted that each patient has a unique perception of his/her disease (Santos et al., 2018). Personality traits have a considerable influence on the perception of the disruption caused by the disease, with decisive consequences on QoL and happiness (Santos et al., 2018). Accordingly, treatment strategies focusing solely on the control of the disease process have a limited effect on disease symptoms, on QoL and probably a minor effect on happiness (Ferreira et al., 2019; Ferreira et al., 2017; Santos et al., 2019a; Santos et al., 2018; Silva, Duarte, Ferreira, Santos, & da Silva, 2019). To fully grasp the dimensions affected by the disease and the psychosocial context, a more holistic assessment of patients is needed as a basis for subsequent interventions that go beyond pharmacological treatment and control of the pathological process (Santos et al., 2019c). Patients and society have rising expectations of healthcare and their perspectives and priorities need to be adequately and sufficiently considered, i.e. incorporated in management decisions. This can be achieved in clinical care through the use of validated PROMs (Weldring & Smith, 2013). In order to maximize the benefit of PROMs in clinical practice the targeted domains (disease process, disease impact or personal goals) need to be clear and relevant, to both patient and health professional.

2. Inclusion of PROMs may challenge the treatment target(s)

In rheumatology, and specifically in RA, two international consortia achieved consensus regarding the need to regularly collect PROMs in addition to objective or physician reported outcomes. The first initiative, by the American College of Rheumatology, recommended a core set of patient-reported measures such as pain, physical function, and patient global assessment of disease activity (PGA) to be used in clinical trials. The PGA is a single question assessing patient perception of disease/arthritis activity on a 0 to 100 mm visual analogue scale. These measures were meant to complement the standard medical assessments such as tender and swollen joint counts, acute phase reactants, and the physician global assessment (PhGA) of disease activity (Castrejon & Pincus, 2012; Felson et al., 1993). In the composite measure of disease activity (DAS28), PGA represents, at most 1.4 out of the maximum score of 9.4 points (Anderson, Zimmerman, Caplan, & Michaud, 2011). This means that although included, the patient's perspective has a minimal influence (Figure 1).

The second consortium mandated the inclusion of PGA in the definitions of remission used as targets of immunosuppressive therapy (Felson et al., 2011). This decision signified an important step towards patient involvement in treatment decisions (van Tuyl et al., 2011). PGA's importance in these tools has increased significantly over time: from a nearly irrelevant weight, to having the same impact in the final score as the clinical components. Using the Boolean-based definition of remission, a patient with no overt signs of inflammation (score of zero on all clinical measures) is considered to fail remission if the PGA score is >1. See Figure 1.

Figure 1. Growing importance of PGA in different treatment decision algorithms used in RA



1995ᵃ	DAS28(CRP)3v	$=[0.56\times\sqrt{(TJC28)}+0.28\times\sqrt{(SJC28)}+0.36\times\ln(CRPmg/l+1)]\times 1.1+1.15$			
	DAS28(CRP)4v	$=0.56\times\sqrt{(TJC28)}+0.28\times\sqrt{(SJC28)}+\mathbf{0.014\times PGA\ (0\text{-}100mm)}+0.36\times\ln(CRP\ mg/l+1)+0.96$			
		Remission <2.6	Low ≤3.2	Moderate ≤5.1	High >5.1
2005	SDAI	=SJC28 + TJC28 + PhGA (0-10) + **PGA (0-10)** + CRP mg/dl			
		Remission ≤3.3	Low ≤11	Moderate ≤26	High >26
2005	CDAI	=SJC28 + TJC28 + PhGA (0-10) + **PGA (0-10)**			
		Remission ≤2.8	Low ≤10	Moderate ≤22	High >22
2011	ACR/EULAR Boolean-based definition	SJC28 ≤1	SJC28 ≤1	at least one >1	
		TJC28 ≤1	TJC28 ≤1		
		CRP mg/dl ≤1	CRP mg/dl ≤1		
		PGA (0-10cm) ≤1	PGA (0-10cm) >1		
		Remission	PGA-near-remissionᵇ	Non-remission	

This figure shows the components and scoring algorithms of four disease activity tools currently in use in clinical practice and in clinical trials in rheumatoid arthritis. They are presented in chronologic order of development. a. Although the DAS with 28-joint counts was developed in 1995, its original form with 68/66-joint counts was developed in early 1980s b. This definition is not part of the definition endorsed by the American College of Rheumatology and by the European League Against Rheumatism.
Figures in bold show the growing importance of PGA in these tools. The DAS28 has two forms: one does not include PGA and the other attributed to PGA a total of 1.4 (=0.014*100) out of a maximum score of 9.4 points (Anderson et al., 2011).

