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Understanding Heart Failure Care as a Patient Learning Process

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Abstract

The paper deals with the planning of eHealth systems in the area of chronic care from a patient-centred perspective. The particular area is heart failure (HF) and systems that support patients’ possibilities to be active learners during the care processes. A better understanding of this process is hoped to create a basis for the development of appropriate information systems or information technology (IS/IT) support of learning processes. The objective of this paper is the development of a better understanding of the challenges of chronic illness with special focus on HF. The results are presented as a planning framework that guides the choice and design of ICT-based support systems.

Keywords: Heart failure, eHealth, Patient learning, Self-care, Chronic illness, Patient-centred care

1. Introduction

This paper deals with the planning of eHealth systems in the area of chronic care from a patient-centred perspective. The particular area is heart failure (HF) and systems that support a patient’s possibilities to be an active learner during the care processes. Heart failure (HF) is a chronic condition, where the patient’s own actions are essential for dealing with the conditions. This paper does not discuss different ways of treating or organizing care for HF patients as such but is focused on how to communicate and work with patients from the perspective of the patients’ learning process. A better understanding of this process is hoped to create a
basis for the development of appropriate information systems or information technology (IS/IT) support of the learning processes. As eHealth is an area of IS/IT systems for the health sector, it is hoped that it will form part of the solution for current challenges that this sector faces. Changes, like new classes of sickness, more demands from patients for individualization and a general drive for a more effective use of resources paint a conflicting and difficult picture. Care for chronic illness has its special characteristics: the time-line is open-ended, the condition keeps changing and often takes an unpredictable illness trajectory, and the aspects are challenging both from the patient and the societal perspectives. These points are the special learning conditions that a support system faces. The objective of this paper is the development of a better understanding of the challenges of chronic illness with a special focus on HF. The aim is to develop a frame of understanding for the planning of information systems that support the learning need of HF patients during the care process. The approach for achieving this is to investigate reports on care for HF patients. The results we wish to present involve a planning framework that guides the choice and design of ICT-based support systems. The application of the framework will result in a package or portfolio of information systems that covers the needs of HF patients’ care process.

This paper is organized as follows: in section 2 we present the background of care processes from a patient learning perspective, in section 3 we present current research on patient perspective in heart failure literature, in section 4 we make an analysis of the current situation of heart failure patients using the patient learning framework, in section 5 we present and populate a planning framework. A limitation is set for this paper, we do not go into current information systems solutions, as this is a planned development in coming stages of this research project.

2. Care of chronic illness from a patient learning perspective

2.1. The care process as a learning process

In a series of papers, patient learning processes have been explored from a general chronic illness perspective, inspired for example by the chronic care model [1] as a way of organizing information systems for the support of patient-centred care [2,3,4]. Six main areas were outlined in this model together with one overarching area that covers the interactions and conversations between patient and caregiver. Behind this model a traditional decision-making model is used as an approach to understanding a patient's process towards a healthier life.

1) Patient understanding. Patients suffering from HF need to possess knowledge and skills acquired through experience and/or education in order to gain an understanding of their situation, including the cause of HF and its symptoms, the rationale for treatment and lifestyle changes.

2) Monitoring and fact gathering. By traditional measures facts about the condition of the patient are obtained.

3) Planning and formulation of alternative actions. Based on the facts, possible paths of action can be laid out.

4) Decision-making. This is a process of comparing alternatives and choosing the one that is most satisfactory and allotting resources to the chosen path.

5) Action. Performing what has been decided on, for example taking extra medications, e.g. diuretics in HF, following an exercise plan or some additional treatment that is to be performed, e.g. taking annual flu shots.

6) Evaluation and record-keeping. Evaluations are required for understanding the outcome of different activities and the care process as a whole. Here we consider the record-keeping and information handling that are needed for supporting and administrating the process, and how this can be used for learning.

To supplement the above-mentioned phases, we add a final aspect, patient-health care provider interactions. This should not be seen as just any phase among the others, but rather as a focus point for the full care process, where much of the actual work is done. It is therefore important that this is set up to work in a manner that facilitates the learning process. The central position of meetings between the caregiver and the patient warrants a special study.
7) Patient interaction with the health care (doctor/nurse etc.) traditionally takes place in a face-to-face experience format, or through telephone and maybe a written note as support technology.

