Overview and assessment of LUC^3

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Lund University Child Centred Care (CCC) research program

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February
2020

Introduction

We have had the pleasure and honor of acting as scientific advisors of the LUC^3 program since the fall of 2015. The LUC^3 program focused on the child, and especially the vulnerable child. It aimed to develop knowledge and interventions to support the family and professionals in caring for the child, and translate this knowledge and processes/models of care into practice.

This report is intended to briefly review the program and give an orientation to the process of evaluation, and critical contemplations on the outcomes, advancement, and prospects of the program interventions.

We present the main goals and frameworks of the program and the platform of our analysis and review, followed by discussion of the processes, outcomes, and contributions of the program for knowledge building in health care.

Frameworks

The development of the LUC^3 program was supported by empirical and theoretical frameworks. As for the empirical framework, the program considered the UK Medical Research Council's guidelines (Craig, Dieppe, Macintyre, Michie, Nazareth, Petticrew. et al., 2008) for the development and evaluation of knowledge. This is an open empirical framework aimed at *the development and evaluation of RCTs for complex interventions to improve health,* and is meant to take into account valuable experience that has accumulated in the guidance of non-experimental methods. It is intended to help researchers to choose appropriate methods and resources to understand the constraints on evaluation design, and help users of evaluation to weigh up the available evidence in the light of methodological and practical constraints.

Several of the clinical areas within the LUC^3 program do not allow for big samples in controlled environments, and existing literature is limited. The MRC model was favorable as a framework to use in the guidance of the program and its projects because it provides helpful guidelines and questions and gives rise to critical thinking in developing, testing, and implementing interventions and evaluating them.

Theoretical frameworks

The LUC^3 program emphasized the development and implementation of care of children from their perspective as belonging to a family, having a voice, and acknowledged needs. The Child Centered Care (CCC) framework enables that focus (Coyne, Hallström, & Söderbäck, 2016; Söderbäck, Coyne, & Harder, 2011) and is the underlying theoretical framework in the LUC^3 program. Some studies of the program however built on a Family Centered Care (FCC) framework. The employment of FCC means working in partnership with a family and caring for children in the context of their family, wherein health providers are expected to recognize and strengthen families' special knowledge and skills whilst creating the right environment for the child (Shield, 2015; Uniacke, Browne, & Shields, 2018). However, the families' or parents' needs may not be synchronous with the child's needs

(Söderbäck, Coyne & Harder, 2011). There was a risk in the program of confusing the two frameworks of CCC and FCC that the program leaders were well aware of (Coyne, Hallström, & Söderbäck, 2016; Ford, Campbell, Carter, Earwaker, 2018). In addition, individual project areas within the LUC^3 program also employed a number of theories relevant to the topics and concepts studied, as will be addressed later in this report.

The scope and goals of the LUC^3 program

The LUC^3 program organized the interventions and implementations into three interrelated project domains based on their areas of research.

1. Promoting early childhood health; supporting parents and vulnerable and challenged children.
2. Hospital-Based Home Care (HBHC) for children with longterm illness (LTI) (diabetes, cancer, pre-term, HIV, critical congenital heart disease).
3. Knowledge development and translation in implementation of CCC.

Domains 1 and 2 were interrelated through knowledge development and translation in implementation, when appropriate.

The goals of the research program and each project domain where to:

1. Develop, evaluate and implement Child Centered Care (CCC) and support to the families in Child Health Services with the aim to promote and improve health and prevent illness for children and especially those who are identified as vulnerable.
2. Develop, evaluate and implement Home-Based Health Care to increase the family's participation in care, decrease strain on the family and reduce health care costs.
3. Increase the knowledge of context and culture that facilitates versus obstructs implementation processes, and generate theoretical and methodological models on how to successfully implement CCC in Child Health Services.
4. Enhance the integration of new research findings within CCC into care services by supporting health care professionals in their provision of evidence-based care and, by new means of communicating research, such as the use of internet-based platforms, translate and communicate research results to stakeholders and society.
5. Enhance the research and communication capabilities of senior and junior researchers in CCC nationally and internationally through collaborative approaches in inter- and multidisciplinary groups.

