Design, Learning and Innovation in Developing a Physical Activity Training Network: L.U.C.A.S Project

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Abstract. This paper introduces a seven-country international partner consortium project carried out under the Erasmus+ Program of the European Union. The project was titled L.U.C.A.S. (Links United for Coma Awakenings through Sport). Targeted user-group was acquired brain injured, spinal cord injury, and patients recovering from coma – many being profoundly impaired some being vegetative state. Elaboration and sharing of rehabilitation models to consider best practices targeting physical exercise, especially adapted sports, was catalyst of the project theme investigating a posited methodology. L.U.C.A.S. ran from January 2015 to December 2016 and was built upon an earlier Lifelong Learning European Program funded five-country project titled L.U.C.A. - Links United for Coma Awakening having its focus on learning and dissemination of good practices.

The specific focus of the contribution is to briefly share both the Scandinavian research element of the project as well as the holistic outcomes to enable others to use, reflect, and critique the methodology. The paper also introduces the annual European Day of Awakenings that emerged under the L.U.C.A.S. project.

Keywords: Acquired Brain Injured (ABI) · Spinal Cord Injury (SCI)
Physical training methodology · International network development
Design · Learning

1 Introduction and Background[1]

Brain Injury is a huge problem such that Traumatic Brain Injury (TBI) is forecast to surpass many other diseases as major cause of death and disability by the year 2020 [1]. It is estimated that approximately ten million people are affected annually by TBI and the burden of mortality and morbidity that this condition imposes on society makes it a pressing health and medical problem [2]. Acquired brain injury (ABI) is the single greatest cause of permanent acquired disability in our society [3, p. xi]. It affects body, brain, life, status, and future and it is said that these people do not 'get better', 'recover' or 'return to a normal state of health, mind, or strength' [4]. Independent of what is 'known' about the prevalence of brain injury; far less attention has been paid to self-

[1] NB: Selected text abridged/cf our overall project report documentation as url linked

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awareness of those with brain injury: This self-awareness is a complex issue as pointed out in [5, p. 3]. The L.U.C.A.S. project, by targeting adaptive designed sports and physical exercise (PE) activities, offered a platform for those with TBI/ABI and Spinal Cord Injury (SCI) to learn self-awareness. Innovatively, the project also targeted those in regular contact (e.g. family members, caregivers, or health-providers) to participate in the same adaptive designed sports and physical exercise (PE) training and activities to potentially give opportunities to improve shared experiences toward optimizing well-being and quality of life via shared participation. This aligns with [5, p. 5] who posited how self-awareness is discovered for themselves, through participation, things they could do to help themselves. Further, it is posited that adaptive designed sports and physical exercise (PE) – as tailored physical activities – supports a whole person approach offering possible reconstruction potentials and their lives [ibid, p. 6]. Self-awareness can also be supported via knowledge gain from reading about the injury and related issues e.g. books or acknowledged Internet sites such as that created by Dr. Glen Johnson, Clinical Neuropsychologist - http://www.tbiguide.com.

Within this context, the project L.U.C.A.S (Links United for Coma Awakenings through Sport), funded by the Program Erasmus + Sport Collaborative Partnerships and co-funded by the European Commission, was initiated to create a stable European network for sharing information, expertise and good practices on rehabilitation through sport for people with Acquired Brain Injury (ABI) (in particular after a coma) and Spinal Cord Injury (SCI), including families, caregivers etc. The Danish partners of the consortium carried out a pilot study including children with multiple disabilities, including ABI and SCI. This pilot study was based on the L.U.C.A.S methodology and applied a specific technical tool, which enabled the children to move, dance, and jump in a playful way. This pilot study is presented after sharing the L.U.C.A.S methodology and the overall outcomes of the interventions through this methodology.

2 L.U.C.A.S Methodology

The L.U.C.A.S collaborative partnerships developed and tested a multidisciplinary experimental methodology of rehabilitation through sport and physical activity training, with specific objectives for the final beneficiaries (people with ABI and/or with SCI and their families, caregivers, etc.):

- To facilitate physical rehabilitation through the improvement of motor aspect
- To improve perception of quality of life and psychophysical well-being
- To facilitate social reintegration and to help to reduce loneliness
- To improve quality of relationship between ABI person and family/caregiver
- To improve awareness and self-awareness of the disability
- To give the opportunity for the ABI person to practice adapted sports.

