

Commentary & Discourse Forum

Eight Key Areas in Need of In-Depth Examination in the Field of Psychosocial Adaptation to Chronic Illness and Disability

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The primary aim of this brief paper is to suggest fertile research areas that could serve to both navigate and enrich our understanding of psychosocial adaptation to chronic illness and disability (PACID). More specifically, the paper seeks to outline broadly, for future consideration, eight such areas that span a wide range of theoretical and research venues.

Included are, first, PACID-associated domains based on concepts that may be regarded as predictors, as well as moderators and mediators, of PACID. These include concepts such as duration of CID, level of existing psychological energy (e.g., motivation, vigor), presence of denial, and the influence of early-in-life, single, and cumulative traumatic events. Second, consideration of concepts embedded in the adaptation process itself is offered, including personal perceptions and beliefs about CID impact, such as illness intrusion and self-identity; the nature and unfolding of personal growth following onset of CID; and more generally, the inherent veracity of models advocating imminent psychological growth following traumatic experiences, including the onset of CID.

The *raison d'être* of any scientific field, including fields regarded as representing “soft science” such as psychosocial adaptation to chronic illness and disability (PACID), is the ability to pose theoretical and research questions that not merely cement the field’s current status, but pave the way to future developments and contributions. The scientific underpinnings of the field of PACID have been in existence for roughly three quarters of a century, since the pioneering work of Roger Barker, Tamara Dembo, Beatrice Wright, Lee Meyerson, Mollie Gonick, and other somatopsychologists in the late 1940s and early 1950s. Back during that earlier era, several theoretically motivated themes, as well as applied research endeavors, emerged which are still being considered, debated, and explored nowadays. Among the most prominent and time-honored themes are those that have focused on subjects such as: the influence of the passage of time on PACID; the impact of internally driven attitudes, perceptions, beliefs and representations of one’s CID on adaptation; the influence of physics-informed concepts, such as biological and psychological equilibrium, energy, drives and forces on PACID; the role played by ostensibly adaptive (e.g., problem-solving, cognitive restructuring) and nonadaptive (e.g., denial, avoidance) coping modes in moderating adaptation; and more recently, with the advent and influence of the field of positive psychology, also the nature and unfolding of psy-

chological growth following adversity and CID onset. Other themes, not included among the suggested areas in this paper, are those regarded as already emergent or established and these include, among others, positive psychology-entrenched constructs such as personal resilience, positive emotions, mindfulness, virtues, and values; self-management of disabling conditions approaches; core self-evaluations; and acceptance- and commitment-based therapeutic interventions.

In this brief paper, the author seeks to highlight several of these themes as they are reflected in the current literature, and suggest several areas in need of further exploration for future theorists, researchers, and educators associated with the field of PACID. In what follows, then, the author relies mostly upon personal acquaintance and subjective impressions of the field of PACID, as it has evolved during a period of over 40 years. No claim is made to vouch that the chosen areas for discussion represent consensus among most researchers and theorists. The presented areas are phrased as questions, followed by a brief list of rationale statements for their selection.

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Key PACID Areas in Need of Exploration

PACID and Time Since Onset of Condition

Under what circumstances, such as type, severity, functional level of CID; age of onset; pre-CID personality attributes; and sociocultural and environmental characteristics, does the passage/duration of time since CID onset, or initial diagnosis, impact PACID?