2.2. Perspectives on learning

To gain a broader perspective on learning issues in relation to the HF care process we use the analytical “learning level and perspectives” framework [5]. This framework provides an integrated approach and offers opportunities to start discussions in many dimensions. Here different views on learning are related to each other in an integrated framework of knowledge and learning. Three perspectives are used to understand knowledge and learning support, including:

• A cognitive perspective that treats knowledge as something that can be obtained through the human senses (cf. [6]) and could be supported by different technologies.

• A social perspective where knowledge constitutes an agreement among people [7].

• A critical perspective where knowledge is seen as the pivotal issue of personal or institutional power. Here, knowledge support has political, ethical and power dimensions [8].

All three views can be studied on different levels, including individual, group and organizational ones.

To focus clearly on the two key concepts of learning and knowledge we also use two additional theories. The theory of tacit knowledge explains that the human mind is assumed to operate on two levels, one focused and explicit and the other tacit and partial [9]. Every time someone tries to perform a conscious act, by focusing on a phenomenon and acting on it, a number of unconscious or tacit knowledge parts are simultaneously relied upon. This tacit dimension is central to shaping the actions, but the actor is not aware that this is happening. The process of tacit knowing is a dynamic and automatic function of our brains. Only when focusing on this partial and hidden knowledge, by using conversational techniques, is it possible to reach some self-awareness about the tacit dimension.

A practical model of learning is “experiential learning”. This model for learning is sometimes referred to as the “Lewinian experiential learning model” [10]. According to Kolb [10], learning is a process of gaining new knowledge by transforming experience. The model presented by Kolb [10, p. 30] contains four types of abilities that a person should master in order to learn: 1) observation and reflections, 2) concrete experience, 3) testing concepts in new situations, and 4) formation of abstract concepts and generalizations.

3. HF patients’ learning situation

The literature study that is the basis of this overview takes the form of an expert selection. Researchers (co-authors) in the heart failure area have selected representative articles for each one of the seven areas. The selected articles are intended to give a proper representation of the current situation in heart failure research.

3.1. HF – chronic illness and self-care

HF as a chronic illness, where the role of patient is of crucial importance, places the knowledge and abilities of the patient in focus. In general, a long range of factors have been identified that affect the self-care of chronic illness. In Riegel et al. [11] ten factors are presented as a mid-range theory for self-care, including experience, skill, motivation, culture, confidence, habits, function, cognition, support from others, and access to care. This broad set of perspectives indicates the need of a multi-dimensional analysis of HF care. The person suffering from the illness needs to learn to live with the HF condition, by changing lifestyle, diet, taking medications, exercising etc. These instructions for self-care are well explored and documented and many of the problems concern how to engage and motivate HF patients to adhere to them. They include patients’ need to understand the cause of heart failure, why symptoms occur, important prognostics factors and different treatments; indications, dosing, effects, common side effects of drugs; the importance of following treatment recommendations, diet, exercise, immunization, travel, smoke, alcohol, drugs recommendations; common aspects regarding sexual activity, sleep and breathing disorders and psychological
aspects; and knowing how to contact healthcare providers, what to monitor and how to exercise and keep a diet. There is a documented lack of relevant knowledge about HF among the general public [12], with only 3% in Europe being able to identify HF on the basis of typical symptoms. In one study [13] where patients that had received education were asked what they knew about HF the result showed that 37% said “little or nothing”, 49% said “some”, and only 14% said “a great deal”. Poor self-care by patients contributes to poor outcomes, something that is too often associated with HF.

3.2. The life situation of HF patients

To develop a better understanding of the complex needs of patients with HF, qualitative studies have been performed to explore the experiences of patients with HF through the disease trajectory. This also affects the possibilities and conditions under which the learning process occurs. It has been shown that patients with HF gradually experience an increasing difficulty in fulfilling their usual roles. They may even be forced into a more physically dependent position in their day-to-day living. Patients might not even be aware that they have been diagnosed with HF; in one study 20% of the patients with a HF diagnosis were unaware of this [14]. The social disruption of isolation and loneliness commonly associated with chronic illnesses is especially common within this vulnerable group [15, 16]. In Chriss et al. [17] factors that influence the impact of education are investigated, while in this study age and gender constitute the factors. This study shows that elder males with fewer comorbid illnesses were more successful with their self-care. In another study, formal education and symptoms of severity predicted a better knowledge of HF [18].