Activities:

- Adapted sport activity for persons with acquired disability;
- Physical and motor activity for caregivers;
- Motor, physical and sport activity for the 2 groups together.

2.1 Implementation of the Methodology

L.U.C.A.S. consortium of seven countries initiated eighteen adapted sports/physical exercise activities (Fig. 1): Methods implemented aligned with [1]. Evaluations were pre- and post- the activity periods using indicators described in the following, however, these methods were flexibly applied and other methods/tools supplemented as necessary. As "L.U.C.A.S. Methodology" included activities that affected various and different fields of a person's life (physical, psychological, relational, emotional, environmental, well-being perception, social, etc.,) no specific questionnaire was used, rather a set of evaluation tools already validated to analyze action indicators of the activities were used.

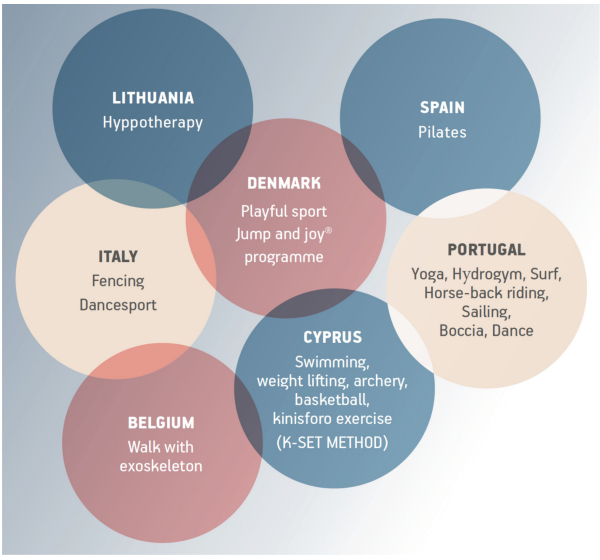

Fig. 1. Seven partner countries and LUCAS activities © L.U.C.A.S. report document

2.2 L.U.C.A.S Tools

To assess the holistic approach of the L.U.C.A.S methodology including the participants with ABI and SCI as well as their caregivers (e.g. parents, siblings, assistants), we identified a set of indicators for each of the targeted participants and, moreover, used different types of established and validated questionnaires. The tools covered different areas of well-being, such as quality of life, psychophysical well-being and social integration. The following indicators and questionnaires were used:

Indicators for People with Disability:

- Disease awareness and functional abilities
- Perception of quality of life and psychophysical well-being
- Perception of social integration.

Validated Questionnaires for People with Disability:

- Patient Competency Rating Scale (PCRS)
- Patient Form ("PCRS-patient")
- Activities of Daily Living Scale ("ADL scale")
- Short Form Health Survey ("SF-36")
- Community Integration Questionnaire ("CIQ").

Indicators for Caregivers:

- Disease awareness about his/her relative
- Perception of quality of life
- Perception of social integration
- Caregivers' physical and emotional overhead of assistance.

Validated Questionnaires for Caregivers:

- Patient Competency Rating Scale (PCRS)
- Caregiver Form ("PCRS-caregiver")
- Community Integration Questionnaire ("CIQ")
- Short Form Health Survey ("SF-36")
- Experienced Pressure by Informal Caregiver ("EPIC").

3 Results

87 participants (49 persons with ABI or SCI and 38 caregivers) completed a 24-week physical activity program consisting of 48 training sessions with separate and combined activities. The program should increase the general health and quality of life of the participants. A comparative analysis of people with disability and caregiver characteristics across all partner countries indicated that an overall pre- versus post-intervention comparison was allowed. This means that the characteristics between persons with ABI or SCI and caregivers, but also between the partner countries were similar. Consequently, all data were pooled into one large data-set. As such, the effect of the 24-week physical activity programs was analyzed for all participants. An additional analysis on the effect of the intervention on people with disability and caregivers separately was completed to provide a more complete understanding of the results. Statistical analysis (Pearson χ^2 with significance level $p < 0.05$) revealed the following findings:

Quality of Life (SF-36):

- Physical Functioning: No significant improvement
- Role Limitations due to Physical Health: Significant improvement for persons with ABI or SCI, not for caregivers
- Role Limitations due to Emotional Problems: Significant improvement for persons with ABI or SCI, not for caregivers

- Energy/Fatigue: Significant improvement for persons with ABI or SCI and caregivers
- Emotional Well-Being: Significant caregivers improvement, not for persons with ABI or SCI
- Social Functioning: Significant improvement for persons with ABI or SCI, not for caregivers
- Pain: No significant improvement
- General Health: Significant improvement for persons with ABI or SCI, not for caregivers.