Rationale

- Research on the association between duration of CID, that is, time since condition onset or diagnosis, and indicators of PACID, including subjective well-being, life satisfaction, depression, and anxiety, has resulted in inconsistent findings (Horgan & MacLachlan, 2004; Livneh, 2013; Livneh & Martz, 2007).
- Since time is regarded, by physicists and others, to be one of the integral components of a broader concept of spacetime, assessment of time and space distortions following CID onset should also be considered. Reports of time slowing down, including time dilation and truncated future time, and space constricting following CID onset and extended hospitalization have been reported in the clinical and empirical literatures (Livneh, 2013; Seymour, 2002; Zimbardo & Boyd, 2008).
- Most studies employ “objective time” (i.e., clock time) as a measure of CID duration. That is, time is typically measured in standard time units, such as days, weeks, months, and years since onset. However, subjective time may be just as important to consider. Measures of subjective time exist, including time orientation and time perception, but further refinements are sorely needed (Livneh, 2013; Zimbardo & Boyd, 2008). Zimbardo’s Time Perspective Inventory (ZTPI; Zimbardo & Boyd, 2015) and Gjesme’s Future Time Orientation Scale (FTOS; Gjesme, 1983), among other existing measures, may offer additional perspective on the link between the passage of experienced time (perceived time) and PACID.

PACID and Perceptions of Impact

What is the role that perceptions, beliefs, attitudes, expectations, and representations of CID impact play in moderating/mediating PACID? The scope of these perceptions includes the following constructs and PACID models: (a) Common Sense Illness Representations (illness-related beliefs and expectations, based on Leventhal’s self-regulation theory; Leventhal & Nerenz, 1989); (b) Illness Intrusiveness (illness-induced disruptions to valued activities and increasing CID burden; Devins et al., 1984); (c) Disability Centrality (disruption of functionality in important, central

life domains; Bishop, 2005); (d) Illness Centrality (internalized stigma associated with illness identity; Charmaz, 1991; Helgeson & Zajdel, 2017; Park et al., 2011); (e) Disability Identity (self-concept based on one’s disability perceptions; Bogart, 2014); (f) Injury Centrality (an extension of illness self-perceptions to self-concept following severe injuries; Shiloh et al., 2018); (g) Survivor Centrality (the integration of cancer experience, and its associated negative label, into the self-concept; Helgeson, 2011), and (h) Shifting Chronic Illness Perspectives (perceptions of magnitude of illness impact are an ongoing process and continuously shifting; Paterson, 2001).

Rationale

- Personal perceptions and beliefs about the role CID plays in navigating one’s lifestyle, unleashing coping efforts, and influencing quality of life (QOL) are often internalized, and serve as important mediators and moderators of future PACID (Bishop et al., 2007; Livneh, 2022a; Telford et al., 2006).
- A substantial conceptual and empirical overlap exists among the above constructs. To better understand the unifying themes of these constructs, as well as appreciate their uniquely differentiating features, a thorough research agenda must be undertaken.
- Perceptions of the impact of CID on one’s life and functioning often stem from internalized societal negative stereotypes and labels. These perceptions distort one’s self-identity and impede PACID (Vash & Crewe, 2004; Wright, 1983).
- In her earlier work, Beatrice Wright discussed a range of formulations that linked PACID to both self- and societal perceptions of the onset and aftermath of CID, including self-esteem, requirement for mourning, spread, attribution of blame, and similar facets of societal attitude internalization (Wright, 1983, 2007). These internalized perceptions could likely serve as mediators between type, severity, and cause of CID and eventual PACID.¹

PACID and Psychological Energy

To what extent do psychological energy-linked concepts, such as motivation, vigor, vitality, and productivity, play a role in influencing PACID? There is a dearth of information on their contribution to our understanding of this important area.

Rationale

- Several models have promoted the importance of depletion/exhaustion of both physical and psychological energies (i.e., depletion of personal/ego re-

¹ These influences go beyond Wright’s four value changes as empirically depicted in Linkowski’s (and Groomes & Linkowski’s revised) Acceptance of Disability (AD) Scale (Groomes & Linkowski, 2007; Linkowski, 1971), and encompass generalized belief systems that range from succumbing to the impact of CID to overcoming it through coping efforts and active participation in valued activities.

sources) due to traumatic, stressful experiences and presence of CID. The contributions of Selye (1975; general stress syndrome), Hobfoll (1989; conservation of resources), Baumeister (2002; self-regulation), and Ryan and Deci (2008; self-determination), among many others, point to significant role played by the construct of energy in understanding human behavior and motivation following the onset of CID (Livneh, 2022b; Rozanski & Kubzansky, 2005).

