Examining components of community psychosocial stroke interventions using concept mapping

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Abstract

Background

Stroke impacts psychosocial well-being and engagement in occupation. Psychosocial interventions reduce depression and anxiety but may not impact occupation. Knowledge of key processes and components of community psychosocial stroke interventions can inform future intervention development.

Aim/objective(s)

To determine the essential elements common to three psychosocial interventions for stroke survivors.

Material(s) and method(s)

Concept maps were created for three community psychosocial stroke interventions based on published literature and communication with researchers who tested the intervention with stroke survivors. The concept maps were then compared to identify common elements. Ongoing communication with researchers ensured accurate representation of each respective intervention.

Results

Similarities in intervention processes and components included, support for autonomy; individualized information exchange; coping, life skill development, and adaptation support; competence development; and the incorporation of goals. Differences included intervention delivery (individual versus group), and the avenues in which psychosocial needs are addressed (occupation versus dialogue).

Conclusions

Concept mapping identified similarities among the three interventions that can be best understood using Self-Determination Theory. Clinicians may utilize findings revealed in the process to inform evidence-based psychosocial stroke interventions.

Significance

Knowledge of key "active ingredients" for psychosocial community stroke interventions, can be used to guide clinical reasoning and inform development of interventions.

Key words

Introduction

As many as 13.7 million people experience a stroke globally each year [1]. A stroke has a significant impact on survivors' psychosocial well-being, occupational engagement and consequently, quality of life (QoL) [2,3]. Approximately one-third of stroke survivors develop depression following a stroke [2], contributing to restrictions in life participation [3]. A systematic review and meta-analysis conducted by Minshall et al. [4], found that psychosocial interventions can reduce depression but there was limited evidence for improvements in anxiety, coping and QoL.

Participation in personally meaningful activities or occupations contributes to a satisfying quality of life, therefore, acting as a mediator for poor psychosocial outcomes [5,6]. In addition, engagement in occupation is critical to maintaining hope for recovery [7]. Participation is tied to one's existence and sense of self. In other words, losing the ability to do what one desires, has a detrimental effect on how one expresses their sense of self as a 'doer' [8]. During the transition period from the hospital to the community, stroke survivors grapple with uncertainty, understanding of, and the adjustment to, a new sense of self [9]. Success in regaining valuable occupations post-stroke preserves one's sense of self [8,9]. Such findings confirm the significance of occupational therapy in stroke recovery.

Several factors influencing re-engagement and participation in occupation are identified in the stroke literature. These factors include "social connections" and "being in charge" [8]. As cited by Kessler et al. [10], many of these factors are modifiable, such as, self-efficacy, functional ability, knowledge and information, support, apathy or depression, and having goals.

Community-based programs can offer tailored stroke interventions to ensure individual needs are met [11]. There is, however, a lack of consistency with regards to how psychosocial interventions are defined, delivered, and evaluated [4]. According to Thompson & Ski [12], this lack of consistency makes the evaluation of intervention efficacy difficult. The terms "psychosocial" and "behavioral" are often used interchangeably in reference to interventions. Thompson & Ski [12], argue the term "psychosocial" should be reserved for interventions that incorporate psychological or cognitive behavioral and social (i.e. social support) components.

Three of the authors of this paper (XX, XX, XX) have been researching and evaluating separate psychosocial interventions with the goal of improving participation in everyday lives after stroke. Specifically, these interventions are Occupational Performance Coaching (OPC) [10], Person-Centred Lifestyle Intervention (PCLI) [13], and a Dialogue-Based Intervention (DBI) [14]. While these interventions have different structures, components and processes, they share the following similarities: (1) they meet Thompson & Ski's [12] definition of "psychosocial intervention"; (2) they have the therapeutic goals of promoting psychosocial well-being and increasing participation in everyday activities for people who have experienced a stroke. **While other interventions may also meet these criteria, we selected these interventions as they provided diversity with regards to focus (dialogue vs occupation), and format (group vs individual), are promising for improving participation. While quantitative evidence to support the benefit of these interventions over usual care has not yet been firmly established [15–17], qualitative findings support the value of these approaches to improve participation among participants. For example, participants taking part in the PCLI reported that it "stimulated them to become active and take responsibility" [18] (p.131). Those who took part in OPC reported it was helpful; they**

experienced success in achieving participation goals through receiving emotional support while developing strategies and testing plans [19]. Themes from the qualitative evaluation of the DBI included becoming aware of needs, gaining support, taking control and using resources to move forward [20].