Competency (PCRS):

- No significant improvement.

Community Integration (CIQ):

- Home Integration: Significant improvement for persons with ABI or SCI and caregivers
- Social Integration: Significant improvement for persons with ABI or SCI and caregivers
- Integration into Productive Activities: No significant improvement for persons with ABI or SCI, not for caregivers.

Activities of Daily Living Scale (ADL): For Participants Only

- No significant improvement.

Experienced Pressure by the Informal Caregiver (EPIC): For Caregivers Only

- No significant improvement.

The results of the study suggest that a 24-week physical activity program increases the general health and quality of life of persons with ABI or SCI, as well as their informal caregiver(s). The increased quality of life of people with disability (ABI or SCI) seems to be manifested in physical, psychological and social aspects of quality of life, whereas in caregivers, the improvements are mainly situated in psychological and social aspects. The latter can be expected given the physical consequences of brain injuries or spinal cord injuries versus the unchanged physical abilities of care- givers. Furthermore, the results also suggest a positive effect of physical activity on the social (re-)integration of people with disability and caregivers. On the other hand, no significant improvements could be demonstrated based on this study with respect to pain treatment, functioning in ADL, and experienced pressure by the caregiver(s).

In conclusion, physical activity improves the physical, psychological and social well-being of persons with ABI or SCI, as well as their informal caregiver(s). Further interventions are necessary to optimize the nature and content of the L.U.C.A.S methodology.

4 L.U.C.A.S Pilot Study: Jump and Joy (Scandinavia)

The L.U.C.A.S methodology was adapted to a specific technical tool i.e. Jump and Joy [Hoppolek], targeting joyful physical training for children with disabilities - see Fig. 2 and [6].

Fig. 2. Jump and Joy [Hoppolek] device © Dalén with permission

The Jump and Joy device is developed by Ylva Dalén, who is graduated as a physio- therapist and has a degree in special pedagogics at the Swedish School of Sport and Health Sciences in Stockholm, Sweden. Furthermore, she has a licentiate degree from the doctoral students program at the Department of Neurobiology, Care Sciences and Society, Division of Physiotherapy, at Karolinska Institutet, Stockholm, Sweden. Dalén has functioned as an expert in the Danish L.U.C.A.S. methodology pilot case study and she has set up the field studies carried out within this pilot case study.

5 Physical Activity as 'Sport' in the Context of Children

In line with the definition of the term sport applied within the LUCAS methodology, sport can be considered as an activity involving physical activities and skills where individuals or teams are involved for pleasure and enjoyment. In line with this, related studies (c.f. Physical Activity During Youth Sport Practices, 2011; U.S. Department Health and Human Services, 2008) states that the most common reasons for why children initially choose to play sports are: having fun, learning new skills, making friends and to be challenged. Yet, free play has shown to produce higher levels of physical activity than organized sports. In addition, a genre of sports is termed "mind sports", where minimal physical activity is involved. Aligned with this, this pilot case study considers the participants' self-agency [7, 8] as significant. In line with this, we

argue that the Jump and Joy device intentions, i.e. to create conditions for the child to be in control of own physical activity, is essential and an integral tool in the child's self-agency in creating a meaningful physical activity for play and development. Drawing upon the concept of Zone of Proximal Development (ZPD) [7], this pilot case study views the physical activity by means of Jump and Joy as a situated activity involving negotiation of meaning between the child and the operator guiding the child during the activity.

5.1 Pilot Study Methods

In contrast to the L.U.C.A.S methodology study, the pilot study applied qualitative methods within a case study framework. Interviews, video observation, and note taking were used to identify the children's experiences when using the Jump and Joy technical tool. The study included 12 children between 5 and 14 years of age and 12 special teachers and physiotherapists.