The focus was on prevention, care-taking and support through interventions involving vulnerable children, their parents, families and care-takers. The organization of the care was through hospitals, health care centers, and home health care services. A variety of theories, concepts, and interventions were drawn upon to meet the goals of the study. This has produced new knowledge relevant to the health-related needs of the population under study that has been used in the development of new ways and means of caring for children and their parents in health promotion, illness prevention, and treatment.

Process and deliverables of the program

LUC^3 was an inter-Nordic multidisciplinary collaborative program applying different theoretical perspectives when addressing nursing care and intervention development in different health care settings and in the community. The program encompassed different clinical areas and populations of vulnerable children and their parents. The program and its results have been presented at scholarly venues, as well as among clinicians and the public. Findings have been published in local outlets, and scientific Nordic and international journals. The program has resulted in a number of Master's and PhD theses. Thus, the program grant from FORTE awarded stipends for students and post-doctoral fellows and enabled national and international collaboration in terms of research and theory advancement in the area of health care for vulnerable children and their families. It also had impact in evaluating and providing health care to children and parents, integrating project areas into health care, and developing knowledge to improve education of health care professionals. Regular engagements with stakeholders in data collection and discussions of findings further strengthened the project.

Method of evaluating the program

This internal review of the processes and findings of the program is based on several elements. The LUC^3 program included internal evaluation involving scientific advisors to strengthen the path of each project going forward. The program held regular workshops with its members and assembled collectively each year to present its milestones. During these workshops project domain leaders, post-docs, and doctoral students presented their findings to the group, and at the collective annual workshop, the scientific advisors gave their comments. Discussions about methods used, interpretation of findings, implementation processes and challenges, where at the forefront of the exchange.

The workshops ended in discussions of ways to correct or strengthen the projects. Working this way, based on the overall program goals, calls for knowing what others in the program are doing and how individual projects can be strengthened at the meeting point between different researchers and research areas.

In Fall of 2018, the program group and the scientific advisors met in a final workshop in Båstad for a concluding evaluation of the program, the project domains and areas of research, to discuss the outcomes, the future of the research, and the implications of the program. Participants where organized into five groups and each group had the assignment to discuss one of the five overall goals of LUC^3 based on selected questions that the scientific advisors had sent to each participant in advance. Following the workshop each project area leader made a report based on the evaluation questions used and reported to the scientific advisors. These where:

- How did your research:
  - Advance the goals in the program domains?
  - Apply research methods related to the goals (sampling, data collection, data analysis)?
- How did interventions and the goals meet up?
- How were health and health care outcomes advanced?
- How will you proceed with the project based on the findings?

The final report of the program builds on answers to these questions.

Strenghts of the LUC^3 program

The LUC^3 program had a number of strengths. These included a theoretical/conceptual grounding, a focus on clinically important problems, client-centeredness, and an interdisciplinary approach at multiple levels using multiple methods. We will now discuss each of these.

Conceptional/theoretical grounding

The LUC^3 program was based on the conceptual framework of **child-centered care (CCC).** Within this concept, the family has an important role because of its influence and implications for the child's health and well-being. Therefore, a child-centred approach not only works directly with the child, but also needs to work closely with the child's custodians. However, when addressing and servicing parents or other family members, the needs of the child are central. This means that in order to provide patient- or child-centred care, the focus in not on the parents or family per se, but on the parents or other custodians as responsible agents affecting the health and well-being of the child. Within this conceptual framework, individual LUC^3 studies derived research hypotheses and research questions from different theories depending on the topic under study, including Bronfenbrenner's Ecological Theory, Bowen's Family System Theory, Early Start Denver Model, the Theory of Planned Behavior, Bandura's Social Cognitive Theory, and Leininger's Culture Care Theory. In addition, the concepts of Health Promotion, and Health Literacy were employed where applicable.

Importantly also, the LUC^3 program was set out to contribute to knowledge development and the development of analytical models related to processes of implementation within health services, with an emphasis on Hospital-Based Home Care for children. This involved identifying factors that both facilitate and hinder the implementation of a program or service within hospital-based home care (Nilsson, Hansson, Tiberg, & Hallström, 2018). It also involved understanding the meaning of patient or client involvement in health care. This work has been followed by the development of guidelines for implementation of hospital-based home care for children and their families (Fioretos, Hansson, & Nilsson, 2013; Hallström, 2013; Hansson and Nordmark, 2015; Tiberg, et al., 2014, Tiberg, et al., 2016). The full effects of the theoretical work and guidelines on the quality of hospital-based health services for children await further investigations and dissemination.

