New Frontiers of People-Centered Integrated Care for Complex Chronic Disease

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Abstract

Objective: Heart failure is a chronic, progressive clinical syndrome with an unpredictable trajectory and difficult prognosis. In 2012, the Italian region of Friuli-Venezia Giulia was appointed pilot leader of a European-funded project for ICT-supported integrated care addressed to European frail citizens, to test the viability and evaluate the impact of health and social care integrated services through an extensive deployment program involving 23 European regions.

integrate motivation to enhance self-management with awareness of disease progression and fina acceptance of its terminal nature [15]. Moreover, the complexity of the disease and the presence of

interventions largely focus on the illness rather than on the person sufferin from such an illness.

SmartCare: European Union ICT-supported Integrated Care for European Citizens

Th European Union technology-supported health and social care infrastructures may be powerful tools for promoting change and improving the quality and efficien of care provided to patients and to their caregivers. In 2012, the Italian region of FVG became pilot leader of Smart Care, a European-funded project for ICT-supported integrated care addressed to European frail citizens, to test the viability and evaluate the impact of health and social care integrated services through an extensive deployment program involving 23 European regions. Th goal of the project is multifaceted and involves assessing impact of services, optimizing service provision, generating empirical and practical evidence to enhance integration of health, social and third-sector people-centred care, with a strong focus on independent living and domiciliary care.

In Italy, the Smart Care pilot project involves all Local Health Authorities within FVG and it includes 20 Healthcare Districts. It is t tt cia l'ci T_tc l' HanhipFVÏ/ er Fe. ↴ ! _!

Figure 1: Integrated Care Stakeholder's Recruitment and Short term – Long term Care delivery

Th District nurse will be in charge of completing the assessment by contacting all parties involved within the multidisciplinary team. Subsequentlo ntllsm

Users / Stakeholders	Role
End users (>50, min. 1 moderate-to-severe chronic condition (HF, diabetes mellitus, COPD)	End users (patients) are the main focus and the beneficiaries of the service. At home, they are provided with medical and environmental devices which automatically transmit data to the call center and care team. They can also autonomously communicate through the platform by means of journal entries, or directly to the Help Desk/Call Center staff through a 24/7 active 800 number.
End users‘ family members	They play an essential supporting role by monitoring patients’ parameters and meeting their healthcare and social care needs in real time within a predefined scope and to the full extent of their abilities. They have to be allowed to communicate at any given time with the patient’s case manager, or appointed person. They act as end users‘ caregivers.
Caregivers (cg)	They play an essential role by helping elderly users to measure those parameters which need to be monitored. If given right of access, they can communicate with healthcare/social care professionals. Oftentimes, such a role is played by the end user’s family members.
Third Sector	Volunteers who may either sistematically or from time to time play a supportive role in the end user’s care process. They may be neighbours or members of non-profit organizations, active citizenship’s organizations, etc.
Case Manager	The case manager plays an active monitoring and coordination role of the whole end user’s cure and care process. Oftentimes, such a role is being played by a district nurse, but it may be played by a physician (District/GP), or by a social worker. The functions related to such a role may be carried out either within the District or at the end user‘home.
Physicians (GPs and specialists))	They may access the system to provide decision-making support during the course of the disease. They may signal through the system any change in conditions that require intervention. GPs play a pivotal role in the end user’s clinical management and they may act as case managers. District physicians may play a clinical support and coordination role. One or more specialists (cardiologist, diabetologist, pneumologist) may be called to be part of the care team in complex cases.
Nurses	They are at the forefront of healthcare interventions. Their goal is to meet end users ‘care needs through domiciliary interventions. A nurse may be appointed as end user’s case manager and become the ‘family’ nurse, acting as a link between the end user, his/her family and the rest of the team.
Social workers (SW)	They work for the Municipality and have to provide real time response to the needs signalled by end users. A social worker may be appointed as the end user’s case manager.
Staff from the Help Desk/Call Center:	They are in close constant contact with all the stakeholders and play a role in the randomization process, setting up of devices at end user’s home, alarm protocols, providing training and remote support to all the stakeholders involved in the integrated care process.

his acute cardiac event and is more motivated to look afte himself. He is eventually discharged from the Short-Term Hospital Discharge Pathway. Th multidisciplinary team assesses Paul's overall clinical and social situation and jointly decides to enrol Paul in the Long-Term Care Integrated Pathway.

Paul's perspective

Illness: 'First I was a man, someone who was not afraid of anything. Then all of a sudden I became a child again… not a happy child; a scared, vulnerable, weak child. It all started many years ago. BPCO, heart failure, diabetes, allergies, you name it. Several hospitalizations I slowly kept fading away. Now, I ofte see my wife and my children as if I were in a fis tank. I would like to do more, I would… But in some twisted way I cannot make myself do anything. My body has shut down and so has my mind.'