- Overextended use of coping efforts results in their weakening and inefficiency (Baumeister, 2002; Lazarus, 1993; Lazarus & Folkman, 1984), thereby impeding psychosocial adaptation to traumatic events and the onset of CID.
- Personal resources are replenishable, by physical, psychological, and social means (Baumeister, 2002; Hobfoll, 1989). This line of useful theoretical and empirical implications offers a rich source of clinical interventions following the onset of CID.
- Kurt Lewin (1935), a major contributor to the somatopsychological movement, was influenced by Freud's concepts of energy and drives and physics models of energy and forces, as well as the earlier observations on energy made by Newton, Maxwell, and Einstein. Many of his subsequent contributions centered on the applications of forces, tension, and energy to psychic processes and environmental influences, cardinal benchmarks of the somatopsychological movement (Barker et al., 1953/1977; Lewin, 1951).
- More recently, Hobfoll's conservation of energy (COR) model (Hobfoll, 1989; Hobfoll et al., 1996) has sparked some interest among PACID researchers in its applications to rehabilitation settings (Roessler et al., 2019; Rumrill et al., 2022; Sorenson et al., 2021); yet the clinical scope of the model's potential contributions to understanding the lives of people with disabilities is far from being fully realized.

PACID and Posttraumatic Growth Authenticity

Which experimental procedures can be effectively used to study the authenticity of posttraumatic growth (PTG) and related positive growth constructs, such as meaning finding, benefit finding, and adversarial growth? Several methods have been proposed in the literature; however, only scant data are available on their effectiveness and usefulness, especially in the field of PACID.

Rationale

- How can we differentiate between genuine and illusory reports of personal growth? Both exist (Taylor & Armor, 1996; Zoellner & Maercker, 2006). Although several strategies have been suggested (e.g., using prospective, longitudinal research designs to mini-

mize recall issues; validating clinical observations of personal growth by use of proxies, actual behaviors, and positive changes in psychosocial resources; measuring relationships between personal growth and denial over time, where the two should depict different trajectories; correlating scores between measures of personal growth and social desirability; Livneh et al., 2019; Tennen & Affleck, 2009), they appear to be sorely missing in the field of PACID.

- Differentiating genuine from illusory, or fake, psychological growth following adversity, generally and more specifically to CID, is of utmost clinical significance. Whereas real growth has been consistently associated with higher levels of adaptation, QOL and well-being, disingenuous growth has been linked to maladaptive functioning, use of denial, and wishful thinking (Tedeschi & Calhoun, 1995, 2004). Yet, contradictory findings on the empirical association between personal growth and successful adaptation have also been reported (Kelly et al., 2018; Park et al., 2023; Zoellner & Maercker, 2006), and their clinical implications must be uncovered.
- Posttraumatic, or adversarial, growth is ostensibly an amalgam of various, and often loosely connected, constructs, including appreciation of life, sense of meaning, and spiritual growth, among others. Studying each of these constructs' unique contribution to PACID, as well as its authenticity as a standalone predictor of perceived QOL, is a task that needs to be more carefully explored.

PACID, Personal Growth, and Equilibrium Seeking

A major inconsistency, or quandary, confronting the field of PACID is determining whether adaptation trajectories following onset or diagnosis of CID seek a return to previously preferred "normal" or "typical" functional levels (equilibrium) or transform (change) into higher functional levels. Can this inconsistency be successfully bridged?