3.3. Teaching for HF patients

Patient education is an integrated part of the care of HF patients, both for in- and outpatients. Teaching patients is an important factor for improving their situation [19]. A common element in patient education is instruction to self-care. Such an instruction could consist of a written, detailed instruction that is given to patients about how to behave once the hospital treatment is over and they have gone home. The purpose of this education is to ensure their adherence to the self-care instruction. There are many examples of extended support programs and processes for patients after hospital stay. By putting together several activities over time, the adherence to instructions has improved. Examples of frameworks for teaching processes have been reported. For example Strömberg [20] suggests a five-step programme: 1) the assessment of patient’s prior knowledge, 2) the assessment of patient resources and barriers and learning needs, 3) the planning of education with the patient, setting goals are set and choosing educational interventions, 4) the delivery of education and 5) evaluation.

There seem to be problems with the effectiveness of education [13]. To increase this, more elaborate support programmes have been tried. Teaching in combination with other activities in disease management programmes decreases readmission in one study by 40 % [21]. The concept of disease management provides a broader perspective on patient education. Edwardson [22] provides a review of examples of successful multi-disciplinary interventions. These include among others: 1) nurse home visits with or without complementary telephone calls, 4) combined coordinated efforts of drug therapy, patient education, telephone calls, and 3) multi-disciplinary teams providing support, like titrating medications, frequent symptom monitoring tracking mediation and diet compliance, telemonitoring, and education. A meta-analysis of the use of telemonitoring as structured telephone support shows improvements in life quality and reduced costs [23].

3.4. Barriers for HF patient learning

There are many aspects of a HF patient’s situation indicating obstacles to learning of diverse kinds. These problems are an important aspect when planning HF patient learning processes and support systems. Systematic studies of these problems have been reported. For example, Strömberg [21] reports five types of barriers for patient learning: 1) functional limitations – visual, hearing or mobility, 2) cognitive limitations, memory problems, 3) misconceptions and a lack of basic knowledge, 4) low motivation and interest, and 5)
low self-esteem. Cognitive impairment includes a number of problems with basic mental processes accompanying HF [24]. Problems can occur in several domains including attention, visual-spatial memory, visual-spatial intelligence, verbal attainment, memory and executive functions. There are differences between HF patients as to whether or not they develop any cognitive problems, or whether they acquire some problems but lack others. Some might even come through without any problems. There is also a problem of low levels and subtle cognitive impairment, problems that are hard to discover but still affect the abilities of the patient.

4. Analysis from a HF patient learning process perspective

4.1. Understanding

The understanding phase seems central to HF patients, especially from a motivation and attention point of view. In order to be able to learn about something a basic frame of understanding of it is necessary. To see the big picture and the long-term outlook for the future is important to preparing and sustaining new life-changing programs of action. Problems are well documented in that all too many patients have low awareness or even non-awareness of their sickness. At the same time it does not seem to be exactly a direct lack of facts that have been pushed onto patients, but rather problems of motivating them to take the time and effort to build a personal understanding. Personal contacts from health care personnel by telephone calls seem, however, to be a success factor. Constant reminders and a one-on-one care attitude from care personnel are also important. It should be possible to make use of personalized information systems that keep reminding people of the basics of HF and the importance of patient activities. It is possible to include background facts, for example specific drugs, doses, effects and side effects, diet restriction (personal fluid intake with individual context factors such as weather or physical activity, due to malnutrition or weight reduction, for instance), individual exercise recommendations, etc. Overall, many of the problems of low HF patient adherence seem to stem from this phase of the learning process, and it is naturally hard to achieve any real commitment for the following steps if the basic understanding falters.