Problem orientation

What made the LUC^3 research program particularly relevant was its focus on either known or discovered problems of unmet care needs, or insufficient care of children and their families? In most cases, problem identification was based on experienced or suspected limitations of available care, or the absence of certain kinds of care (Björquist, et al., 2014; Dahav & Sjöström-Strand, 2018; Ekelin, et al., 2018; Lefevre, et al., 2014; Pålsson et al., 2017; Pålsson et al., 2018; Sjöström-Strand & Terp, 2017; Tornoe, et al., 2014). Thus the program opened new avenues for health research and health care.

Client-centeredness

The LUC^3 program was distinctly client-centered, rather than institution-centered. The studies within the program focused on the needs of the child and the child's family and

effective ways to meet them. It is well known and widely documented that client-centered health care tends to be of a higher quality than task-oriented care based on tradition, practicalities, or interests of institutions. Task oriented care is typically more standardized and lacks the variation needed to meet individual needs (Sharp, et al, 2018). Although it can create desired efficiency, task-oriented health care is often provided at the cost of desired quality. The LUC^3 program did include economic assessment of the interventions, but with a view towards the provision of good quality and cost-effective care.

Interdiciplinarity

The LUC^3 program addressed health care needs in an interdisciplinary fashion. The research teams included nurses, midwives, physicians, physical therapists, psychologists, anthropologists, computer scientists, and economists, with disciplinary combinations depending on the topic of each study. Interdisciplinary teamwork is important when studying complex multifaceted problems, and it is particularly relevant in health services research, not the least when attempting to understand and meet the needs of individuals with chronic health problems, as was the case in many of the LUC^3 project interventions, as the needs are typically physical, psychological and social, all at the same time. Interdisciplinary health care research can provide a holistic understanding of clients' needs and strengthen collaborative teamwork when addressing these needs.

Multimethod/mixed method

LUC^3 included a number of multimethod/mixed method projects. Using different research methods is particularly important in health services research. This applies for example to new research areas, which can typically start with a qualitative study which is followed by a quantitative survey or experiment. Also, a qualitative study may follow a quantitative study for fuller understanding of the topic in question. Generally, the complexity of the research area may require the combined use of qualitative and quantitative methods. The research methods applied within the program included qualitative interviews, cross-sectional and prospective observational studies, quasi-experiments, and randomized controlled trials.

Multilevel approach

Finally, a multilevel approach is sometimes needed in health services research. Health services operate at the levels of systems (health regions and districts, hospitals and community health centers, payment systems), organizations and professions (roles, authority structures, etc.), and individuals (practitioners and clients). Some studies within LUC^3 paid special attention to the multilevel reality of health services when interventions were prepared, launched, or assessed (e.g., Castor, Hallström, Hansson, & Landgren, 2017; Nilsson, Hansson, Tiberg, & Hallström, 2018; Tiberg, Hansson, Holmberg, & Hallström, 2017).

Challenges encountered in the program

No program of research is without challenges. A program succeeds when it recognizes and takes notice of the challenges and finds fruitful ways to encounter them ((Guthrie, Wamae, Diepeveen, Wooding, & Grant, 2013. The LUC^3 program anticipated many of its challenges

through the use of the MRC model (Craig, et al., 2008) and designed its projects accordingly. Following are six of the major challenges.

Randomized controlled trial (RCT) not performed or not feasible.

