Editorial

Challenges in “Tailoring” Adjustment

New Ways of Improving the Response to Chronic Conditions

Maria João Figueiras¹ and David Dias Neto²,³

¹ ISEIT, Research Education and Community Intervention (RECI), Instituto Piaget, Almada, Portugal
² Psychology and Health Standing Committee of the European Federation of Psychology Associations, Brussels, Belgium
³ APPayCI – Applied Psychology Research Center Capabilities & Inclusion, ISPA – Instituto Universitário, Lisbon, Portugal

Given the increase in life expectancy and improvements in health care, chronic illnesses have become a major concern for Europe and other Western regions. Chronic illness also poses specific challenges since the focus is not only in seeking a cure – which is often inexistent – but in managing symptom and reducing disability. Considering this focus, patients are asked to be literate and proactive in their treatments which make psychological processes like adjustment to be particularly relevant. This special issue includes reviews on cutting-edge research areas of adjustment to chronic illness. Firstly, we will consider behavior change interventions and the importance of considering mental health issues on the treatment. Secondly, we will review the implications of using technology and the importance of considering practice guidelines. Finally, we will consider the role of adherence and health literacy in mediating the impact of the proposed interventions. In this Editorial, we provide an overview of these areas and will argue for the importance of considering the dimensions of adjustment in tailoring treatment. Only then can the goal of providing the best care, for a particular person in a given time can be achieved.

Introduction

The experience of living with chronic illnesses carry important psychological and social consequences, since prolonged illnesses can significantly disrupt the lives of patients and their relatives (Golics, Basra, Salek, & Finlay, 2013; McAndrew et al., 2008; Stanton, & Revenson, 2012). The different nature of chronic versus acute illness means that health and well-being outcomes will not only depend on the course and severity of the illness but also on the adjustment process to the condition. By adjustment process, we mean all the cognitive, affective, and behavioral changes conducted by the individual to adapt to the manifestations and consequences of the illness. It is a chronological process influenced by the characteristics of the individual, the illness, and the context. In general terms, adjustment implies a change in attitude, behavior, or both by an individual based on some recognized need particularly to account for the current environment or changing, atypical, or unexpected conditions. A well-adjusted person is one who satisfies needs in a healthy, beneficial manner and demonstrates appropriate social and psychological responses to situations and demands (VandenBos & American Psychological Association, 2015).

The adjustment process also has several implications with respect to treatment. Given the nature of chronic illnesses, treatment is not focused on the cure but in ameliorating symptoms and reducing disability. In this sense, the involvement of the individual in its treatment and consequently the need of self-management gains an increased importance. This self-management involves coping strategies of the patient, illness and treatment perception, the influence of formal and informal carers, healthcare utilization, adherence to medication or lifestyle recommendations, and perceived quality of life (McBain, Shipley, & Newman, 2015; Stanton, Revenson, & Tennen, 2007). The same authors argued that in the context of chronic disease, examination of indicators of adjustment in research can enrich its understanding, as well as the integration of environmental variables and the translation of protective factors for adaptive outcomes into interventions.

In this Editorial, we will argue that the consideration of factors, such as the ability to engage in the use of technology to monitor and control illness, the perception of the condition and its treatment, and interventions for behavior change, represents an opportunity to increase the potential of adjustment. Further, the consideration of these factors
provides indicators of relevant variables to tailor interventions and foster self-management for better health outcomes. The existing evidence indicates the need to consider the complexity of factors involved, as well as new challenges, questions, and thoughts about this process. The aim of this special issue is to present a review of core themes which contribute to update and expand our understanding of adjustment to chronic illness.

Back to the Concept of Adjustment

The impact of chronic illnesses in terms of suffering and disability makes the adjustment process particularly relevant and involving several life domains. Many of these conditions can be treated and managed through behavior change interventions, which provide individuals with the skills to have control over and improve their health (Tougas, Hayden, McGrath, Huguet, & Rozario, 2015). It has been acknowledged that due to changing contextual factors, adaptation to chronic illness is not linear (Stanton & Revenson, 2012; Stanton, Revenson, & Tennen, 2007). For instance, disease progression may involve symptomatic and asymptomatic periods, cancer recurrence, or repeat myocardial infarction which requires constant readjustment, being seen as a process rather than an outcome. The consideration of adjustment as a process can focus both on the relation between the individual and the health condition, and the chronological evolution of such relation. These two perspectives are not incompatible.