In the SDAI and CDAI tools, if the PGA is 4 and all other components are (near) zero it is impossible to be classified as in remission. In the Boolean-based remission, even a 1.1 in PGA will preclude patient to be in remission.

Abbreviations: CDAI, Clinical Disease Activity Index; CRP, C-reactive protein; DAS, Disease Activity Score; ln, natural logarithm; PGA, Patient Global Assessment; PhGA, Physician Global Assessment; SDAI, Simplified Disease Activity Index; SJC28, swollen 28-joint count; TJC28, tender 28-joint count.

Studying the group of patients with RA who have no overt signs of inflammation but fail remission solely due to having a PGA>1/10 (PGA-near-remission or near-misses) has become of great interest. The question is then, "How can we understand and overcome this paradox where we see patients whose disease process is under control, but still report substantial disease impact on their daily life?" Our research tested two main hypotheses: (1) the integration of PGA in tools to define remission blurs the treatment target, and (2) the patient's needs and goals should be addressed through separate management targets.

First, we demonstrated that the number of patients in PGA-near-remission status were almost twice as many as the ones in ‘full’ remission in an international cohort (Ferreira et al., 2019), and up to 37% of all patients in some settings (Ferreira et al., 2018a). Among these PGA-near-remission patients, about one third scored PGA>4/10 (Ferreira et al., 2019). This demonstrates that despite having no measurable signs of inflammation, many patients perceive considerable disease impact. Understanding the reasons driving the high PGA in the absence of active disease is, therefore, essential in order to address the causes with appropriate interventions (other than immunosuppressive agents).

Second, following focus group interviews, we showed that different wordings (arthritis, disease, health), time references (last week, today, no reference), and scales (0 to 10 or 0–10 cm) used in current PGA formulations are open to different interpretation by patients and influence their responses (Ferreira et al., in Press). Most patients are also unaware of the purpose of PGA and have difficulties completing the measurements reliably (Ferreira et al., in Press). With a quantitative study we were able to confirm that the use of different versions of PGA introduces systematic errors in the rate of remission (Ferreira et al., 2018b)

Finally, we showed that PGA from patients in near-remission is not associated with disease activity but rather with fatigue, pain, anxiety, depression, physical well-being and functional limitations (Ferreira et al., 2019; Ferreira et al., 2017; Ferreira et al., 2018a).

In summary, PGA, a PROM very commonly used in RA, raises a number of concerns regarding its validity, not only due to the inconsistencies in its formulations, but especially because it has little relationship with the domain it is supposed to represent: disease activity. Additionally, due to its inclusion in treatment decision algorithms (Figure 1), some clinicians may disregard other domains of interest to patients. A more comprehensive assessment of the patient perspective, necessarily meaningful to the person, is needed in order to provide guidance to the selection of adjunctive measures (addressing fatigue, depression, or pain) in the context a multi-professional management team.

The above-mentioned considerations derived from studies in RA are naturally adaptable to a variety of chronic diseases given that, in all conditions, clinical and personal targets ought to exist and coexist. Inflammatory bowel and neurologic diseases are two examples of the increasing tendency to adopt a treat-to-target strategy in different fields (Agrawal & Colombel, 2019; Jacobs, Giovannoni, & Schmierer, 2018).

3. To be useful in practice, PROMs need to be valid and meaningful

The use of PROMs, initially established in clinical trials, is increasingly getting more recognition by regulators, clinicians and patients (Gossec, Dougados, & Dixon, 2015). However, their implementation in clinical practice has not been easy (Ganesan, 2018; Nelson et al., 2015). One of the main barriers to its implementation lies in the willingness of healthcare professionals, who already have high workloads, to focus on individual needs and perceptions of disease impact in addition to disease activity measures (Fautrel et al., 2018). Clinical consultations are short and it may be difficult to determine and interpret PROM scores in order to make clinical decisions in accordance (Ganesan, 2018; Porter et al., 2016; Talib et al., 2018). Patients do value PROMs but these can only improve care if clinicians prioritise and use them (Talib et al., 2018). The combination of PROMs with innovative technologies, such as mobile devices, apps and computer-adaptive tests, creates new opportunities for patients and health professionals. However, further research and consensus are needed (Basch, Barbera, Kerrigan, & Velikova, 2018; Fautrel et al., 2018; Porter et al., 2016).