Rationale

- Historically, a philosophical contrast has been drawn between physical, biological, and psychological models that favor equilibrium- or homeostasis-seeking processes² (i.e., return to previous functional levels) and those that favor transformation, or growth-pursuing processes, including existential transcendence and spiritual ascendance to higher functional levels (Livneh, 2023; Vash & Crewe, 2004).
- The roots of homeostasis-pursuing processes can be dated back to ancient times, but its modern reincarnation can be traced back to the works of physiologists Claude Bernard (19th century) and Walter Can-

2 Homeostasis is traditionally viewed as a form of *dynamic* equilibrium. In this paper, the two constructs are used interchangeably.

non (20th century), and 20th century psychodynamic psychologists Sigmund Freud, Kurt Lewin, and Jean Piaget. In contrast, modern contributions to growth and transformation-pursuing processes can be traced back to the contributions of a wide range of humanistic and existentialist psychologists, such as Carl Rogers, Abraham Maslow, and Victor Frankl, and more specifically within the field of PACID to Beatrice Wright and Carolyn Vash (Livneh, 2023).

- The contrast between deviation-minimizing systems that favor homeostasis and deviation-amplifying systems, favoring transformation into a more complex organization, may have profound implications to understanding the nature, structure, and temporal unfolding of PACID (Livneh, 2023; O'Leary et al., 1998).
- A research agenda focusing on which event-related characteristics (e.g., type of CID), coping-associated processes (e.g., ruminating, active coping), psychological reactions (e.g., shattered worldviews, personal goals reappraisal), personality attributes, and socio-cultural and environmental factors play a role in determining the nature and veracity of the ensuing growth process should be orchestrated and implemented (Kelly et al., 2018; Tedeschi & Calhoun, 2004).

PACID and the Unfolding of the Growth Process

Relatedly, the “angle of trajectory” derived from the initial trauma, such as the onset of CID, is not well understood. Several models have described more gradual, incremental progress in psychological growth following traumatic experiences. Other models have described abrupt, sudden, “quantum leap”-type changes in psychological growth. The latter may be analogous to “phase transitions,” as recognized in the physical world (Joseph & Linley, 2006; O'Leary et al., 1998; Tedeschi & Calhoun, 2004). Are both models viable? Is there a preference for one model over the other? If so, under what circumstances?

Rationale

- There is a pressing need to delineate which factors (i.e., event-related, psychological, sociocultural) play a role in influencing the resultant growth trajectory following the onset of trauma-initiated CID.
- Several models suggest a link between the emergence of posttraumatic growth (PTG) and the nature/essence of the traumatic event and its processing (Aldwin, 1994; Joseph & Linley, 2006; Tedeschi & Calhoun, 2004). More specifically, it has been speculated that there may be a relationship between the levels of severity and suddenness of the CID onset,

the internalized perception of a “shattered world,” the deployment of coping and ruminative strategies, and the probability of subsequently experiencing gradual versus sudden growth. This possible link between the growth angle of trajectory and its ostensible determinants needs to be explored more thoroughly.

- Reports of a “flood-like” personal growth immediately following the onset, or diagnosis, of life-threatening CID may signify illusory perceptions of CID-transcendence, or attempts at wish fulfillment, rather than a genuine psychological change (Livneh et al., 2019; Tomich & Helgeson, 2004; Zoellner & Maercker, 2006).

PACID and the Role of Denial

What role does the elusive construct of denial play in the PACID process? Whereas a large percentage of the available literature indicates that the deployment of denial is associated with poorer adaptation, some empirical data are available to suggest that, under certain conditions, denial may actually serve a useful role in promoting PACID (Byra & Gabrys, 2023; Kortte & Wegener, 2004; Livneh, 2009; Voss et al., 2007).