5.2 Jump and Joy Tool

The height of Jump and Joy is 150–180 cm, depending on the adjustment of the stand (a form of upright spine that parts lock onto); the weight of the base is 43.5 kg; and the stand with knee, pelvic and trunk supports and maneuverable arms weighs 10–12 kg. The length of the platform is 74 cm and the width is 65 cm. Manufacturing mate- rials consist of steel plate; platform 4 mm, and the other details 2–3 mm.

The tool includes a control panel with yellow, red, green, blue, and black buttons. By pressing these buttons, it is possible to experience vibrations, bounces, and rotations – either individually or together (i.e. 1, 2, or 3 feedbacks simultaneously). The vibration is oscillating motion around a horizontal axis simulating a sine wave with peak-to- peak displacement being 0.2 mm, with frequency of 40–42 Hz, and acceleration of 33.35 m/s^2. The dynamic bounces are 3 cm, numbering 77 bounces/min with an acceleration of 17.65 m/s^2 (1.8 G). The rotation has a load on the base of 67 kg: 8.5 revs/min and without any load 10 revs/min. Furthermore, a CD player can be connected for child-control by a button press. The device is patented.

The child stands on a round platform (Fig. 3), with or without standing shell, and is strapped in a safe way. By pressing the above-mentioned buttons, the child controls the feedback vibrations, bounces, and rotation and can, thereby, carry out activities such as spinning, jumping, dancing, and at the same time physically train and strengthen the skeleton [6]. Based on this, the aim of Jump and Joy is to offer children with disabilities possibilities to joyful physical activity on their own premises.

5.3 Procedure

The Jump and Joy activity session started with the operator, sometimes assisted by a colleague, placing the child in the device and adjusting the stand with the knee, pelvic, and trunk supports to fit the height of the child. When this is done, the operator secures the straps so that the child is safely positioned to start using the Hoppolek by him/herself (see example Figs. 3 and 4).

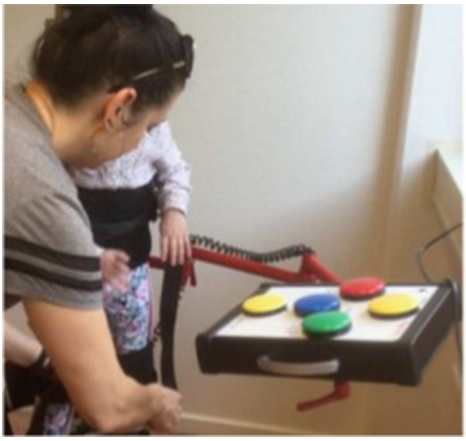

Fig. 3. (Left) operator secures the straps to support the child's trunk and knees.

Fig. 4. (Right) two operators adjusting the knee and pelvic support

5.4 Pilot Study Results

Childhood acquired brain injury has impact on cognitive, physical, language, social and behavioral functioning as well as on participation in home and school activities. Furthermore, it has impact on the child's play, in particular a child's playfulness and ability to approach play. Play is an important childhood activity as it contributes to meaning and quality of life and provides opportunities for skill development. By limiting the child's engagement in play and playful activities where such skills are practiced it may further impact the child's quality of life.

This pilot study used the Jump and Joy device to explore children's actions when they are enabled to, through the device, move on their own premises. As mentioned, the device has a control panel with buttons, which the child uses to push forward movements from the platform. These movements charge the child's skeleton and stimulate balance organs: jump, spin and vibrations. The child can choose if (s)he wants to utilize one movement at the time or all together. It is also possible to press for music and experience dancing.

A theme analysis was applied, identifying three themes: *I am able to…*; *I can express myself…*; and *The child's desire as a starting point*.

'I am able to…'

- Ability to initiate activities and actions
- Increased degree of being awake
- Be in charge; to be able to take own decisions
- Keep doing; forgetting that the activity/actions are tedious and/or painful.

NB: A child has a natural need and desire to jump, spin and move: When the children started to spin and jump, and could do as much as they wanted to, first one direction

and then another one – they experienced that they were able to be in control of their own actions = Cause and effect.