From a learning perspective, people need a basic mental frame which directs attention to a cognitive level and enables the patient to even start taking in information on a subject. The frame consists of a context of facts, values and emotions that people use when they relate to an incoming new fact in order to make sense of it [25]. People need knowledge to be able to learn more of the subject, and this first phase is a form of bootstrapping exercise that has to be successful. Trust is an important factor to get this process going. To start building a person’s mental frame typologies and labelling are often used. These might be crude and simplified but are needed for the person to set off in the right direction [26]. The desired frame of mind is one where, given the basic restrictions and problems associated with the diagnosis, the patient, by acting in a proper way, can achieve a decent everyday life. This is the key factor to the understanding phase, which could be spelled out as creating a frame of mind for learning and acting as an HF patient.

However, there is more to this picture. The life-long and often irreversible nature of HF seems to discourage people from thinking about their condition. To forget about it and live “normally” is of course desired, as the constant reminder of bad future outlooks in itself drags the perceived life quality down. Self-identification and self-perception are important aspects in this phase. To become a person with a weak heart who always needs to consider this in actions and life choices is not desirable, but for many it is necessary. Framing the self-understanding into a situation of control is important, because otherwise the path is open to resignation, learned helplessness and apathy.

4.2. Facts and measuring

There are a number of important everyday facts that a HF patient needs to keep track of, many of which can already be supported by using a smart phone. Guidelines [27] prescribe that HF patients should record weight, drug and fluid intake, monitor signs and symptoms (typically, breathlessness, fatigue, ankle swelling, orthopnoea and reduced exercise tolerance), drug effects and side effects, physical activity and food intake
(malnutrition/weight reduction) and recognize depression symptoms. Facts could be recorded from day to day, either automatically or manually by the user. All of these are important for monitoring and providing information for further planning, decision-making and action. These should also be used to reinforce the basic understanding of the general HF diagnosis and what it means for the patient. Many of these support systems probably exist today in one form or another; however, neither the coordination of different measures in the same application nor the integration into a coherent learning environment is easily found. The facts and data gathered during measuring activities must also be stored and prepared for future analysis and presentation. This could involve local databases or maybe a centralized storage where these facts could be shared with the health-care system. Analyses of the material with the help of graphics and warning signals also constitute a part of this aspect by alerting the patient. The measurements that have been recorded by the health professionals should also be accessible to the patient. Presenting figures is easy by means of IT, but the design and intended ways of use must consider the basic conditions that a HF patient lives under, so that they actually function as support and do not drag people down or scare them away. Having information and facts presented as patients’ own experience should help the learning process and the understanding of cause and effects.

4.3. Planning

Planning seems to be an area that has not been focused on very much. Planning is the formation of possible future action, which should be compared and selected in the further decision-making process. Plans for how to conduct care activities appear to be relatively standardized. In general, planning and decision-making seem to be rationalized into handing out standardized sheets of paper describing what to do for the patient when the self-care phase starts. Much of the personalized part comes out of the personal meeting between patient and caregiver. At the early stages it may just be enough to set up a plan whereby the patient gets familiar with the tools and tries to achieve an understanding of the new condition. New IT-based systems could be used to promote the individualization of planning processes, making this process more “patient-centred”. In patient-centred care, planning should be a shared activity within the care dyad (care givers, relatives and patient).

It is important to note that this phase should not be too integrated with decision-making; it should be open to exploring possibilities and finding new perspectives. During the planning it is good to really explore possibilities without too many restraints, not to try to solve problems directly, but to open up the situation and apply a fresh broad view of the whole situation.

4.4. Decision-making

From a theoretical perspective, a decision is an irreversible commitment of resources; basically, it is the consumption of resources. For an HF patient a choice is a commitment to act according to a chosen plan. But when is the decision really made: when things are purchased, a new scale, a gym card, healthier food etc., or when the shoes are used or the food consumed? In the end, decision and action will merge if we follow the resource consumption line of thought. Here the decision would be the commitment of the patient to a program of action. Two types of support can be imagined. First, help with the selection of a set of actions (a choice between one of the possible sets of action explored and specified in the planning phase). For this situation, a comparison between different paths of action and their expected outcomes could be a good form of support system. Support is needed for the patient to better understand the desired goals. Uncovering the real needs among possible goals can be difficult. Generally, there are many types of decision-making traps that have been recorded [28], which can be helped by creating systematic decision processes supported by IT. For example, the order of the alternatives presented will favour the latest one, one of many points that can be avoided by a good support system design. In practical terms, the support could, for example, consist of a list of addresses or telephone numbers, sets of recipes or downloadable training programs. There is also a contingency perspective on decision-making, that is, how the patient should deal with emerging problems.
This type of day-to-day decision-making and the ability to adjust the plan to new circumstances are problematic and hard to support. Patients will face the problem of keeping to their standard action or breaking out of the plan or, even worse, how to face unknown situations or physical conditions. When it comes to making decisions and taking actions, the patient must be able to rely on the understanding of the cause and the effects of different possibilities in order to solve upcoming, unplanned situations. Situations like changing symptoms, travelling, missing taking pills, sudden weight gain, different social activities, and fluid intake etc., change the original plan.

