Contemporary Developments

14

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Contents

14.1 Learning Objectives

- Explore how to plan care to support the person's resources
- Understand how various telecare solutions require different cognitive interactions
- Appreciate why older people should be involved in designing their own care solutions

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14.2 Introduction

When focusing on the contemporary developments in today's services for older people it is necessary to pay attention to the resources possessed by today's older generation. People live longer and are healthier and more socially active than previously [1]. However, a general feature is often to present older people as being solely dependent passive receivers of care. The biological changes due to age differ widely and decrease in physical and mental capacity are only loosely associated with a person's age in years [2]. Many older people have unused resources and given the right opportunities they may make better use of these to increase their quality of life [3]. Remaining and living safely in one's own home is not only the policy in several governments, it is the goal of older people in general as it may support them with healthy ageing [4, 5]. To understand the best way to enable older people to remain at home their voice must receive attention, as it is the fundamental aspect of all health and social care: the persons in question are the experts of their own lives.

The demographic prospects forecast a rise in the gap between health service providers and those in need for their services and thus this entails a transfer of more responsibilities to the relatives. Relatives often provide different kinds of assistance to older persons, however, regarding relatives as "carers" might conceal kinship and cause confusion of roles [1]. In this chapter, the term *relative* is thus preferred instead of *carer* even if the relative has an additional role as carer for the older person. Relatives account for many hours of (often unpaid) assistance and their contribution is essential for sustaining the care services.

Healthcare services are transforming from being institutional care to becoming more based on home care, and technology offers possibilities at home that are otherwise difficult to achieve [3, 6]. Several research projects emphasise how correctly adjusted telecare improve older people's abilities to remain safe in their own home for longer [3, 7, 8]. Different terms appear in research regarding the use of technology in care settings and the ambiguity in terms complicates comparisons and reviewing [8, 9]. By using technology an older person may first and foremost rely on their own physical and cognitive resources instead of relying on assistance [10]. However, implementing technology in care might challenge how health and social care professionals work. I will address these topics by using examples and findings from a recent telecare project conducted in Norway [9].

Reflective Question
What is your understanding of telecare and assistive technologies? If at all—how do you differentiate between these terms?

14.3 Telecare: A Necessary Competence Within Contemporary Care

People live longer and despite many experiencing significant deterioration in health, a large number have little change in their physical and mental capacities [2]. Treating people as a homogeneous group tends to mask differences [11] while the varieties in older people's functioning are increasing and thus the diversity in their perceived needs is expected to expand [2].

Technology to enable older people to manage everyday life autonomously is receiving increased attention from researchers and policymakers [6]. In this chapter I use telecare as defined by the Department of Health (United Kingdom) [12]:

> Personal and environmental sensors in the home that enable people to remain safe and independent in their own home for longer. 24 hour monitoring ensures that, should an event occur, the information is acted upon immediately and the most appropriate response put in train.

This perspective on technology, named telecare, emphasises how the person *is not required to interact*, and thus offers different possibilities and challenges from technologies that entail interaction. One well-known device that requires interaction is the social alarm, which has a button that the users must push to alert when they need assistance. To activate the social alarm you must (1) understand the concept of pushing the button for it to alert, (2) you must consider yourself being in a situation to which you need assistance, and (3) you must have the social alarm within reach when you need it. Nurses report how older people frequently do not use the social alarm due to missing one or more of these requirements [9].

Contrary to social alarms that require the persons themselves to assess a situation when it occurs, telecare requires that the conditions have been assessed in forehand. Each situation needs thorough assessment by a nurse or therapist in close cooperation with the persons that are to receive telecare in their home, and their relatives. Telecare consists typically of various sensors that are wireless connected to a home unit. One sensor might have different functions from another similar sensor as they might require different response. In one situation, a movement or pressure sensor may cause the lights to turn on, in another to turn them off.

Older people appear to be reluctant to display their lack of cooping as they want to refrain from burdening others [13]. In general, they want to remain living in their own home [4, 5, 9, 14]; however, they prioritise safety to independence [15]. Many fear becoming a burden to others (relatives) if they do not comply with well-meant suggestions of moving to an institution when their safety is at risk.