Analysis of components and processes of complex interventions can provide insight into the "active ingredients" **or causal components and mechanisms** of effective interventions to promote occupational engagement following the experience of stroke [21,22]. Given that evidence to support the effectiveness of the above interventions is **mixed with regards to quantitative and qualitative findings**, the aim of this project was to identify and compare key components and processes of these interventions to inform the development, implementation and evaluation of current and new community psychosocial interventions for people stroke survivors.

Materials and methods

A concept-mapping process was used to identify the essential components and processes of the three psychosocial interventions, OPC, PCLI and DBI. Concept maps are organized, visual representations of a concept or intervention [23]. Concept maps are typically arranged in a hierarchical fashion with broader concepts positioned near the top of the map, and more specific concepts situated closer to the bottom. Relationships among concepts are then identified through the use of specific linking terms [24]. Concept maps are used to develop theory, plan and evaluate programs and interventions, and develop measures and scales [23]. They may be created collaboratively, allowing for the building of shared knowledge to take place, making concept maps a popular format to use when creating an intervention [23]. The process of developing a concept map involves the developers to recognize meaningful relationships among concepts within an organized structure [25]. In addition, the concept mapping process enables the

intervention developers to critically reflect on how clinicians may interpret the intervention development process.

The concept mapping process **was carried out by two master level occupational therapy students (XX, XX) with guidance from the co-authors. The process** involved the following steps: (1) Principal concepts, or components of each intervention were extracted and deliberated upon using a charting system and whiteboard visual; (2) Concepts were organized into three separate concept maps utilizing Microsoft Word (3) Several Skype or face-to-face meetings were held with each co-author involved in intervention development/evaluation. The purpose of these meetings was to ensure concept maps accurately represented each intervention; (4) The co-authors compared the concept maps to reveal commonalities and differences between each intervention. **Following grouping of key concepts, the authors noticed an alignment of several concepts with Self-determination Theory (SDT) [26] and then used this theory to further guide analysis.**

Results

The concept maps are presented first with explanations of each intervention, followed by a comparison of common intervention themes (*Table 1*).

Concept maps

[Figure 1 near here]

Concept map description (PCLI)

The PCLI [13] consists of two parts: first, occupational performance issues and goals of individuals are identified using the Canadian Occupational Performance Measure (COPM); second, the COPM results are extracted to tailor intervention content for group sessions. Group

sessions are led by a group leader (i.e. occupational therapist). The leader utilizes methods such as peer exchange, self-reflection, performance of co-occupations, and didactic presentation to assist with the exploration of client needs, choices, and desires [13,18,27].

The Canadian Model of Occupational Performance and Engagement (CMOP-E) [28] and occupational transactionalism [29,30] form the theoretical basis for the PCLI [13]. The CMOP-E is especially useful for the understanding of how the person, environment, and occupation interact in a dynamic fashion to result in occupational performance and engagement in daily life [29]. Occupational transactionalism helps clinicians to understand how the relationship between the person and their occupation has changed as a result of their stroke, allowing the therapist to develop an individualized intervention [29,30].

The PCLI is informed by the Lifestyle Redesign (LR) programme for older adults, a manualized method of occupational therapy intervention [31]. User orientation is a key component of the LR programme and is conceptualized in the PCLI as the perpetual collaboration of interventionists with intervention clients. Session topics are informed by an individual preliminary needs assessment, guided by the COPM [13]. Throughout the group sessions, clients are invited to add personally relevant and meaningful topics to the sessions.

The intervention methods of didactic presentation, peer exchange, direct experiences, and personal exploration originate from the LR programme. Each method is linked to everyday life and occupation and appeals to the four dimensions of occupation: *doing, being, belonging, and becoming* [32]. *Doing* can be conceptualized as "the medium through which people engage in occupation" [33]. The *doing* dimension was evident throughout the PCLI as clients actively engaged in group meetings and in personally relevant occupations to enhance competence in coping following a stroke [13,18,27].

Being "is the sense of who someone is as an occupational being" [33]. Occupation can act as a focus for *being* or *being* can exist independently of occupation during self-reflection and discovery [33]. The *being* dimension was incorporated through client engagement in self-reflection linked to their everyday occupations to enhance competence in coping and regain an occupational sense of self [13,18,27].

The continual process of growth, development, and change that occurs throughout a person's life characterizes the occupational dimension of *becoming. Becoming* "is directed by goals and aspirations which can arise through choice or necessity from individuals or from groups" [33]. In the PCLI, goals were initially identified through the preliminary needs assessment. These goals could be revised, or new goals added, based on the needs and aspirations of the group. *Becoming* includes the need for clients to adapt their everyday occupations and life post-stroke. Clients actively worked to find new solutions to arising challenges and adapt their everyday lives, thereby enhancing competence to cope with life post-stroke [13,18,27]. *Belonging,* also refers to "a sense of connectedness to other people, places, cultures, communities, and times" [33]. Clients fostered this sense of *belonging* through peer-exchange, relationship-building and active interaction within the lifestyle groups. The groups provided a context through which clients provided mutual support and challenge during the process of post-stroke adaptation [13,18,27].