A minority of the studies within the LUC^3 program used and RCT design (e.g. Tilberg et al., 2015). In other studies within the program, the investigators presented results of a quasi-experiment or an observational (correlational) study, and when discussing the results, they frequently called for an RCT study to confirm and validate their findings going forward (e.g. Derwig, et al, 2019). In most cases within LUC^3, the choice of a non-RCT design was methodologically justified or required. It is true that not doing an RCT constitutes a certain limitation when attempting to establish causality in relation to interventions. However, an RCT study can have its own causality problems (Deaton & Cartwright, 2018). Also, an RCT is not always feasible. Sometimes it is not possible to randomize, or control the setting or environment in which the study takes place, as was evidenced within many research areas of LUC^3. Importantly also, RCTs are not always realistic, e.g. when the experimental setting differs markedly from real life settings (Deaton & Cartwright, 2018). In addition, RCTs may not sufficiently handle the holistic nature of the study in question, as they typically involve one or few causal factors, while the study concerns a complex multivariate causal reality. And in certain cases, RTC's may not even be ethical, e.g., when a comparison group would get substandard or no care with a high likelihood of serious consequences. All of this means that the knowledge and intervention development within health care sciences in general, and nursing in particular, will always rely heavily on qualitative, correlational, and quasi-experimental research designs, like the ones that were carried out within LUC^3. In many instances such studies will not be followed-up by an RCT.

Problems of implementation.

Systems of health care are complex, multi-leveled and hierarchical, with numerous often, opposing forces and interests. Not surprisingly, the LUC^3 studies encountered a number of challenges and problems when implementing and running the interventions. Some of the problems were related to economic concerns, others to lack of administrative support, or lack of manpower or staff training, some to restrictive routines, and still others to conflicting professional views and interests. More specifically, among important issues and problems of implementation discovered were:

- Low hospital department referrals of children to a home care service (Castor et al., 2017).
- Professional turf protection (turf battles) (Nilsson et al., 2018).
- Professional insecurity and anxiety (Nilsson et al., 2018).
- Hospital resistance against early discharge (Nilsson et al., 2018).
- Lack of support for specialized nursing care outside the hospital (Tiberg et al., 2019).
- Complex and challenging role of the facilitator of change (Tiberg et al., 2017).
- Challenges encountered when developing and integrating a new technology – Internet of things (Johansson, Nordahl, & Magnusson, 2017).

Importantly, issues and problems of implementation were included as a special project domain of the LUC^3 program. Explanatory and technical models have been developed to

organize and bring together research results relevant to implementation both from research outside and inside the program. The work by Tiberg and Hansson, as well as Sjöström-Strand and Magnusson, specifically address the problems of integrating research results and technical solutions in communication into the "real world" of health care. Within the LUC^3 program, new technology has been developed for communication between the home (parents) and the care personnel and the hospital, supporting collection of measurements, reports, texts, pictures, and video communication (Johansson, Nordahl, & Magnusson, 2017; Sjöström-Strand & Terp, 2017). This technology has successively been used in two interventions, neonatal and corrective surgery, but faces challenges of technical advancements and steady change, and need for updating of systems to be applied into routine care. An RCT study suggested that Home-Based Health Care (HBHC) with individualized support is equally safe and effective for the newly diagnosed child with type 1 diabetes as hospital-based care (Tiberg, et al., 2014). An implementation study however reported that the intervention of HBHC was only partially implemented and consequently the same results were not achieved. Shorter in-hospital stay was implemented following the study, but increased support by a diabetes nurse was not implemented (Tiberg, et al., 2014). The results strengthen the importance of involving policy and decision makers, local political leaders and stakeholders in implementation research. The results further indicate that new strategies need to be developed to assist healthcare professionals in adequately supporting children and parents (Tiberg, et al., 2018; Astermark, et al., 2017; Tiberg, et al., 2016).

These studies show the significance of follow-up of research results into the "real world" of care. The importance of this work for future design, introduction and maintenance of interventions in health care remains to be seen.

Problems of continuity of care

Successful initial implementation of an intervention or service in connection with a research study does not mean that the service will continue. Implementation does not secure continuation. Often, the same factors that hamper implementation also hamper continuation. And sometimes, other factors come into play. Thus, staff turnover can jeopardize continuation despite a successful earlier implementation. Also, the educational level and/or training of nurses and other health care professionals within the service units can facilitate or hamper both implementation and continuation, as evidenced by some of the LUC^3 studies (Sivberg, Jacobson, & Lundquist, 2019; Skoog, 2018). It should be noted though that assessing and understanding problems of continuation of service fell largely outside the scope of LUC^3. It remains to be seen whether the interventions implemented through LUC^3 will continue, be changed, or relinquished.