To demonstrate the importance of remaining at home, I will use examples from a resent telecare project where service users, relatives and service providers give voice to what is important for them in their everyday lives. The following cases and solutions are constructed from several actual experiences from my research [9]:

Case 1: Living an Independent Life at Risk

Olivia is 88 years old and loves to be independent and mobile. She is a widow of 20 years and is proud to manage on her own. Olivia goes by bus to the nearby village where she does her shopping, sees her GP and joins in several activities and enjoys the company of her friends. She has a variety of medical conditions among these are diabetes, a minor heart condition and dizziness. Her main concern is the dizziness that occurs when she changes position from lying to standing, especially at night when she has to visit the bathroom. Olivia has no problems with managing her medication. She lives in her own house where she has lived since they were married 65 years ago. The ground floor contains the entrance, the kitchen and the living room, while her bedroom and the bathroom are on the second floor. She therefore must use the stairs several times a day. "*The stairs keep me fit as a fiddle*", she says. According to Olivia the stairs seldom cause any trouble; however, due to a couple of incidents where she fell and injured herself, her daughter Sandra holds a different opinion. "*She fell on the stairs last winter when she came back from the village. Fortunately, I came shortly after but that was sheer coincidence. What might have happened if I hadn't come? She was not able to get up or to move*".

Olivia receives no help from community care and she reject any offer of help. "*I have always managed by myself and I enjoy being able to rise, eat and shower according to my own schedule and not following that of others*". Olivia and Sandra speak on the phone every night before bedtime but Sandra is worried, as she is aware of her mother's dizziness and knows that she needs to negotiate the steep stairs to go to bed and also to use the bathroom a couple of times during the night. Sandra respects and understands Olivia's decision to remain living in her home but still discusses the advantages of moving to a care centre. The situation now threatens their relationship; Olivia feels that her way of life has become a burden to her daughter, which she in turn feels increasingly burdening and as a result is diminishing her joy of living independently.

The above situation illustrates how many older people experience that their wish to continue living autonomously in their own home, may challenge their relatives' peace of mind. Thus, the older person might refrain from being open about difficulties as they seek to avoid provoking further discussions about moving. Several of my interviewees emphasised how they valued being autonomous and planning their days and life according to their own preferences [9].

The relatives in my interviews usually had caring obligations in various ways; however, they regarded themselves as daughters and sons and not as carers, as did their parents. For further reading: Judith Phillips [1] comprehensively discusses the mix up of roles between relatives being carers.

In the above case, Olivia risks losing her home and her life as she knows it if she wants to remain in a good relationship with her daughter. Sandra hates herself for imposing her worries on her mother and dislikes having to encourage her to move. Mother and daughter realise that their ongoing discussion is far from fruitful and potentially leading to a deterioration in their relationship. They therefore agree to discuss the issue with the home care nurse, and they make an appointment for her to meet them in Olivia's house.

14.4 The Nursing Process in Telecare Assessment

When the community care nurse arrives, she listens attentively to both women aiming to understand and assess the situation from their diverse perspectives. Firstly, she emphasises how the activities in Olivia's everyday life improve her abilities to remain home and meticulously highlights her resources. Then she encourages Olivia to present her challenges. She includes both women in analysing the situation, they agree upon there being an issue with safety but that abandoning her home is too high a cost for Olivia. The nurse informs about telecare that is part of the new service offered by the community care team. She explains briefly the main functioning of the different sensors and gives them a pamphlet for further reading. Olivia is reluctant to be included as a service user despite wanting the safety that telecare offers. The nurse explains how the various sensors might go directly via the response centre to her relatives, for example to her daughter Sandra, without involving the community care. She does however advocate the benefits of including home care for safety reasons if the relatives are unable to respond. Likewise, she informs how Olivia may benefit from being included in the local government emergency plans in case of severe situations. She illustrates this by explaining how the local government maintains safety in situations caused by severe weather conditions that occur frequently during the winter season.