[Figure 2 near here]

Concept map description (DBI)

The DBI [14] involves a series of eight meetings between an individual stroke survivor and a trained Registered Nurse (RN) or Occupational Therapist (OT). The majority of the

meetings occur within the client's home, and are designed to take place during times of heightened vulnerability and uncertainty, such as discharge, slowing of physical improvement, and resumption of new challenging roles or activities [14,34]. The development of the DBI was informed by previous qualitative research and systematic reviews of psychosocial interventions, narrative theory, empowerment philosophy, and guided self-determination (GSD) [14,34].

According to narrative theory, encouraging and supporting one's storytelling, as well as responding to, and sharing in one's stories, stimulates reflection [34]. The process of reflection allows the individual to consider making adjustments in their lives, strengthen their identity, self-understanding, and self-esteem [14,34].

Empowerment philosophy highlights the necessity of being in control of one's recovery [14,34]. Self-determination is a key concept in the philosophy of empowerment. Self-determination emphasizes people's inherent tendencies toward growth and self-actualization through the satisfaction of the basic psychological needs for autonomy, competence, and relatedness [26].

Guided self-determination (GSD) is a decision-making and problem-solving method that aims to empower both the client and healthcare professional. GSD can be used to guide the client and the professional in "overcoming barriers and exploiting the possibilities which have been empirically identified as crucial to patients' ability to make self-determined decisions" [35],

In the DBI, chaos and lack of control, bodily changes, and identity threat experienced after a stroke are addressed through the use of semi-structured dialogues that incorporate reflection through narratives, empowerment philosophy and GSD [14,34]. Each dialogue provides an opportunity for clients to discuss the challenges they deem most important with a trusted healthcare professional. The dialogue-based encounters are guided by the use of

prefabricated worksheets that provide a topical outline for each meeting. The worksheets address a variety of common challenges experienced by individuals post-stroke including: bodily changes, emotional challenges, personal relations, daily life issues, meaningful activities, existential issues, and important values. The worksheets are given to the clients prior to each encounter, to allow the client to review and reflect on issues they want to discuss. In order to maintain client-centredness, the healthcare professional may change the order in which the worksheets are addressed if a client chooses to discuss a different topic [14,34].

Healthcare professionals involved in the intervention assume the role of a "coach" or "supporter," guiding clients toward self-determination to promote coping and the development of new life skills. Overall, this process contributes to a sense of coherence and the ultimate goals of improved mood and psychosocial well-being [14,34].

[Figure 3 near here]

Concept map description (OPC)

Occupational Performance Coaching (OPC), an intervention originally designed to improve occupational participation in children, was applied by Kessler et al. [10,16,36], to the context of community stroke rehabilitation. OPC is carried-out in an individual format in client homes, with approximately 10, one-hour sessions provided over a period of 16 weeks. Both occupation- and client-centred practice provide a foundation for OPC [10].

OPC consists of three components: information exchange, a structured process, and support [10]. *Information exchange* within the context of community stroke rehabilitation, follows principles from adult learning theories, and involves the use of individualized education, that draws on the person's own knowledge and is relevant to each clients' unique goal [10].

The intervention follows a *structured process that is* solution-focused and guided by the goals selected by clients. Occupational therapists, who receive training in OPC [16,37], guide clients through this structured process towards attainment of self-identified participation goals. The structured process involves the following steps: setting goals, exploring options using collaborative performance analysis, developing a plan of action, carrying out the plan, checking performance, and generalizing, or, applying strategies to other situations [37,38]. Collaborative performance analysis (CPA), is a process by which the coach can further explore "goal-specific performance situations". CPA supports goal-setting and achievement, as the OT collaborates with the client to identify and reflect on what is currently happening related to the identified goal, what the client would prefer to happen, and what the client needs in order to implement changes [37].

Within this *structured process*, the identification of personally valued and meaningful goals serves as a motivator for increased participation and goal attainment. Other necessary ingredients for motivation include: autonomy, competence, and relatedness [37]. The therapist supports the client's need for autonomy throughout the structured process and during information sharing. Competence, the perceived efficacy to achieve personal goals, can be supported by the therapist in the OPC process. Successful goal attainment may be aided by the drawing on the person's own knowledge, scaffolding of skills, and the client learning how to modify the task or environment [37]. Relatedness, or the need to be connected to others, and the sense of being cared for, can facilitate an improved sense of engagement. The need for relatedness is addressed in OPC through support [37].

