Towards a Decision Support Personalised Self Management System for Chronic Conditions

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***Abstract*—People with long term health conditions often experience a radically reduced quality of life and suffer from a range of symptoms. Self management can encourage patients with a care support and reduce the burden of the costs of traditional face-to-face healthcare delivery. In this paper, we present a new approach to support selfmanagement for patients with long term conditions using assistive, rehabilitation and telecare technologies. A personalised self management system is proposed to effectively monitor, model and analyse relevant signs, symptoms and lifestyle consequences of long term conditions. Information on changes in chronic conditions will be fed back to the users in a meaningful and usable way and can be presented to patients to promote health behavior and to adjust life goals.**

I. Introduction

CHRONIC health conditions are those that a person has over an extended period of time, or for life. In the UK, 17.5 million adults may be living with a chronic disease (e.g. arthritis, respiratory disease, cardiovascular disease, multiple sclerosis, stroke, emphysema and congestive heart failure) and WHO data indicates this is a global issue, with 75% of the total population having one chronic condition [1]. People with long term health conditions often experience a radically reduced quality of life and suffer from a range of symptoms such as pain, fatigue, physical limitations and disability, anxiety and depression. Chronic ill health frequently results in unemployment, social withdrawal, fears over an uncertain future and an increasing dependence upon health and social care services. Consequently, the treatment and care of people with long term conditions consumes a large, and potentially unsustainable, proportion of health and social care resources [1].

Living with a long term condition involves a number of challenges; first, achieving an understanding of the condition and participating in the agreed treatment and rehabilitative regimen (e.g. physical and occupational therapy). The intensity of clinical intervention is often greatest following diagnosis, but over time should be re-visited and tailored to changing needs. Aspirations, ambitions, goals and values are adjusted, to accommodate life with a long term condition [2]. Success in achieving such adjustment is thought to be critical to retaining quality of life. Acceptance and emotional adaptation requires on-going support, such as access to reliable, relevant information [3]. Concerns regarding the increasing prevalence of long term conditions, the severity and complexity of patient need, the rising costs of traditional face-to-face healthcare delivery and a philosophical move towards promoting self reliance and patient empowerment have led to the introduction of self management initiatives in many countries.

Self management involves encouraging the person with a long term condition to solve problems, take decisions, locate and use resources, identify an action plan and take action to manage their condition [2]. People living with chronic conditions know best how to manage their conditions, but a good self management can only be achieved by a good self care support.

In this paper, we present a new approach to support self management for chronic conditions using assistive, rehabilitation and telecare technologies. A personalised self-management system (PSMS) is proposed to monitor patients activities unobtrusively using sensor technologies, and the information on changes in chronic conditions can be collated and fed back to users in a meaningful and usable way to help them understand their condition. Via telecommunication, such information, remote from a medical/care practitioner, can be presented to promote health behaviour change; and how this can allow people to adjust life goals to accommodate and aid acceptance of their condition.

The remainder of this paper is organized as follows. Section II presents the related research. Section III describes the research methodology with the proposed PSMS, followed by description of work in monitoring upper limb movements in Section III. Section IV the presents a summary and discussion of challenges and future research.

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II. Related Research

In the United States, the form of self management is being integrated within a managed care framework [5]. In the United Kingdom self management is central to the Government's long term conditions agenda. This is comprised of the related principles of *patient choice, care tailored to individual, independent living, community engagement* and *inter-agency partnership working*, exemplified by The Expert Patient Programme [6]. However, it is only relatively recently that consideration has been given to other services, and in particular home or community located technologies that might be developed to assist the person with the tasks involved in managing their own condition [7] –[9].

In recent years, a new research area of interactive computing technologies for self management of long term conditions has emerged [10], [11]. A prominent example is from the USA, where a company is marketing a "health buddy" system capable of providing feedback to users with chronic health conditions [12]. However, in this system, feedback is restricted to information on vital signs to the user and professional, and supporting research evidence for the system is not accessible. In the UK, computerized cognitive behaviour therapy (cCBT) is now available to assist therapists and offer patients more choice following a national framework agreement[13]. The SAPHE project for example considered how technology can be used to detect *deteriorating health in individuals, with the focus being upon* the technological system [14].

III. Methodology

A. Conditions

Our research focuses upon three very different conditions, namely *stroke*, *chronic pain* and *congestive heart failure (CHF).*

1) Stroke: People who have a stroke were often fit and well beforehand. Stroke can leave the person suddenly physically disabled. It can also result in communication problems. Treatment and rehabilitation can continue for a long time to help recover mobility and ability to communicate. Sometimes the person can be left with a permanent disability, which they and their family will have to adjust to living with.

2) Chronic pain: This is a symptom of many long term illnesses and leads to very poor quality of life for sufferers. Over time, people with chronic pain and those for whom chronic pain is the primary complaint tend to do less and become more upset by their condition. Treatment called cognitive behavioural therapy (CBT) can help people to manage the negative consequences of pain.