In the first level, illness and treatment common-sense models are key determinants because they provide targets for intervention and predict variables that will affect the adjustment process. Beliefs about illness and treatment need to “make sense” in order to promote adherence and adjustment (Hekler et al., 2008; Horne et al., 2013; Leventhal, Brissette, & Leventhal, 2003; Howard Leventhal, Leventhal, & Breland, 2011; Mann, Ponieman, Leventhal, & Halm, 2009; McAndrew, Mora, Quigley, Leventhal, & Leventhal, 2014). These models should be considered to promote self-efficacy to engage in self-management behaviors in a coherent fashion, promoting the link between tailored action plans and individual’s level of competence to build self-confidence and trust in new resources to manage illness. For instance, the Common-Sense Model (CSM) of self-regulation is a complex, multilevel framework depicting the process of self-regulation of health and illness, and it has been instrumental in understanding how individuals self-regulate chronic illness (McAndrew et al., 2008). Both the prolonged nature of the condition and the need for the patients to be active on their treatment highlight the importance of the psychological reaction of the individual to the condition. Heterogeneity in adjustment is apparent between individuals and throughout the course of the disease trajectory (Hoyt & Stanton, 2012) requiring individuals to understand transition and to adjust and modify their behaviors and attitudes according to the circumstances (Kralik & van Loon, 2009). This idiosyncratic reaction and its evolution throughout time can be thought within the concept of adjustment. Another factor to be considered is self-monitoring, as the patient undertaking self-measurement and interpretation of vital signs, symptoms, behavior, or psychological well-being; and/or self-adjustment of medication, treatment, lifestyle, or help-seeking behavior as a result of self-awareness and/or self-interpretation (McBain et al., 2015).

In the second level, the chronological dimension of adjustment implies both the consideration of how the illness progresses, as a transition process, and the resources available to minimize their effects. There have been references to models of stress and coping (Walker, Jackson, & Littlejohn, 2004), self-regulation (McAndrew et al., 2008), and social cognition models (Vallis et al., 2003), as frameworks to understand the process of adjustment in relation to the illness trajectory. Over time, as people learn to live with chronic illness, there can be an increased understanding and elaboration in the meanings people attach to their illness and other aspects of their lives (Kralik & van Loon, 2009). Considering these two levels of adjustment requires the use of integrative approaches. One can be to explore illness and treatment perceptions, and the way patients are able to cope with it. Another is to identify the determinants of behavior change according to the context in order to promote self-management. Additionally, the operationalization of theoretical models which include this combination of factors provides a clearer picture of salient issues for adjustment and self-management in chronic patients.

Interventions for Behavior Change in Chronic Illness

More recently, the shift from a medic to a multidisciplinary approach for interventions has considerably improved their impact in modifying the determinants of behavior from a wider perspective (Hollands et al., 2017). Although major theories of behavior change do not include explicit predictions about behavior change in the context of chronic illness, the basic tenets of several health behavior models suggest that the onset of chronic illness should motivate lifestyle changes (Newsom et al., 2012), while other aspects of health behavior models suggest that these lifestyle changes after the diagnosis of a chronic disease may be difficult to make. Further, with the aging of the
population, research is focusing on ways to enhance individuals’ abilities to self-manage chronic disease. To help individuals better self-manage, healthcare providers must understand clients’ attitudes toward chronic disease, health behavior change, barriers to change, and the role social support plays in the self-management process (Sell, Amella, Mueller, Andrews, & Wachs, 2016). A recent review has indicated that interventions that include self-monitoring can lead to significant reductions in specific areas of health-care usage, but this is dependent on the characteristics of the chronic illness (McBain et al., 2015).

This gives further support to the need to guide intervention principles in line with existing good evidence but adapted to the context and target groups, providing a better translation of findings. Further, the development of interventions for behavior change in chronic illness seems to benefit from a multidisciplinary approach, allowing flexibility for implementation, adjustment to the stage of the illness and to the context where it occurs. This is supported by Araújo-Soares and colleagues’ (2019) contribution in the present issue, as well as the need to consider the possibility of adapting an existing intervention with a good evidence based, using integrative approaches. In the same sense, the contribution of Hudson and Moss-Morris (2019) calls for the need to deliver CBT treatments for anxiety and depression which can synergistically target illness distress for patients with chronic conditions. Both contributions for this special issue highlight the need to consider integrative approaches and synergies in order to promote self-management for the wide range of challenges posed by adjustment to chronic illness.