Support refers to the therapeutic relationship between the client and the occupational therapist (OT) [37] and is necessary for the structured process of goal-setting and attainment.

The OT acts as a coach, providing emotional support through interpersonal techniques such as active listening, empathizing, reframing, guiding, and encouragement.

Comparison of interventions

The concept mapping process revealed similarities in components and processes among the community psychosocial interventions despite some differences in theoretical orientations and structures. The similarities are highlighted in *Table 1*.

[Table 1 near here]

All interventions included components of support for autonomy, support for adaptation and skills development, competence development, a goal focus, and individualized information exchange as evidenced in the concept maps and above descriptions. Along with similarities, differences were noted in the focus and structure of each intervention. OPC and the PCLI draw specifically on the therapeutic benefit of engaging in occupation during intervention delivery, whereas the DBI focuses on the therapeutic benefit of dialogue between the healthcare professional and the client. Both OPC and the DBI are implemented with individual clients, whereas the PCLI uses an individual assessment component followed by a group intervention.

Discussion

The concept mapping process facilitated identification of common intervention components and processes of support for autonomy, support for adaptation and skills development, competence development, a goal focus, and individualized information exchange. These components and processes can be situated in self-determination theory (SDT) [39] to inform future development of psychosocial interventions to promote participation following

stroke. According to **SDT**, people have three basic psychological needs: autonomy, relatedness, and competence. Through meeting these needs, the individual becomes empowered toward growth and self-actualization and is more willing to make a lasting change [35,39]. Each need is discussed below in relation to study findings and the stroke literature.

Support for autonomy

Autonomy involves acting with a sense of volition and the feeling of willingness [40]. An autonomy supportive healthcare practitioner will elicit and acknowledge client perspectives, offer choice in the intervention, support client initiatives, and provide personally relevant information. In addition, the healthcare provider seeks to minimize pressure and control. Autonomy-supportive interventions involve eliciting and acknowledging the perspectives of clients and supporting clients' desires and initiatives [40].

The concept of user orientation in the PCLI, closely resembles what is commonly referred to in health literature as individualized or person-centred care, concepts evident in the DBI and OPC. Enacting a user orientation supports the client's need for autonomy through encouraging the active participation and control of the client [40]. In the DBI, semi-structured dialogues support autonomy by providing opportunity for clients to choose the challenges they deem most important to discuss with the healthcare professional. OPC supports autonomy throughout the structured process and information exchange process through promoting client choice, building on a client's expertise, and recognizing the client as an expert on their own life.

Information exchange processes implemented in the psychosocial interventions include didactic presentation (PCLI), prefabricated worksheets (DBI), and sharing of information related to goal setting and attainment (OPC). In each intervention, information exchange processes were directed by the needs and desires of clients. These individually tailored information exchange

processes support autonomy through attaching value and relevance to the information [40]. Individualized education thereby contributes to goal attainment and building of competence in problem-solving [41].

Relatedness

Support is a necessary component for successful recovery post-stroke. The support system of a stroke survivor may include, but is not limited to, family members, friends, and healthcare professionals. A good support system provides emotional support, which is fundamental as it gives an individual someone to talk to and rely on [9]. Having a support system positively influences an individual's ability to resume desired occupations and increase participation [8]. Further, the presence of a support system improves an individual's mood, social interactions and functional outcomes [42-43]. It also helps the individual cope with the uncertainty of an unfamiliarity of their new situation [9].

The PCLI places emphasis on peer support through group intervention. Peer support provides information, resources, and emotional support to clients, allowing them to have a support system that has a first-hand knowledge of what they are experiencing [44]. Therapeutic benefits of involvement in the peer support group include a sense of belonging, security, learning novel ways to cope, empowerment and inspiration, having the space to express feelings, helping others, and increased agency/independence [44].

The DBI provides emotional support through collaboration with clients on a one-to-one basis, allowing them to express their personal narratives, and explore solutions to problems they may be facing. Similarly, in OPC, the occupational therapist coach provides emotional support through interpersonal techniques such as active listening, empathizing, reframing, guiding, and encouragement. Emotional support is used to develop the therapeutic relationship whereby

client's sense that they are understood and respected by the coach and their values and interests are reflected in decision-making.

A key difference in how support was provided during the interventions was the individual versus group–based format. Both group and individual interventions may be used alone or simultaneously in a psychosocial context. Post-stroke symptoms manifest differently in every person and individualized interventions allow tailoring to the person's needs. By individually assessing a person's perceived difficulties in occupational performance, healthcare professionals can develop a better picture of the individual's strengths and barriers to participation [11,45] and thereby tailor interventions to the needs of the client.