3) Heart failure: Heart failure means that the heart does not pump enough blood to meet the needs of the body. People with heart failure are restricted in what they can do and often have to go into hospital if their condition suddenly gets worse.

These three conditions are among the top five most common in the UK, with services struggling to meet demand for treatment and rehabilitation. Prevalence of chronic pain is up to 46% with 8% reporting severe disability [16]. Even though CBT is an effective treatment for chronic pain, less than 20% of people have access [17]. There are approximately 100,000 new episodes of stroke in the UK each year making it a leading cause of disability [18]. The National Sentinel Stroke Audit of 2002 reported that 64% of stroke survivors were unable to access specialist stroke rehabilitation [19]. The 2006 audit showed that this has improved in secondary care but not in primary care, where only 22% of Trusts have specialist stroke teams to support rehabilitation after discharge home [20]. CHF affects 1% of the population and 10% at 70 years of age [21]. Up to 50% of hospital admissions for CHF could be prevented if individuals comply with necessary medication and undertake self-monitoring, self-care and lifestyle modification strategies [21].

We have chosen conditions with different intervention models: chronic pain for which the therapeutic goals are largely *accommodative*; stroke for which the therapeutic goals are largely *restorative* and CHF for which the therapeutic goals are largely *preventative.* The activity monitoring for these three conditions are timing of activities of daily living; gross motor activity / wrist sensor for upper limb activity and bed sensor for sleep monitoring; and gross motor activity / sleep patterns / activities of daily living with the measurement of weight, blood pressure and heart rate respectively.

This enables us to compare not only the different users' needs but also establish whether technologies can be used to enable the self management of different intervention models.

For all three conditions the therapeutic regimen is underpinned by a need for the individual to change their behaviour and maintain those changes in the long term. Therefore, any assistive technological solution has to be positioned within a context of therapeutically guided behaviour change. For people with chronic pain, guidance with activity pacing and habit reversal is frequently identified as being necessary [22]. Following stroke, therapeutic aims are focused on maintaining and improving physical activity and function. Management of CHF is largely by drug therapies but also, increasingly, through self monitoring, and lifestyle modification strategies. However, without support, compliance with both drug therapy and self-care strategies can be problematic, leading to clinical instability and worsening heart failure [23]. Currently, people with all three conditions have limited access to assistance to help them to make the necessary changes to behaviour in order to accommodate their condition, promote continued recovery

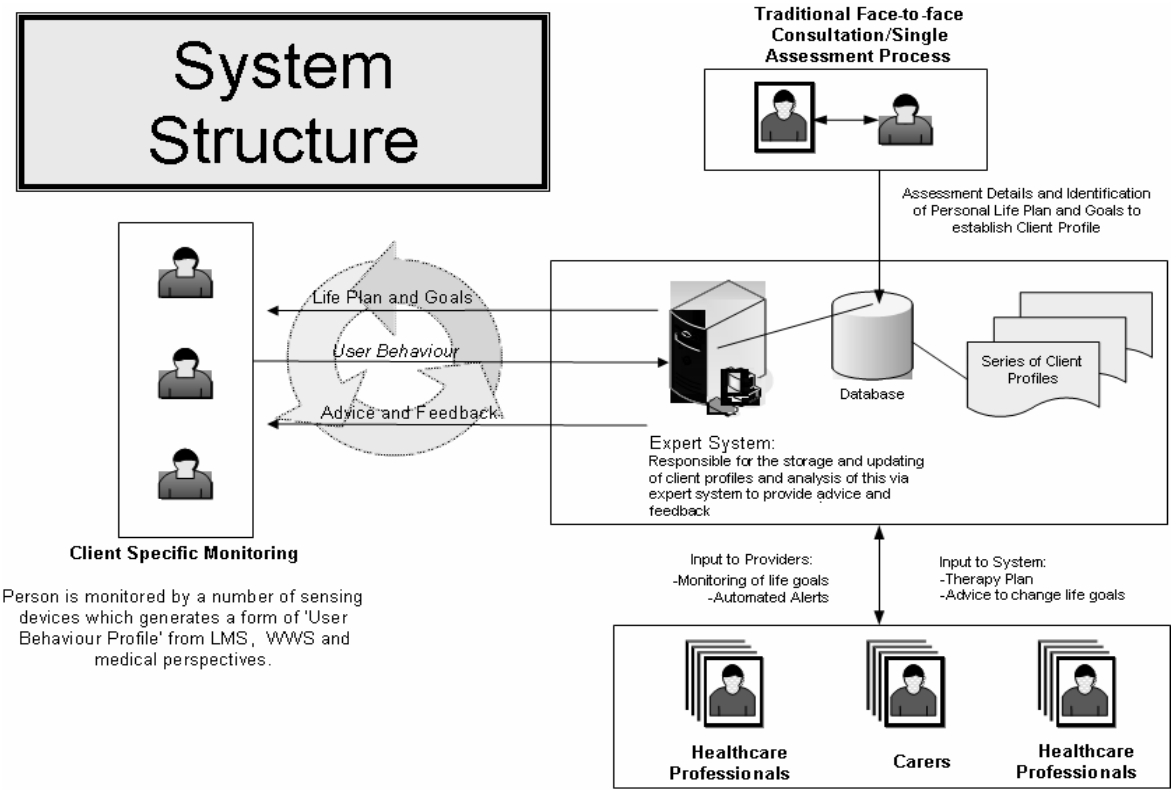

Figure 1 PSMS System Structure

where possible and/or prevent deterioration.