4.5. Care action and motivation

Nothing can improve until the patient actually performs certain things, or abstains from doing other things. To begin with, the patient just plans to do things. When the choice has been made, support for the implementation process is needed. Such support could, for example, be the scheduling of activities, booking times with experts, buying the necessary items, training the use of equipment, or food preparation; in essence, it could be anything needed to make the patient committed to action. The adherence to or compliance with decisions and plans is a really hard part of this process. From a learning perspective, this is the process where personal knowledge is actually achieved, as learning comes from doing things. Systems for reminders and follow-up can be easily designed and devised. Systems for quick help when the patient stands ready to do something, which at the time of instruction or with help from experts seemed simple, could be important. Practice and repetition build habits and expertise, and by trial and error patients will become experts on their own care, as far as it is practical. This is a process of building the tacit dimension of personal knowledge that effectively comprises personality and identity building. This is a process with two faces as, on the one hand, the patient needs to automatically do the necessary things prescribed in order to gain a workable future. On the other hand, there is a wish for not becoming a victim and being labelled as a person with HF with all the limitations and stigmatization that this might entail. Providing care that develops and maximizes the well-being and health of patients with a heart failure is a major challenge. Health care staff can do much to facilitate this process by increasing the understanding of what it will mean for patients to live with a chronic disease, how it will affect their lives and relationships, and by promoting well-being and personal development. To get people with a chronic disease to change their lifestyle and behaviour is very complicated. It is important to try to identify when and how each individual has the greatest potential to succeed in making lifestyle changes and not just believe that it is enough to explain the pathophysiological processes or the usefulness of medications. This dimension of support could take the form of social community building and different forms of social media.

4.6. Records and evaluations

This phase looks at the general information systems and at how the learning process fits into that picture. There is a wide range of health care systems which a learning process can use or be useful for. There are many questions, for example about how the micro system can feed information into these larger systems and how the larger hospital-wide system can be used for the benefit of the patient. There could, for example, exist possibilities to make direct connections to quality clinical registers. This data could be used by the patient to compare personal data with others. Patients and patient groups could also have suggestions about which data would be beneficial for them to monitor as a group, such which may not have a direct medical or clinical value for health professionals. Records can be used as an active part of the care process. The records of monitoring symptoms and improvement records need to be accompanied with descriptions of the situation and of what happened, in order to be able to learn from the situation. The actual writing can, by itself, be a help to start reflecting. This would be a process of trying to understand different patterns in the data or situations and make sense of them. It will also be a way to help patients and relatives to remember and tell the health-related story during the physical meetings with their caregiver. This story will be a health diary/blog, which may be shared with relatives, family or friends. One interesting project could be to make an inventory of what
possible use could be made of general health care systems, and the facts and statistics from past history that they contain. There can be many possible uses of health care information systems, but a careful planning of how to use them is needed. For example, a seemingly simple idea like having easy access to a journal in a personalized patient portal would anyway require some thinking before it becomes effective from a learning perspective. The reverse direction of data is probably even more complicated, that is, how to feed personal data into centralized systems, for the purpose of building statistically significant databases. There are many problems associated with this scenario, but viewed from an IT perspective, there are many possibilities.