**Advances in Technology and Resources**

In the context of an aging society, it is essential to understand the role of technology in providing new resources and challenges for living with a chronic illness. One source of potential disease self-management and healthcare navigation support is eHealth technology. There is evidence that patients with chronic conditions are increasingly using eHealth technology to support their self-management, and using online resources as a primary source of information, reporting increased health-related knowledge and a greater sense of empowerment to improve their health (Zulman et al., 2015). The results of a recent review looking at the intersection of technology and chronic disease self-management support, and the e-health enhanced chronic care model, showed that eHealth tools make important contributions to chronic care but some aspects require modifications, such as eHealth education as being critical for self-care, the need to consider eHealth within the context of community and the need to assure productive technology-based interactions between the patient and provider (Gee, Greenwood, Paterniti, Ward, & Miller, 2015). The potential for new mobile technologies to facilitate health behavior change adds new challenges for health care, raising questions concerning the uptake, acceptability and efficacy of mHealth apps. In recent years, the growth of “electronic health” (eHealth) and “mobile health” (mHealth) interventions have been used in disease prevention and self-management, enabling the collection of data previously based on self-report (Naughton et al., 2016).

This opens the potential of technology to implement user-friendly interventions adapted to context and time, with a possibility of improving self-management and the ability to monitor changes over time. Some of the problems affecting self-management through digital interventions are a consequence of the chronic nature of the conditions. The use of digital resources may contribute to promote adherence to a treatment plan or lifestyle changes (Doughty, 2011). However, one should consider the availability of information versus credibility of sources as well as the updating of contents to promote use and engagement. There is a shift of adherence from traditional formats to implement treatment to the engagement with digital media, in which engagement is seen as a multidimensional construct and a dynamic process (Perski, Blandford, West, & Michie, 2017). Personalization seems to increase engagement and success with the intervention, providing the rights of the users such as anonymity, confidentiality, trust, and safety are assured. Although digital interventions are based upon technology, the use of persuasive designs in which a sense of human contact is considered may contribute to build trust and improve self-management. Further, as stated by Walsh and Goarke in their contribution for this special issue (2019), the advent of mHealth can benefit behavioral science research and theory, particularly the advantage of providing objective measurements for health behavior may promote self-management and better health outcomes. However, the speed of growth of eHealth and mHealth technology may increase usability of health apps. This calls for a multidisciplinary approach from technologists, medics, and health psychologists, as well as the need to consider guidelines for equal access and use, and for the quality of electronic devices for health monitoring. In that sense, Karekla and colleagues’ (2019) contribution argued the need to consider user’s characteristics in digital intervention development, and the implementation of research informed and consensual recommendations. Recent research recognized the need for alignment of system tools as well as the urgent need of bridging gaps, as the synergies between these domains have enormous potential for tackling long-term conditions (Gamon, Berntsen, Koriho, Sygna, & Ruland, 2015). The use of technology for self-management in chronic conditions allows personalization
which in turn promotes user engagement, greater adherence, and better adjustment.

**Adjustment, Literacy, and Adherence**

The ability to use and correctly interpret health information is important for people in general and in particular for those with chronic conditions, who have to manage complex medical needs, and are likely to take multiple prescription drugs. Previous research has focused on health literacy as a safety issue for patients in relation to misunderstanding instructions on prescription medication labels. The results indicated that lower literacy was associated with misunderstanding the instructions on prescription medication labels (Davis et al., 2006) While medication management is an important aspect of health literacy, the consequences of low health literacy can have a wider impact. These may include failure to recognize signs and symptoms of illness, negligence to preventive care or self-management, and unwillingness to talk with medical providers out of fear or shame. Among people with long-term conditions, this can be critical. For instance, oral or written instructions for medication management may be insufficient or confusing. According to existing research, pharmaceutical prescriptions are essential to the treatment of most chronic illnesses, yet only half are taken as prescribed (Barber, Parsons, Clifford, Darracott, & Horne, 2004; Horne et al., 2013), and adherence rates are poor. Although there are several determinants of adherence, health literacy seems to be associated with adherence. However, this association seems to be inconsistent. According to a recent meta-analysis, there were very small correlations, between health literacy and adherence, mainly for non-medication regimens. The same study argued that moderator analyses revealed greater intervention efficacy when health literacy and adherence were assessed using subjective measures compared to objective measures (Miller, 2017). This gives further support to address individual beliefs and perceptions of patients concerning illness and treatment and the extent health literacy may influence their understanding and motivation to adhere in the context of chronic conditions. Furthermore, one should consider that with culturally diverse patients, providers will have to go well beyond scores on health literacy tests to accurately anticipate patient understanding, adherence, and health maintenance (Shaw, Armin, Torres, Orzech, & Vivian, 2012). The same authors argued that the health literacy scores may be affected by culturally shaped models of health and illness, and consequently, it is important to expand our understanding of literacy to include the strengths that patients bring to chronic disease self-management.