Rationale

- Denial has been described along several conflicting, or at least opposing, ends of continua, including conscious vs. unconscious, minor vs. major, adaptive vs. nonadaptive, proximal vs. distal to CID onset, of single vs. multiple layers, and internally directed/blocking off internally threatening stimuli vs. externally directed/blocking off externally threatening stimuli (Goldbeck, 1997; Kortte & Wegener, 2004; Livneh, 2009). Better understanding of the nature of denial, along with the development of new and comprehensive psychometrically sound measures, is warranted.³
- Various types and levels of denial have been proposed, including Breznitz's (1983) iconic seven types of denial, Levine et al.'s (1994) two-component denial, and Kortte and Wegener's (2004) three levels of denial. No consensus has ever been arrived at as to the manifestations of denial in the field of PACID (Goldbeck, 1997; Livneh, 2009).
- Factor analytic measures of denial seldom produce a single factor. Empirically, denial appears to be multifaceted (Havik & Maeland, 1988; Levine et al., 1994).
- The various manifestations and vicissitudes of denial may be clinically dependent upon the type of CID, its onset, age at CID occurrence, and severity of the CID,

³ Although several measures of denial exist, most are CID-specific and seek to depict its existence in survivors of heart conditions (e.g., the Levine Denial of Illness Scale; Levine et al., 1994) and cancer (e.g., the Denial in Cancer Interview; Voss et al., 2007). Additionally, these measures rely mostly on semi-structured interviews and possess limited psychometric soundness. Finally, although brief denial subscales can be found in several of the existing generic coping scales, they are fraught with questionable validity and reliability indices, small number of items, and seldom address CID populations.

as well as enduring personality attributes (Kortte & Wegener, 2004; Livneh, 2009; Telford et al., 2006).

PACID and the Impact of Earlier Life Traumas

To what extent do (a) repeated, or continuous vs. single-episode traumas, and (b) earlier (distal, occurring in infancy, childhood) vs. later (proximal, occurring within the past several years) occurrences affect, interact with, or play a role in determining subsequent PACID? Some findings have been reported, in areas such as adaptation to family adversities and natural disasters, but are mostly lacking for PACID (Alonzo, 2000; Eagle & Kaminer, 2013; Livneh, 2023).

Rationale

- The impact of earlier life traumas—adversities, losses, injuries, parental divorce, or death—has often been overlooked in PACID research.
- The notion of “accumulated burden of adversity” or “continuous traumatic stress” has gradually emerged as an important consideration in the domains of coping with adversity, trauma, and crisis, but its potential influence on PACID has been scarcely addressed (Alonzo, 2000; Eagle & Kaminer, 2013; Sacchi et al., 2020).
- Preliminary research findings suggest that the occurrence of multiple traumatic events early in life (e.g., infancy, childhood) has a substantial impact on later psychosocial adaptation, but scarcely any findings have been reported in the field of PACID (Bonnanno et al., 2010; Gerber et al., 2018; Martin & Martin, 2002).

Summary

The study of adaptation to the onset of chronic and life-threatening illnesses and physical disabilities has captured the interest of theorists, researchers, educators, and clinicians for over three quarters of a century. During this period, and since the pioneering work of a small group of dedicated theorists and researchers who referred to their newly created field as somatopsychology, the field of PACID has grown exponentially. In this brief paper, the author sought to highlight eight theoretically challenging and empirically viable areas whose future exploration is likely to lead to better understanding of PACID; at the same time, these serve to bolster QOL among individuals who have sustained CID, and have concurrently faced societal and environmental barriers.

Roughly, the eight suggested PACID-linked areas range from those reflecting the more traditional CID models, occasionally labeled as “biomedical”, “functional” and PACID-specific; to “psychodynamic” models (i.e., the impact of CID duration, role of denial, and influence of cumulative, early in life traumas on PACID); to more modern models, periodically termed “environmental”, “sociocultural”, and “disability identity.” These are all, in turn, informed by the contributions amassed over the past century from existential-humanistic philosophy and, in the more recent 30 to 40 years, the advent of the positive psychology movement (i.e., linking psychological energy-like constructs, perceived personal growth and transcendence to PACID). These suggested future research areas, although far from being all-inclusive or consensually arrived at, do nevertheless offer a prism through which the lives of people with CID could be better studied, understood, appreciated, and used as benchmarks for improved future rehabilitation services.

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