4.7. The patient-care giver meeting

The face-to-face meeting plays a central role in the learning process. Many of the activities mentioned above are discussed and framed at this meeting. The face-to-face situation endows what is discussed with a higher feeling of reality and importance to make it into self-evident truths (cf. Berger and Luckmann, 1966). The problem of using IT solutions in this process might occur if they reduce the actual contact. Careful attention must be paid to how any type of IT solution changes the effectiveness of this meeting. On a positive note, we should look for ways of extending the feeling of direct contact between patient and care-giver. Being in the presence of an authority while making important decisions and later having to act in solitude are problematic aspects of this general process. Adherence is a central theme in the contact between care-giver and patient. The examples from the HF area, as related above, show that as long as there is a direct contact, the patient seems to act according to plan. The general idea of PCC is changing the role that the patient takes. This is also an important theme in this review of the HF area, as the outcome of the care process relies on what the patient actually can achieve when left alone.

5. Planning IT support for learning in HF Care

Patient learning is a central part of HF care. However, when comparing the theory of teaching with knowledge transfer in general, there seems not to exist any learning framework that is used as an organizing principle. The “experiential learning” model could be one example of what this might mean. This would provide a full learning cycle that ends with a patient that has both a personal/tacit knowledge of being a person with HF and an explicit knowledge of what HF is and how it should be treated. This cycle points to the difficulties that come with tacit and personal knowledge. This aspect of human knowledge refers to a state of mind where central actions required for successful care are internalized and personalized. This could very well be the outcome of such a learning process, but special attention must be given to the transfer of knowledge on this level. This is a process of personal knowledge creation, which means actually being able to perform the right actions without extra instruction or help. Although these issues are central to a learning process, we also need to see this complex of problems from a broader perspective. There is a whole range of aspects that must be discussed and dealt with. The findings from the analysis can be organized in the learning perspective / learning level matrix. In Table 1 below we have summarized in a matrix some key problems and possibilities for the design of learning processes and support technologies. The items expressed in the matrix should only be seen as a snapshot example of how it could work for identifying problems and possibilities. On the individual level, we view the two central actors in care – the patient and the health professional. At the group level, we find the dyad of care – with patient and the health profession, the total group of different health professions involved and the patient with relatives/family. At the organizational level are the health care organizations (including insurance, pharmacy and service organizations) and here we also include the patient organizational context and community.
Table 1: Learning levels and perspectives matrix applied on the HF area.

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<td>- Individual</td>
<td>* Information and fact-based teaching versus personal knowledge, taking the tacit knowing and emotional aspect into consideration.</td>
<td>* Supporting motivation and creating a will to succeed, in a context and interaction with others.</td>
<td>* Promoting a feeling of being in a position of power as a patient accesses and uses knowledge; making decisions and acting.</td>
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<td>- Patient</td>
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<td>- Health professions</td>
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6. Concluding discussions

In this paper we have looked at a HF patient as a potential user of IS/IT support systems. We have studied the conditions of these patients. The outcome points towards a number of opportunities, but also towards a number of challenges. There is a problem when the ability to learn is degraded by the HF condition. The diminishing mental faculties, which might be a reason in itself to use IT support, also make it harder to actually use the support. Declining faculties might cause the patient to become less and less capable to process information and make decisions. In general, these perspectives have to be kept in mind when looking at all possibilities with IT. With a slow and gradual decline of faculties it can be hard to tell when and how much support is needed. On the other hand, to feel that people are nagging and pointing fingers in a do-this-do-that manner might be humiliating for patients who have a hard time reconciling themselves to feeling their faculties slipping away. The problem is the conflict built into the patient’s learning situation. The patient is in a quite stressful situation and may not really be in a rational mind set, whereas the current view of teaching assumes a rational actor. Even if patients do commit themselves to the actions decided and planned, there is the matter of actually getting down to doing the right things. While this analysis focuses on the possibilities of IT, it should also be remembered that IT does not solve problems, but just aid to some degree. There is a balance between IT solutions and learning as creating personal knowledge, which is natural and becomes a part of life. This is the tacit dimension of a person’s knowledge, which is gained only through being active and through engaging attentively in problems. Putting too much trust in a support system might detract from the active attention needed to create this type of knowledge that is in the long run more effective and desirable.

Future empirical studies are planned for, containing interviews with HF patients, as a base for further exploration of this planning framework. The planning matrix is now populated with possibilities and challenges for information system support from a patient learning point of view. It is probably rather easy to imagine a number of current technologies that could be used as support systems, however these investigations are planned for in future research projects.

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