However, in their review contribution to this special issue, Neter and Brainin (2019) found an inconsistent association between health literacy and health outcomes. This result calls for the need to use general health literacy instruments that can enable cross-context comparisons (Mackert, Champlin, Su, & Guadagno, 2015) and to further explore this association in longitudinal studies given the nature of chronic conditions. The opportunity to expand the study about the influence of e-health literacy for adjustment and self-management may also contribute to explore barriers which in turn may endorse a more pragmatic approach to adherence in chronic conditions. In that sense, Horne, Cooper, Wileman, and Yan Chan (2019) contribution to this special issue outline the key features of the Perceptions and Practicalities Approach as a framework to address how the understanding of the illness and treatment impacts on the patient’s motivation and ability to follow the agreed treatment recommendations. This contribution gives further support to the patient-centered approach, and how the patient’s resources may contribute to tailor interventions and promote better adjustment in chronic conditions.

**Final Considerations**

Adjustment to chronic illness has fostered a large body of research and interventions. Chronic illnesses, given their long-term nature and prognosis, imply a greater attention to adjustment. Treatment itself provides another layer of relevant processes. Given the chronic nature of the conditions, treatment implies a closer contact with healthcare providers. Furthermore, given the nature of these illnesses, an important dimension of treatment is self-management. Self-management implies a greater importance given to health literacy skills, interface with technology, and patient’s motivation and ability to adhere and adjust to the condition (Chapman et al., 2017; Horne et al., 2013; Mackert et al., 2015; McBain et al., 2015; Perski et al., 2017; Simco et al., 2015; Zulman et al., 2015).

The attention given to each particular facet of chronic illness and its treatment is well addressed in each paper of this special issue, contributing for an integrative overview of chronic illness. Some of the challenges raised are direct consequences of the characteristics of chronic illnesses, as well as the development of technology as a resource for self-management. Mental health issues are a concern given the long-term experience of pain or loss of function. Adherence becomes an issue given the need to maintain a treatment that often produces partial results, and as a process to engage in new ways of monitoring adjustment and outcomes. In that sense, interventions must be tailored to the patient and their needs, including the consideration of sociodemographics and user-related characteristics. This will allow to improve effectiveness in the management of
chronic illness. Health literacy becomes important as a tool to improve self-management and health at a lower cost, shifting from framing it as a problem to a solution to reduce costs and improve health (Pleasant, Cabe, Patel, Cosenza, & Carmona, 2015).

Understanding adjustment to chronic illness helps to improve treatment and the conditions that foster self-management, but it reinforces the complexity of the interaction between personal, illness, and chronological factors. Therefore, it is less likely that the best treatment is the same for every person in every disease phase. Understanding the adjustment process will add to the literature on the relevant factors that are used in tailoring interventions. Perhaps it is not only the type of illness or the level of health literacy that must be taken into account, but also the stage of the condition and the motivation to engage in new resources, or illness-awareness that must be considered. This combination of factors requires a multidisciplinary approach addressing the need to "tailor" the interventions as technology develops, considering "what makes sense" to the patients, for the complex endeavor of self-management in the context of chronic illness.

References


© 2019 Hogrefe Publishing

European Psychologist (2019), 24(1), 1–6


Maria João Figueiras
Instituto Piaget – RECI (Research Education and Community Intervention)
Quinta da Arrenel de Cima
2800-305 Almada
Portugal
maria.j.santos@almada.ipiaget.pt

David Dias Neto
Instituto Superior de Psicologia Aplicada
Lisbon
Portugal
d.neto@campus.ulisboa.pt

Maria João Figueiras is a clinical psychologist (PhD, Health Psychology) awarded by Kings College and an Associate Professor at the Piaget Institute (Almada). She is President of the Portuguese Association of Health and Behavioural Sciences, full member of the European Health Psychology Society and coordinated as PI several research projects funded by FCT in cooperation with other entities. Her field of research is in the area of Health Psychology, namely illness and treatment perceptions, adherence and chronic illness.

David Dias Neto (PhD) is a Lecturer at Instituto Superior de Psicologia Aplicada – Instituto Universitário, Lisbon, Portugal. He has published in the areas of process research in psychotherapy and clinical and health psychology. He is the current president of the clinical and health psychology division of the Portuguese Order of Psychologists. He also works as a psychotherapist in private practice.