Together they discuss the situation and agree on Olivia's need being to maintain safety at home due to her risk of falling. The nurse suggests the following solutions: bed and chair sensors connected to light sensors, two movement sensors and smoke detector in both floors.

The bed sensor detects the presence or absence of pressure. Olivia usually needs 10–15 min when she visits the bathroom at night. They agree on the sensor alerting if she is away more than 30 min, as she occasionally needs some more time. They discuss which time the sensor should activate and agree on 11 pm, as Olivia usually prefers to go to bed between 10 and 11 pm. The bed sensor connects to a light that activates with absence of pressure. Thus, when Olivia leaves the bed, a light will turn on and help her to find her way and avoid stumbling. Should Olivia be absent from bed for more than 30 min the response centre is alerted and may contact her to further investigate the situation. This check includes negotiating with Olivia whether she needs assistance from Sandra who wishes to be summoned as she lives quite close. Olivia usually rises at 8 am in the morning but some nights she has trouble sleeping and goes downstairs to sit comfortably in her favourite chair. The nurse

assessed how the nights usually were; however, she paid particular attention to any irregularities, as these often cause false alerts. Therefore, she recommended an additional pressure sensor in Olivia's favourite chair. This sensor also connects to a light but in this situation, it turns the light on when pressure occurs as Olivia likes to knit when she cannot sleep and thus needs the light. They also agree on one movement sensor in the living room and one in the kitchen. These will alert when movement is not detected in any of the two rooms for 4 h during daytime. To enable this solution Olivia will have to inform the system if she leaves the house as well as when she returns. She therefore must deactivate the system when she leaves and activate it when she returns. Since Olivia has no cognitive problems, she expects no problems in including this into her habitual routines when leaving the house. Finally, the nurse suggests changing the smoke detectors to new ones integrated in the system that will alert directly to the fire department.

In addition, the nurse suggests that Olivia receives a social alarm that she can wear around her wrist or as a pendant around her neck and activate if a situation occurs or if she feels unsafe. Politely Olivia declined this offer, as she thinks herself sufficiently safeguarded with the less conspicuous sensors that are hidden under her mattress and under the chair cushion or appear like an ordinary intruder alarm. The smoke detectors are almost like her old ones. Sandra tried to argue for increased safety, but Olivia did not want to display that she needed extra support. She had seen the sensors as the nurse brought them when visiting, and Olivia was content that these sensors would not make her "feel old and frail" as this deviated from her self-image. The social alarm however did not comply with her self-image.

Olivia and her daughter received information and explanation when the nurse and the technician implemented the telecare service. Later there had to be some adjustments as Olivia often went to bed later than 11 pm. Both women were satisfied with the "false alarms" as they experienced it to demonstrate that the system was reliable. One year later, they were happy and Sandra had peace of mind as she said, "*If Mum needs assistance I know the system will alert because we had a few unintended alarms, which actually had a quite calming effect as I felt telecare proved to be reliable*".

Case 2: In Risk of Moving from the Known to the Unknown

Lisa is 90 years, a widow of more than 40 years, she has dementia and lives alone in her small semi-detached apartment. She has a small sheltered garden, which she accesses from her living room. She was in a nursing home for 6 weeks after a hip fracture and both she and her family (two sons and a daughter) were unhappy with that solution. Lisa has a heartfelt desire to remain in her little home where she enjoys gardening and pottering about seeing to everything and nothing. Lisa has problems with taking care of herself, and her family understands that she cannot be left all alone. She refuses to let anybody clean her house and do her laundry. However, she allows a few nurses to assist her when showering, nevertheless reluctantly.

Lisa accepts to attend the day care centre as she meets some old childhood friends there. She has dinner when she is there and appears to join in with her friends. Recently, the neighbours have expressed their worry as they have observed Lisa outdoors in her slippers late in the evening. The family feel they are in a desperate situation, as they have to choose between two hopeless situations, forcing Lisa to move or leave her at home exposed to hazards. Relying on the neighbours observations, the family fears that Lisa leaves her home during night and gets lost and/or harms herself. Both situations, forcing Lisa to move or leave her on her own at home, will cause misery to all involved.