B. PSMS System Structure

The proposed PSMS system, illustrated in Figure 1, consists of four main components, namely client specific monitoring, decision support expert system, patients database and telecommunication. Patients with long term conditions are monitored by a number of sensing devices such as accelerometers for monitor patients limb activities; bed sensors for sleeping measurement, all the information monitored is used to generate a user profile for each patient, together with other information provided by therapists, such as personal life goal, care plan and medical perspectives. The series of user profiles are stored in the database. And an expert system running on the sever analyses each profile and provides advice and feedback to the users, monitor the life goal and send alert when necessary. The communication component provides the facility for the therapists and health carers to access the system from remote to review the care plan, and to advice the change of life goal.

The PSMS provides information on progress with the therapy/ management plan to the user and to health and social care professionals through the Internet/ digital TV. As well as giving information, this will help the person to identify the need for changes to their plan and will help with the emotional consequences of the condition without the need for a professional to be present.

IV. MONITORING OF UPPER LIMB MOVEMENT

Research has been carried out to monitor upper limb movements for stroke patient at home rehabilitation [24]. Two MT9 motion sensors are used to track patients movement during the rehabilitation exercises (Figure 2). One is placed on the wrist and the other one is attached on the elbow. An MT9 sensor consists of a three axis accelerometer, a three axis gyroscope, and a three axis magnetic field sensor, which can measure the movement information including position and rotation.

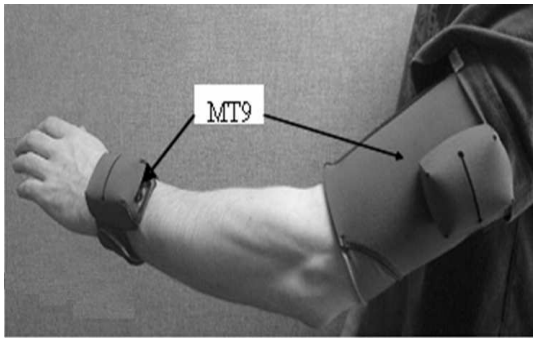

Figure 2 Upper limb motion monitoring

The position and rotation information of the arm is recorded and sent to the computer. The movement is rendered and presented to the patient by a 3-dimentional

visual feedback and other graphic forms of feedback. Figure 3 illustrates one patient movement *verse* the template in 3D models. Patients can observe his/her movement and compare it with the template movement to understand how to improve his/her rehabilitation exercise. Therapists can also review patients movement and according to patients progress to adjust the template.

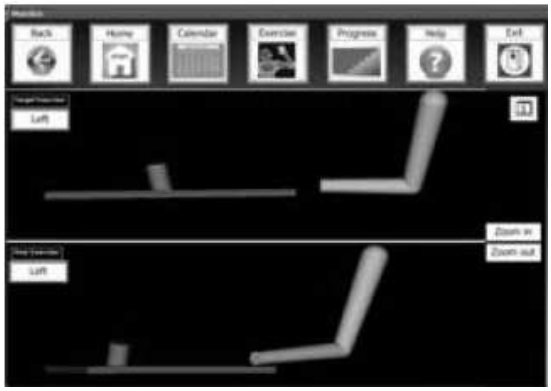

Figure 3 Comparison of one patient movement with the template in 3D models. Upper panel: template movement; lower panel: patient movement.

V. SUMMARY AND FUTURE WORK

The use of technology to support self management for patients living with chronic conditions is now attracting attention. In this paper we propose a personalised self management system for three long term conditions (stroke, chronic pain and chronic heart failure). Our research on monitoring rehabilitation movement for post-stroke patients [25] have demonstrated the feasibility of applying ICT on the support of long term home rehabilitation. But there are some fundamental issues that need to be researched. These include how information on changes in chronic conditions can be collated and fed back to users in a meaningful and usable way to help them to understand their condition; how such information, remote from a therapist can be presented to promote behaviour change and how this information can allow people to adjust life goals to accommodate and aid acceptance of their condition. All these deserve further investigation.

Future work will be carried out to investigate how technology can be used to construct tailored plans of interventions to be undertaken by an individual to meet identified needs; to identify how relevant signs, symptoms and lifestyle consequences of long term conditions can be effectively monitored, modelled and analysed; and to examine the extent to which behaviour change is promoted through personalised feedback, remote from a health care professional, but delivered within a tailored plan of intervention.

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