Another concern is that common structured questionnaires, with closed questions, lack room for patients to express their personal views and needs (Philpot et al., 2018). Patient input in all PROMs development stages will help produce tools that are meaningful to them (Ferreira et al., in Press; Ferreira et al., 2018c).

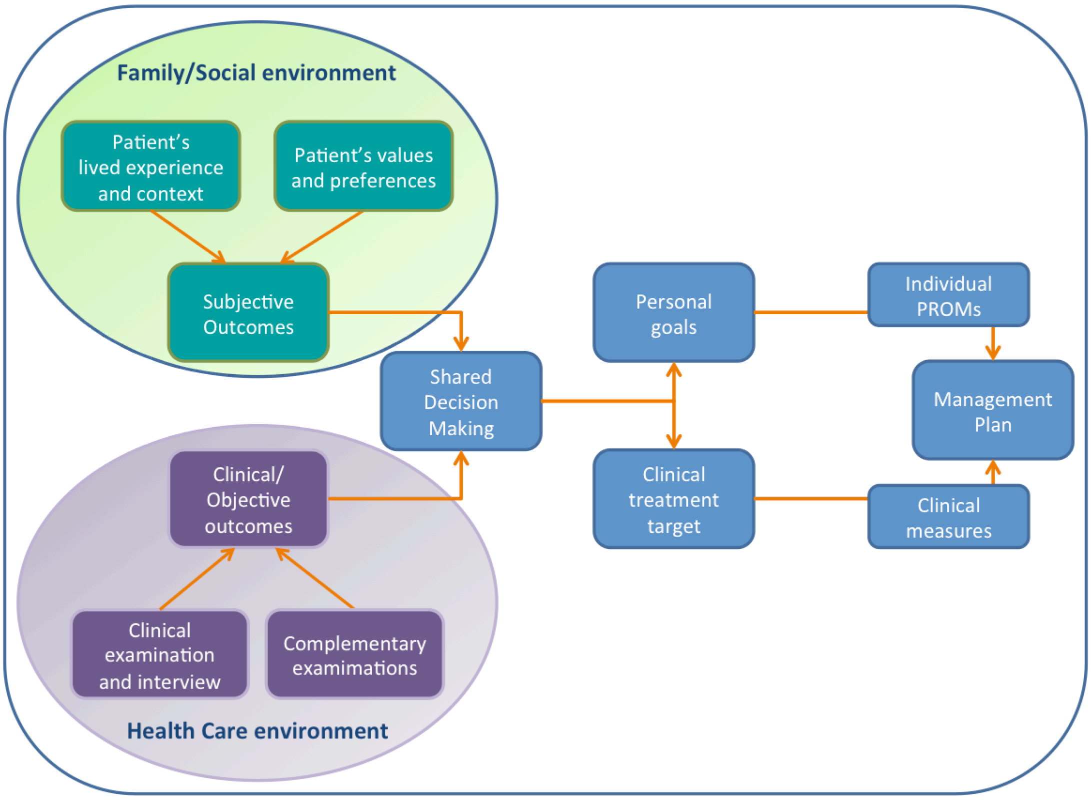
PROMs need to be reliable, transculturally valid and meaningful to patients and health professionals (Santos, Duarte, da Silva, & Ferreira, 2019b). Moreover, in clinical practice, patients should be instructed on the purpose of the measurements, and also on using them proactively to discuss the treatment plan with the multidisciplinary team (Ferreira et al., in Press).

4. The dual target strategy: clinical treatment targets and personal goals

In face of the above evidence, our research group, composed of patient research partners, nurses, psychologists and rheumatologists, proposes an ambitious approach and a paradigm shift: the dual target strategy. According to this paradigm, remission of the disease process (biological remission) should be considered in parallel with the target of remitting impact (patient's remission). The multi-professional team manages both targets, with special emphasis on the physician in the first and on the nurse in the latter (Ferreira et al., 2018d). This represents a structural change in the organisation of care in most countries. We seek to ensure that reaching the patient's remission is considered of equal value as biological remission. This requires the that the multidisciplinary team assesses and manages the holistic impact of the disease on the patient, placing his needs at the centre of the decision-making process (van Tuyl & Boers, 2017).