The relatives discuss the situation with the nurse without including their mother. Together with the nurse, they conclude that the main objective is that Lisa is happy without being exposed to hazards. Documentation from the previous stay in the nursing home and the relatives' descriptions of the changes in Lisa's mood and behaviour give the nurse data to help in her assessment of the situation. She explains the change in policy to help people remain in their home and emphasise that they might try to include telecare in the services for a while before admitting Lisa to nursing home.

Together the nurse and the relatives agree that Lisa will receive home care to help her wash and get dressed every morning. They will make an effort to keep the number of different nurses visiting her to a minimum and try to use the few nurses Lisa accepts when helping her showering. They will increase her number of days at the day care centre from two to three and provide breakfast and dinner while she is there. The family will do her shopping and laundry and the cleaner will come once a week when Lisa attends the day care centre. In addition, the relatives want to have door sensors installed. These will alert if Lisa leaves home during evening or night. If Lisa opens the main door just to peek out while remaining indoors, she will not set off any alarm as a movement sensor overrules the door sensor. However, if she leaves the premises the home care services will be notified. They agreed on a "silent alarm", which means that there will not be any sound to scare Lisa. The alarm summons the home care team. An important consideration when using a silent alarm is how to explain your arrival as a response to the alarm as the person (with dementia) will not be aware of any alarm, and might worry. The home care team are there to assist him/her, which is a plausible reason to give. Lisa's relatives would also use a movement sensor that would alert if there were movement during night to document whether Lisa was restless during night. They agreed not to visit her during night but use that documentation to inform the nurse to make her more aware when visiting in the morning. The nurse explained the option to install a camera that could detect whether Lisa was in bed, had fallen, etc. by using blurred images combined with an alert. They discussed this possibility, but the relatives felt it being too obtrusive and wanted to try without.

Lisa remained home for almost a year with this solution. Telecare was adjusted according to minor changes and after a few months, the relatives agreed to include the camera to check on Lisa if the movement sensors showed activity during the night. The joint solution from community care and relatives gave Lisa the necessary help and telecare increased her safety, as she would receive assistance if necessary. The door sensor documented that Lisa never went out in the evening but remained home. She enjoyed her life at home but due to pneumonia, she was hospitalised and died. Her relatives were content with her being able to remain as autonomously for her last year.

14.5 What These Two Cases Demonstrate

These two cases show in different ways how contemporary nursing will need to cooperate with the persons themselves and their relatives in tailoring better individual support including community care and telecare. The nurse/therapist must carry out and manage the assessment according to the nursing process. The nurse/therapist will need to have a thorough understanding of how telecare works, what it does and what it does not do, as they will need to guide the implementation to individual resources and needs. As an example, Olivia receives a pressure sensor in her bed while Lisa does not. This sensor does not discriminate which pressure activates it, just that a pressure occurs. The nurse refrain from using the pressure sensor with Lisa, because she knows that people with dementia might choose a different place to sleep or have various changes in their sleep pattern. The contemporary nurse needs knowledge of technology in addition to their nursing skills and they must be able to help users and their relatives in finding the better solution to match their needs.

Ethical issues might arise when using telecare, and ethical considerations must be part of any assessment and every situation. General ethical issues that often arise as they also do in the above cases are:

- Who benefit from the telecare solution?
- May telecare cause less contact with community care and may that increase loneliness?
- Is it justifiable that older people remain living at home when they cannot take properly care of themselves?

We should remember that using new solutions often challenge our ethical conscience more than those that are part of our routines without necessarily being less ethical. We need to make ethical considerations with any solution with and without including telecare as part of the service.

Reflective Exercise

- Discuss the above cases from an ethical perspective.
- Think of a situation from your own practice and consider various solutions with and without telecare. Who do you need to involve in the assessments and which goals and needs will you emphasise and prioritise? Which information will you need for being able to find a better solution and how will you know which solution to choose?
- What reasons did you identify for including and not including telecare in your care?