However, the inclusion of a group component in stroke interventions may be beneficial as groups provide an outlet for social connection. This is especially important as many clients noted a sense of isolation and loneliness following a stroke [46]. Contact with others who share similar experiences leads to a sense of support, and shared understanding [44] which are crucial elements of stroke rehabilitation. In addition, peer support experienced in groups may facilitate an increased awareness of stroke consequences and provide an opportunity for members to make comparisons to their peers [47]. Comparing oneself favorably to others in the group may contribute to improved self-confidence [48]. More research is needed to determine whether individual, group, or a combination of individual and group-based interventions in community-based stroke rehabilitation best meet the needs of stroke survivors.

Competence development

Competence refers to the feeling of being able to effectively produce desired outcomes and exercise one's capacities [39]. Competence is similar to the more frequently cited term, self-efficacy. A decline in competence or self-efficacy following a stroke is noted in the literature

(50,51) and is linked to post-stroke depression and decreased well-being [49]. Enabling a person's belief that they can cope successfully post-stroke can assist in diminishing depressive symptoms or prevent symptoms from occurring [49]. Patients with higher levels of self-efficacy have been found to be more independent in activities of daily living post stroke, than patients with lower levels of self-efficacy [50].

According to SDT, a person's' sense of competence is facilitated by autonomy [26]. The DBI, OPC, and PCLI support autonomy and competence through personally meaningful goal setting and action planning, building problem-solving skills, and enhancing clients' self-belief through reflection and support for autonomy.

Goal setting is considered an essential part of the rehabilitation process that can increase clients' quality of life, positive emotional states, and self efficacy [51]. Goals motivate people to achieve their desired outcomes leading to new strategies, tool use, and strengths to achieve their desired outcomes [51]. According to SDT, goal pursuit and attainment is inextricably linked to the degree in which one's basic psychological needs of autonomy, relatedness, and competence are satisfied [40].

All the interventions had a focus on client goals either explicitly or implicitly. In OPC goal setting is the focus of the structured intervention where the client identifies his or her own participation/occupation goals. Successful goal attainment may be aided by the scaffolding of skills, or the client learning how to modify the task or environment [41]. The DBI addresses goal setting through semi-structured dialogues. The overall aim of the semi-structured dialogues is to address what is important to the client now, and what will be important to the client in the future. Through processes of problem-solving and decision-making, the client and the healthcare professional identify resources contributing to actions leading to an identified goal. In the PCLI,

a preliminary needs assessment, supported using the COPM provides an avenue for clients and therapists to collaboratively identify goals.

While including components to support autonomy, competence, and relatedness, the interventions had different foci. The PCLI and OPC interventions focussed on occupation and the return to participation in everyday life with a secondary outcome of enhanced psychosocial well-being. The DBI, however, aims to directly impact psychosocial needs through dialogue. Research has established a reciprocal relationship between participation in meaningful activities and well-being [5], SDT may provide a way to explain the relationship [40]. Interventions that focus on supporting a person's basic psychological needs for autonomy, competence and relatedness through occupation, dialogue or other means may lead to enhanced psychosocial well-being and participation following stroke. However, current research evidence to support psychological interventions to improve depression is limited with no impact noted on secondary outcomes of social activities or activities of daily living [4]. Similarly, research to support occupational-based interventions to improve participation or depression is limited with the moderate evidence to support occupation-based interventions for activities of daily living and instrumental activities of daily living in the community [52]. Further research is needed to test the effectiveness of both occupation-focussed and dialogue-based interventions grounded in SDT for their impact on psychosocial well-being and participation.

Limitations

There are **three** major limitations in this study that may be addressed through further research. First, only three post-stroke psychosocial interventions were examined. Concept mapping of other post-stroke psychosocial interventions would lead to an enhanced understanding of important "active ingredients". Second, the effectiveness of the PCLI, DBI, and

OPC interventions appear to be promising, but is not yet proven. Future research into each intervention and the continued measurement of hypothesized outcomes, will strengthen the results of this study.

Finally, while the concept mapping was done by two occupational therapy students who were not familiar with the interventions, the other authors had a level of investment in the interventions which could have influenced the concept map analysis. One could also argue that in-depth understanding of the intervention components and processes is needed to accurately complete a concept map.