Figure 2 presents our proposed model, combining subjective and objective outcomes guiding shared decision within a dual-target approach: personal goals and clinical treatment targets. The first should ideally be guided and measured by personalised PROMs while the latter by clinical measures. For the purpose of illustration, we present a fictitious case study in Box 1.

Figure 2. Dual-target strategy in the context of a person-centred approach



Box 1. Fictitious case study on dual-target strategy

Maria is a 35-year-old mom who experienced a flare of RA after giving birth to a health boy. She is currently struggling to manage hand joint pain and fatigue. These symptoms strongly affect her capacity to hold and care for the baby, as well as returning to work. Informed discussions take place regarding the reintroduction of an immunosuppressive agent to the detriment of breastfeeding. Clinical targets are established, to reach during the following month: (i) the disease activity would be reduced from a DAS28CRP(3v)=4.9 to ≤3.2, and (ii) joint pain VAS from 7 to 3 following adjustment of analgesics and education on how to maximise their effect. Personal goals are also established, namely (iii) reducing fatigue from 9 to 5, facilitated by readjustment of daily activities and planning time to rest, with the cooperation of her husband. Moreover, the nurse discusses with Maria alternative strategies to reinforce the attachment to her son, so highly valued by Maria, including (iv) the use of a baby sling whenever possible, and daily skin-to-skin contact moments. Here, both Maria's satisfaction and attachment can be measured with adequate PROMs.

A preliminary study has explored the need for a dual-target strategy in the management of RA (n=101) by determining the proportion of patients who achieved biological remission (CDAI) and individual patient treatment goals (Goal Attainment Scale). After three to five months of follow-up, 44% of patients achieved both targets, while 22% achieved only personal goals and not CDAI target, and 18% the other way around (Oppenauer et al., 2019). Further research is needed to test the feasibility and (long-term) effectiveness of this model in rheumatology and other areas of care.

The use of individualised PROMs has different advantages, such as being responsive to the individual aspects of health-related QoL, and a higher likelihood of detecting issues that may be relevant in clinical practice. Individualised PROMs combined with standardised clinical measures may be effective in developing person-centred care plans, goal setting and prioritisation (Porter et al., 2016). However, the establishment of the personal goals and respective intervention requires solid knowledge, experience and specific competencies from nurses and a functional network with other health professionals.

5. Final considerations

Nurses are especially suited to champion the dual-target strategy in clinical practice for the following reasons: First, nursing is characterised by an holistic approach to care, therefore interested in incorporating patients' experiences and responses to the disease and treatments in the overall management and within other life transitions (Meleis, 2010; Shaul, 2010). This facilitates the elicitation of preferences and priorities relevant to patients both in terms of disease and in terms of personal, family and social life (Meleis, 2010; Meleis, 2018). Second, nurses have social and communicative competencies appropriate to facilitate warm encounters, a familial atmosphere and empathy in addition to their professional training. This may explain the high satisfaction, security, confidence, participation, independence, self-efficacy and enhanced patient outcomes seen in nurse-led care (Bala et al., 2012; Komatsu & Yagasaki, 2014; Larsson, 2013; Sousa, Santos, Cunha, Ferreira, & Marques, 2017; Vinall-Collier, Madill, & Firth, 2016). Third, nurses are involved in the development, validation and implementation of PROMs in daily practice. They actively use PROMs to support SDM, and frequently support the patient's completion of PROMs, ensuring they understand the measures and their possible implications in treatment decisions (Ferreira et al., in Press). Fourth, as part of the healthcare team, nurses often act as the interface (coordinator) between patients and other members of the multidisciplinary team (Bech et al., 2019). Nurses should make sure that the patient perspective is not lost during the health care journey; that is, the patient's personal goals are not disregarded or undervalued while pursuing clinical targets. Finally, owing to the diverse training process entailing multiple care settings in the pre-registration and post-graduate studies, nurses are in a special position to provide a first assessment in a multitude of co-morbidities and clinical incidents and to signpost the patient to the most appropriate heath professional or agency (Salisbury et al., 2018).

In conclusion, incorporating PROMs in clinical practice enhances SDM and has the potential to improve care by identifying aspects of disease impact and personal goals that are relevant to the patient but may be missed by clinical outcome measures. Careful selection of PROMs is important to ensure personal goals are addressed in the overall disease management. Nurses are well placed to promote appropriate use of PROMs to enhance person-centred care in chronic diseases. The feasibility of the dual-target approach, tailored to each patient, needs to be further assessed in rheumatology and in other areas of chronic disease.

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