14.6 The Voice of Older People in Research

Providing contemporary care will include using current technology, like telecare, however each situation needs individual assessment. Different people have different needs, demands and expectations towards using telecare. Whether these are conflicting or consistent is likely to affect the over-all results. Bowes and McColgan [6] highlight that research and evaluations have in fact privileged the service providers' point of view and thus reducing the persons using the service merely to a recipient of the service. We know from several research projects that if the technology does not match the users' needs, they may stop using the solution [9, 16]. In an ageing population, it is crucial to gain insight by listening to older people in designing solutions aiming to match their actual needs in health and social care, no matter the character of the services. This topic receives increased attention and when the researchers prepare for the older people to participate, they are both able and willing to give valuable input [17]. When developing telecare solutions it is essential to listen to experiences from older people as there are differences between what people *think* about a solution they have not tried and what they actually *experience* from using it [3, 16]. When people experience benefits from telecare, their opinion regarding advantages and disavantages also appear to be more nuanced [18]. However, people in general, independent of age are reluctant to use any device if it marks them as helpless in any way [19]. Therefore, people should be given the opportunity to try telecare, to experience it as part of their life before deciding upon a solution [9].

Another important issue to consider is who the designers are that design artefacts and solutions for older people. Many designers are younger people with little experience or understanding from older people's perspectives. Research has documented how design intended for older people actually excluded the targeted users (older people) due to the design being unsuitable for them [10]. Experiences from involving people with dementia in developing devices determined for their use provided useful information during the development process [20]. Including older people in research is both necessary and important when designing contemporary health and social care services to their benefit [3, 6, 17, 20].

14.7 Caring for the Carer

As explained in the beginning of this chapter, I use the term "relatives" even if they take on the role as "carer" [1]. Relatives are essential in supporting older people to remain living in their own home [21]. Relatives very often take on a role of caring and taking responsibility for a variety of tasks [22]. They usually attend to needs without perceiving their role to be changed from that of being a daughter, a spouse and a grandchild [1]. Carlsen and Lundberg [22] found that relatives perceived their effort as carer both as a duty and as a choice and thus a meaningful task. Nevertheless, when people are in a situation where they hold responsibility for another person, they experience this becoming a burden over time [21]. Relatives are known to contribute to several hours of assistance but often experience the "not knowing" to be among the most stressful [9, 21]. Caring for the relatives that are in a position of being a carer needs explicit focus when planning the care solution.

When health and social care policies are aiming for more people to remain living in their own home, and the demographics show a continuing ageing populations, it is natural to conclude that the input from relatives will need to increase and will remain an important resource in the provision of future health and social care. Health and social care personnel are usually attentive to the possible strain relatives have when taking on caring responsibilities. However, relatives might play an increasing role in the joint planning for older people to remain living at home. It is important to take good care of these essential resources. Research indicates that traditional arrangements in respite for carers are beneficial [21]. In addition, research emphasises that it is important for the relatives that their effort is acknowledged and appreciated by health and social care personnel [22].

Research from newer care solutions, like telecare, demonstrates that when relatives trust the telecare solution, they express that they have a greater peace of mind [3]. However, for the relatives and the service users to trust telecare, the nurses must have made a thorough assessment of the situation and configured the solution according to the actual needs and resources [8, 9].

14.8 Summary

This chapter reinforces how the field of nursing and social care are changing in line with the demographic of an ageing population. People are living longer and have resources that need to be both recognised and utilised in future care planning. Telecare provides a new dimension in care that when used correctly may support remaining resources in beneficial ways for the older person and their relatives. Positive experiences from using telecare depend to a high degree on how well the nurse or allied health professional assesses the situation and thereafter manages to engage with the user and their relatives to design and apply a tailored care solution. In contemporary and future care, the relatives are essential resources that need to be

respected and acknowledged. To provide optimal care solutions that utilise and support resources the involved persons need to be involved and thus they are able to share their experiences and knowledge of ageing.

14.9 Suggested Reading

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