IT-based integrated care: 'When the nurse suggested I take part in the project, either in the intervention or control group, at firs I was reluctant. I was concerned about privacy, data protection, that sort of things. I was soon reassured; both my nurse and my doctor explained it clearly to me, and I started feeling excited about the potential. Now, I really believe that being enrolled was the best day in a long time, for me. I was a little bit afraid this would raise my anxiety and yet, I wanted to know. Now I feel as if I can at least do something, be active in some way. I don't feel so passive anymore. I asked the smart Care staw to have me signed in on the platform. Training was easy for me, but I've always been working with computers. Taking my weight on a regular basis has always been difficul I'm very lazy… Now, I get on the scale more easily in the morning and I regularly take my BP. Measurements are automatically sent to the platform, I don't have to do anything. Now I know that everybody knows and it's a good feeling. I could ask to be sent pill reminders but I have a very attentive wife and I don't think I need any further help, for the time being. I guess that being able to keep a watch on you makes it easier to actually do the right things for your life and health. I know I'm very sick; I will never be whole again. However, technology has given me back some of the dignity and self-esteem that the disease had stolen away.'

Caregiver's perspective (wife)

for appointments on the platform which I feel can be very useful for everybody. When you are so sick there are many people you need to see; it's a good thing to have a shared schedule so as not to overlap interventions. I feel that the system can help all of us to work more efficient and to feel more like a real integrated team. And it's very good to have active patients and caregivers. It makes work in such a delicate fiel even more enriching, both as professionals and as human beings'.

Social care professional's perspective

Illness: 'Paul's history dates back to several years ago, unfortunately. He has a severe, terminal illness which has disrupted the whole family, taking a heavy toll on his wife and their children. In fact, we, as a Municipality, have been providing support for his children with afte school care and activities'.

ICT-based integrated care: 'Social care is an integral part of District care interventions. However, communication is not always easy and updated. Ther are many phone calls, and plenty of paper that can be lost or simply skip somebody's attention. ICT-based integrated care is providing a common ground where updates to the initial care plan can be shared quickly and with no glitches or risks of misinterpretation. In Paul's case, afte overall assessment, it was decided to set up environmental sensors in his home (temperature, water leaks and smoke detection); a fall sensor was also provided to detect sudden changes in movement and automatically send an alarm to the Call Centre. Video-monitoring was ruled out, since Paul lives in an accessible area of town and does not feel comfortable sharing too much of his private life with carers. Should the situation suddenly change, social services would be immediately alerted and could intervene within a very short period of time to maximize benefit of intervention and minimize burden on end user and his family'.

Comments and Conclusion

While it is too early to draw fina conclusions, the initial evidence shows that integrated ICT-supported care may successfully complement complex chronic care pathways by providing tailor-made eCare multidisciplinary home-based interventions for complex cardiac patients. However, an in-depth quanti/qualitative data analysis will have to be carried out to understand whether the benefit in terms of work overload and economic costs are such as to allow for costly technical and organizational choices. Structuring of supportive pathways and tailor-made interventions needs to build on actual integrated team work experience and requires time and leadership: a common vision needs to be shared by physicians (notably GPs), nurses and social care professionals alike. GPs' roles, responsibilities and economic incentives need to be clearly define in order to make integration viable and sustainable in the long run. In fact, while participation of nurses and physicians has been satisfactory, many GPs have chosen to play a standby role which would have to turn into more active participation in case of actual large scale implementation of the platform. Nurses may play an important role in the coordination and monitoring of services, but workloads and responsibilities require clear definitio and assessment. Training and education of formal and informal stakeholders need to be carefully planned and steadily monitored to maintain retention and support empowerment. Also, while training within the Smart Care Project has been co-led by nurses (together with the technical staff) the question arises whether in the future nurses will be able to bear the burden of patient's training.

Th platform's flexibilit bids well for the future; however, it still remains to be seen whether there will be the willingness and capability to interface it with other systems, devices, and registries to make regional integration complete. Cost-benefi analysis of telecare/ telemedicine programs need to be implemented and results shared, because no structural and/or organizational restructuring may be long-lived without economic sustainability. If successful, the project may reconcile the cure and care aspects of clinical and social domains, fostering inter and intra team communication while tightening and strengthening social networks and support. Also, it may further validate and strengthen nurses' roles in bridging the gap among formal and informal stakeholders through their front line interventions both at clinical and educational level. Given the complicated treatment regimens of HF patients, integrated teams of health and social care professionals should be engaged in collaborative programs, as already happens in oncology [35]. However, technology alone cannot meet the complex, multidimensional needs of frail patients [36]. Hence, integrated ICT-supported care should enhance the subjective and individual quality of IT-supported health and social care interventions which cannot and should not replace personal and social interactions. Persons with long-term conditions, complex clinical and social needs, and terminal illness require simultaneous access to differen services. Intra-organisational integration is of paramount importance and each and every stakeholder's efficien and effectivenes of service needs to

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