The challenge of dissemination of health care information.

There are often significant delays in incorporating evidence-based clinical recommendations into routine practice (Marriott, Palmer, & Lelliott, 2000). Evidence-based practice requires continuous uptake of best available evidence. The challenge is how best to facilitate the general uptake of a new or revised care following a successful implementation in a clinical study, and connect the rapidly expanding knowledge base of health care to the professionals who deliver care based upon it. This is an issue that involves researchers, professional bodies, administrators, and policy makers. The LUC^3 program made numerous efforts to disseminate research results stemming from the program. Meetings were held among professional groups, within hospitals, in community health services, and among the

public. Furthermore, a user-friendly webpage was designed to disseminate results and findings. When it comes to dissemination of health information, there is always room for doing better and doing more, but in this regard, it is our assessment that the program leadership and project investigators have risen to the challenge. Nevertheless, developing organizational and professional linkages even further would no doubt strengthen the dissemination of important clinical results stemming from the LUC^3 studies.

The challenge of cultural sensitivity

Increasingly in the Nordic countries, health care is provided to individuals and families of different cultural backgrounds. This warrants considering different values, beliefs and practices of families and children that may have implications for their health and well-being. Some studies in the LUC^3 program directly addressed this issue and indicated the importance of culturally sensitive care, both in the case of depressed mothers of a foreign background living in Sweden (Skoog, 2018), and Ethiopian children and adolescents with HIV and their families (Biru, Hallström, Lundquist, & Jerene, 2018). These studies are in line with a growing literature finding that culturally sensitive care can improve the outcomes of health care for certain cultural groups in terms of satisfaction with care, lifestyle changes, and treatment adherence, and thus reduce health care disparities (Nielsen et al., 2016; Tucker et al., 2011). Research into culturally sensitive care in the Nordic countries is still underdeveloped and further development of treatments and their assessment is very much needed.

Child-centered care as a challenge

Parents are often intermediaries between the child and health care professional, e.g. by transmitting health-relevant information from, about, and to the child, or by administering treatment. In such cases, care can be viewed as parent-centered, but may not always be child-centered, or even in the best interests of the child, especially in the absence of direct conversation, observation, and assessment of the child by a professional. Parents also vary considerably in their parental skills and their understanding of their child's needs. However, informing, assisting and empowering parents to meet the child's needs, can certainly be viewed as child-centered care. There were notable differences in terminology between studies in the LUC^3 program, as some authors used the term "family-centered", and others used the term "child-centered". The studies in the LUC^3 program, even those that focused primarily on parents, were based on the premise that they were child-centered or that they supported the health and well-being of the child. Nevertheless, in the absence of direct professional contact with the child, the premise of child-centered care is not overtly and directly addressed.

Summary

The LUC^3 program has come to an end. There are different ways of measuring the success of such a complex research program (Guthrie, et al., 2013). One is through longitudinal quantitative methods. Another way is qualitative, going into areas of the research evaluated and asking questions, sharing experiences and discussing processes. These different ways may be formative, flexible, and variously comprehensive, and may or may not produce comparisons to other research. In this review of LUC^3, it is our conclusion that the program

has substantially enhanced the understanding of health care needs of vulnerable children and their families and the ways to meet them. The program has disseminated this understanding among professionals, policy and administrative stakeholders, and the public, in making the case for policy and practice change. The program has shown accountability by efficiently and effectively allocating its resources to produce evidence and knowledge in accordance with its set goals. The program has resulted in numerous scientific journal articles, conference posters and oral presentations, master's and doctoral theses, educational material, and treatment protocols. New measuring instruments have been developed, as well as technical solutions for hospital-related home care services for chronically ill children. The implementation of methods and modalities of treatment, and problems of implementation, have been investigated. Emphasis has been placed on multiple methods and an interdisciplinary approach based on known theories and frameworks. The program has also furthered theoretical models and highlighted new aspects to theoretical and practical problems in child- and family-centered care of children. In short, the program has introduced treatments that strengthen parents in their role, and help improve the health and well-being of parents and children. The instruments and interventions introduced in the program need to be further developed and evaluated. Further research is needed into the implementation of the treatments, as well as into the maintenance and sustainability of the treatments over time.

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