'I can express myself…'

- Initiating communicative and playful activities (for example, dancing, hiding, running after, spinning towards… and away from…)
- Shaping inter-play where all participants can influence the situation
- Child-child
- Child-parent
- Child-facilitator
- Medical results.

The child's desire as a starting point

When having the child's desire as the starting point, playfulness emerges and other outcomes develop as an added value. In other words: If we want to train the child's hand motor skills, this is not the starting point, but play and playful frameworks enabling play. Then, hand motor skills develop as an added value. For example, the study has shown that the children, by using the Jump and Joy buttons to initiate e.g. spinning, also started to use hands in ADL situations.

In Conclusion

- The importance of focusing not only on self-care activities and productivity, but to enable play and opening up for playfulness.
- Play as foundation for physical activity builds confidence and imagination.
- Play as foundation for physical activity makes children (any human being) happy.
- Play as a foundation for physical activity initiates interactions and develops skills – in a joyful and playful way.

Implications and Suggestions for Future Interventions

Experiences from L.U.C.A.S, including the pilot study, resulted in an evolved flexible, open and all-encompassing methodology, that, whilst context and case dependent, innovates by being inclusive of caregiver\families alongside people with disability. Optimization of engagement, fun, play and social interactions is targeted in method-based activities toward participants' benefits, thus advancing the field. NB for others who want to apply this methodology to be aware of the following:

- Be flexible
- Context and case specific
- Pay attention to participants' needs (inclusive of caregivers/family members)
- Optimize engagement fun and play (involvement)
- Promote a multidisciplinary approach
- Feel free to use any adapted sport and motor/physical activity.

Closing

Terms inclusion and accessibility are increasingly heard wide and far in contemporary society. Media channels are active in improving awareness of people with dysfunctional

differences. Reports of adversities and corresponding achievements and courage to overcome are apparent. Sporting activities are especially effective in bringing home awareness and none more so than the Paralympics, Special Olympic World Games, and others. Through projects like L.U.C.A.S, the wider meanings of the terms inclusion and accessibility ring loud so that even those with profound impairment can participate.

A sustained outcome of the L.U.C.A.S project is a common program of events and initiatives in nine countries to raise awareness on the coma awakening and the problems of people with acquired brain injuries and their families, namely the establishment of the yearly "European Day of Awakenings", that obtained the High Patronage of the European Parliament, which involves partners' joint actions in their own countries and takes place in October every year. The activities highlight the L.U.C.A.S. project of Casa dei Risvegli Luca De Nigris through social themes as well as clinical research issues and the topic of therapeutic alliance between health professionals, non-health operators, families and volunteers.

Notes (please also see end notes):

- All images are used with permission or are covered by author 1 ©.
- Consortium partners conducted investigations in their own country –this is apart from the authors who are based in Denmark but were unable to establish Danish collaborating partners. The Scandinavian element of L.U.C.A.S. was therefore carried out solely in Sweden as a pilot project.[2]
- *Outcome booklets were produced in each partner's language: See English at: https://ec.europa.eu/programmes/erasmus-plus/project-result-content/9a3fda1d-3edf-4222-b028-bb42b0772583/LUCAS_Methodology_EN.pdf
- Note: A summary of the L.U.C.A.S. project was presented to the European Parliament by the coordinator organization March 2018. A video in Italian is available for viewing at YouTube https://www.youtube.com/watch?v=AnkDq99j5xQ
- A panel of experts from the Directorate-General for Education, Youth, Sport and Culture of the European Commission selected LUCAS as a "success story" under Erasmus+ Programme for Education, Training, Youth and Sport, Stakeholder Engagement and Programme Impact. "Success stories" are finalized projects that have distinguished themselves by their impact, contribution to policy-making, innovative results and/or creative approach and can be a source of inspiration for others. The award was made on the basis of a selection process according to rigorous criteria regarding the quality, relevance and results of the project. As a consequence of this selection, visibility and acknowledgement was given to the project, for instance on EU websites, social media, and when preparing documentation for conferences or other events with high-ranking attendance.

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[2] http://www.cfp-futura.it/PubblicaAmministrazione/ProgettiEuropei/Progetti/ProgettoLUCAS.aspx.

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