Conclusion

The concept mapping of the three community-based psychosocial stroke interventions facilitated comparison of key "active ingredients", thereby allowing the authors to identify meaningful connections among intervention concepts. Five major intervention themes emerged including, support for autonomy; coping, life skill development, and adaptation support; competence development; a goal focus; and individualized information exchange. These themes can be understood using the three basic psychological needs highlighted by SDT, **autonomy,** relatedness, and competence. Based on these findings, it may be beneficial for intervention developers and clinicians to integrate SDT in planning and implementing interventions to support individuals' psychosocial needs post-stroke. **In particular, g**iven the diversity of experiences following stroke, individually tailored interventions may better meet a client's unique needs. **However**, it is not clear from this analysis whether there is a benefit of occupation-focused over dialogue-focused interventions for addressing psychosocial needs.

Declaration of interest

No potential conflicts of interest were declared by the authors.

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Table 1. Intervention components aligned with intervention themes

Intervention Themes/ Common Concepts	Person-Centred Lifestyle Intervention	Dialogue-Based Intervention	Occupational Performance Coaching
Support for autonomy	-User orientation	-Client-directed Semi-structured Dialogue -Guided Self-Determination Problem-Solving	-Collaborative Performance Analysis -Client-selected goals -Information exchange
Individualized information exchange	-Didactic presentations based on client- identified topics	-Client-selected topic sheets	-Sharing of information relating to client goals and strategies for goal attainment
Coping, life skill development, and adaptation support	-Peer exchange (i.e. sharing of knowledge and experiences among peer -Group leader encouragement (e.g. self-reflection and participation)	-Support through dialogue -Coaching support to guide coping and life skill development	-Emotional support (listening, guiding, reframing, empathy, encouragement) for planning, decision making and actions to pursue goal

|			
Competence development	-Performance of occupation -Didactic presentation -Self reflection -Peer exchange	-Guided Self-Determination Problem Solving -Promotion of Reflection -Coaching support to guide coping and life skill development	-Structured process with Collaborative Performance Analysis Information exchange
Goal focus	-Preliminary needs assessment to identify occupational performance issues	-Semi-structured Dialogues - Outcome of Life skill development	-Client-identified goals
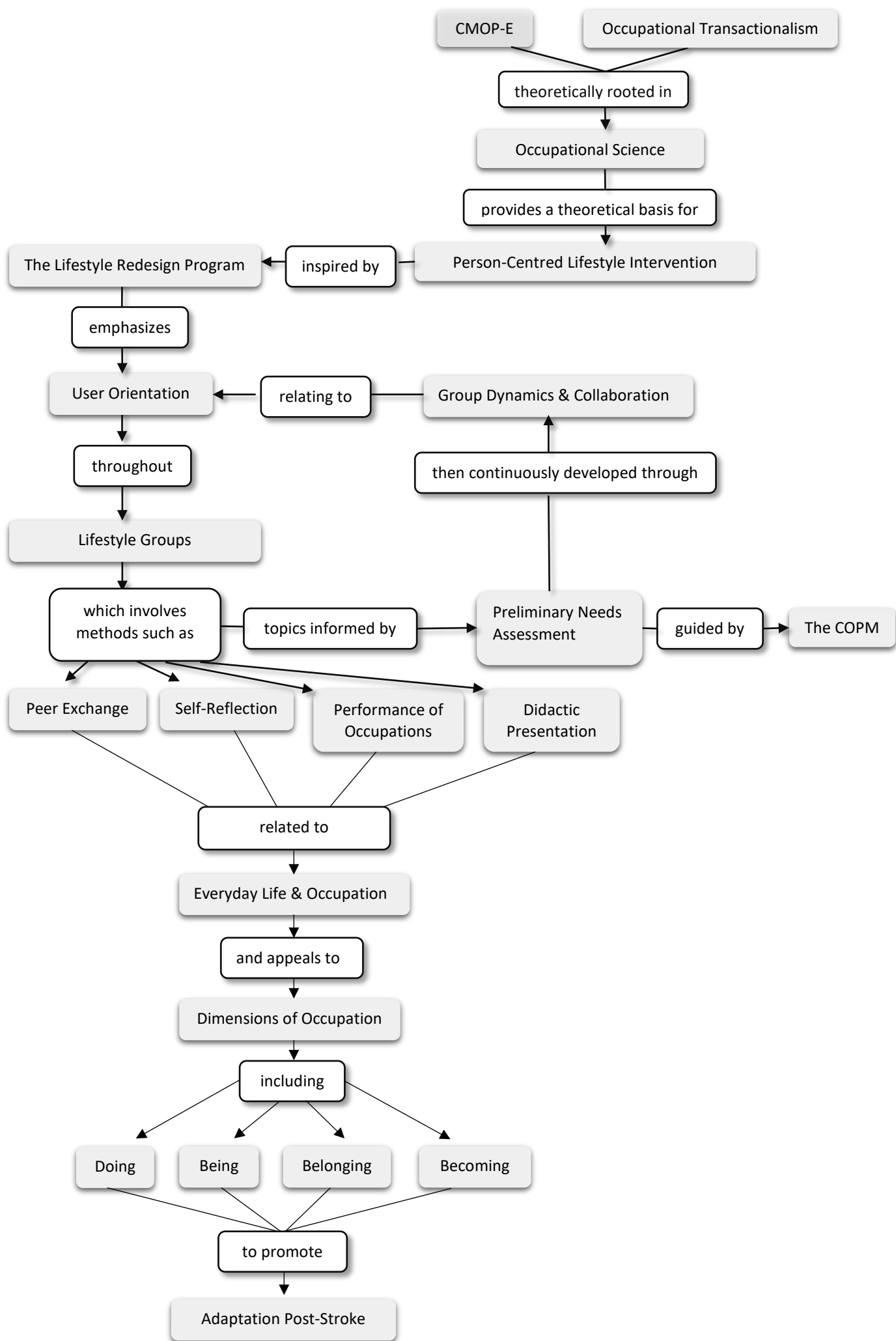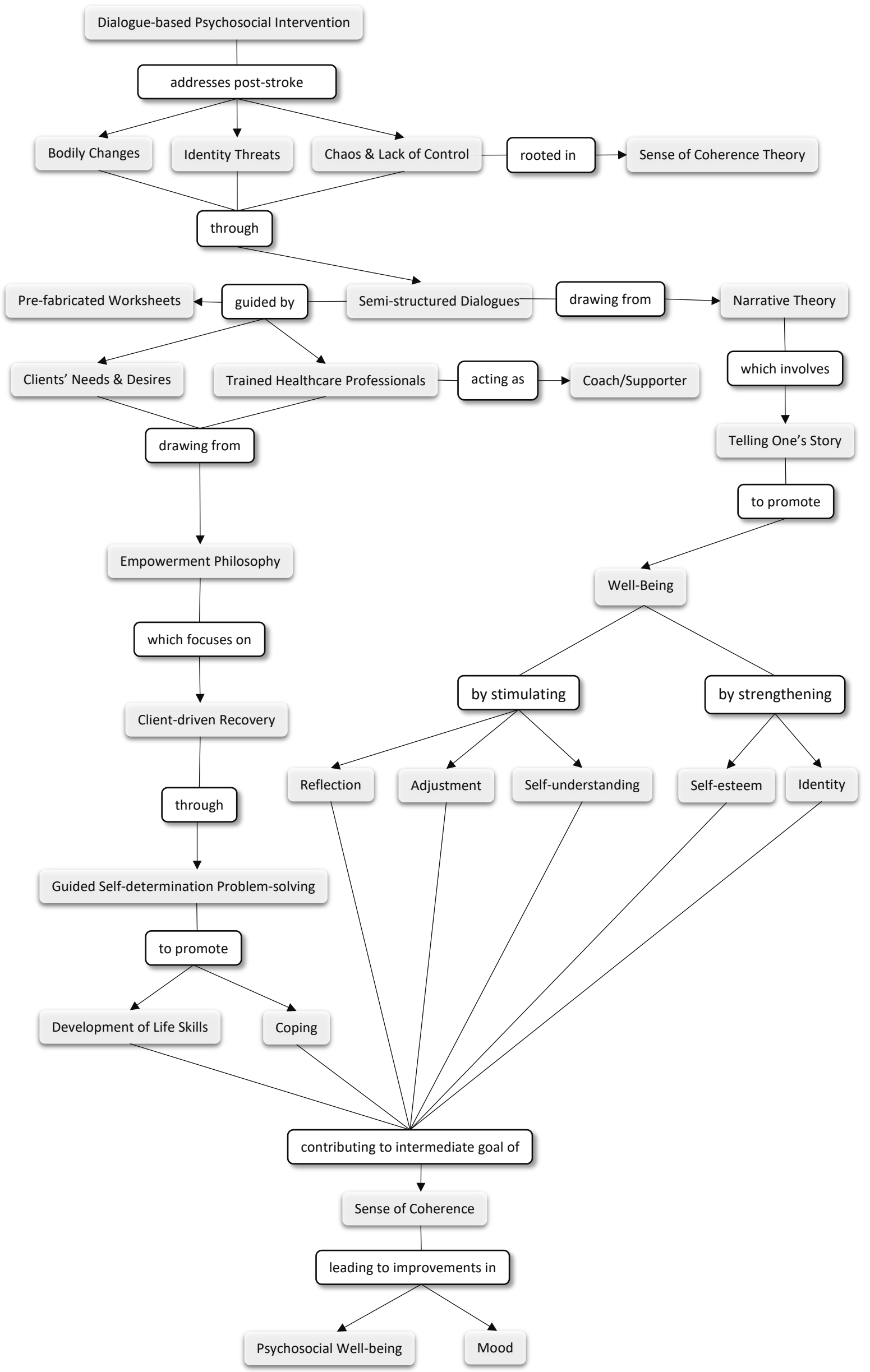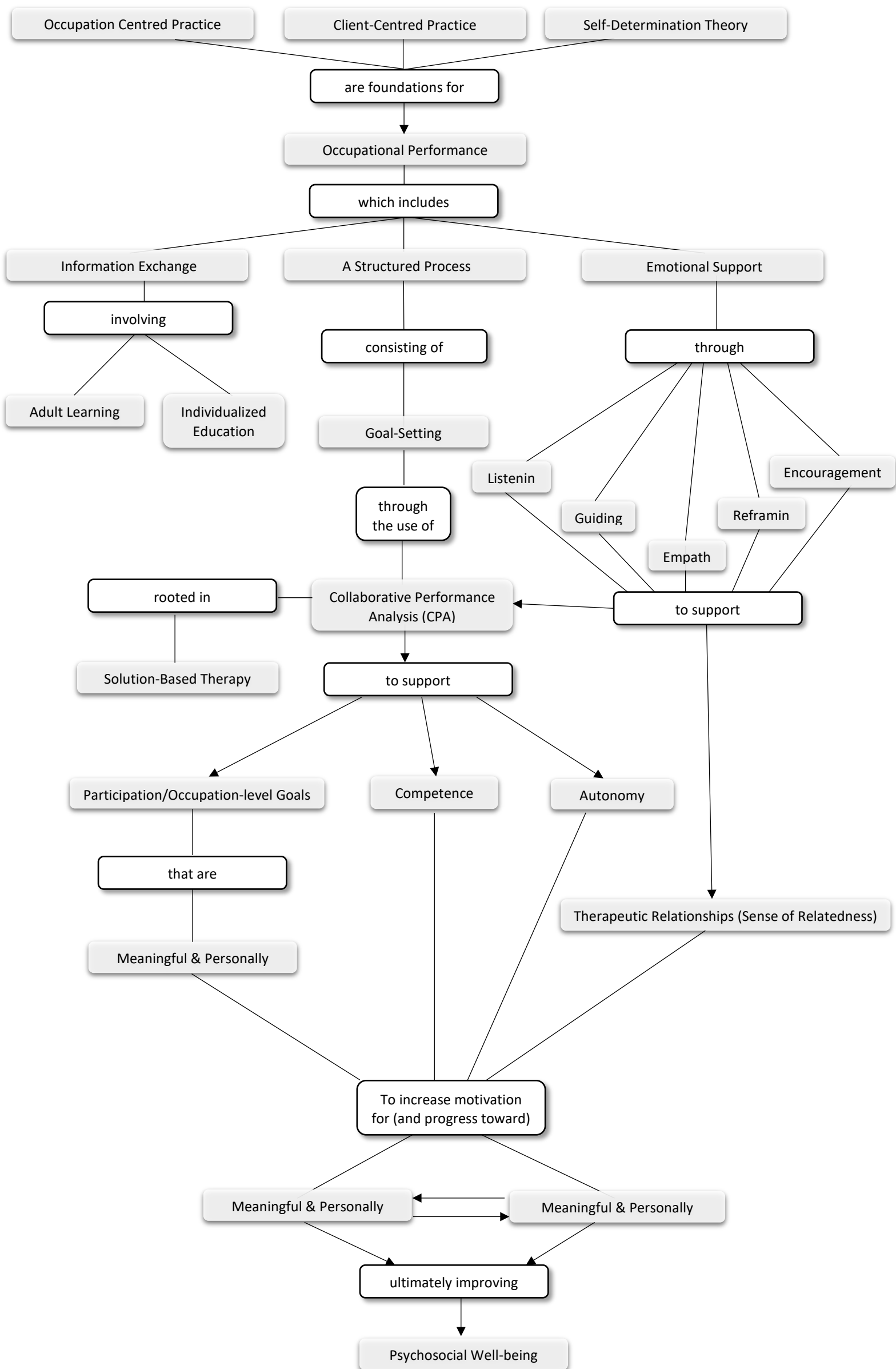
Figure 3: Concept map of the Occupational Performance Coaching (OPC) intervention processes