Module: Long Term Care

Introduction and description

"Long-term care" means helping people of any age with their medical needs or daily activities over a long period of time. Long-term care can be provided at home, in the community, or in various types of facilities that offer different degrees of assistance to residents. Making long-term care decisions can be hard even when planned well in advance.

In recent years, long-term care provision has been an increasingly important issue internationally, as societies have experienced considerable demographic changes thanks to people living longer. While for most people, longer life means more healthy life years, many, if not most people, will require some care and support at some point. As such, providing citizens with a high level of protection from the risk of ill-health and dependence is a crucial objective of the Member States and the European Union (Nagode, et. al., 2014)

Individuals need long-term care when a chronic condition, trauma, or ill-health limits their ability to carry out basic self-care tasks, called activities of daily living (ADLs), (such as bathing, dressing or eating), or instrumental activities of daily living (IADLs) (such as household chores, meal preparation or managing money). Other less severe long-term care needs may involve household tasks such as preparing meals or using the telephone. Basic needs also include relationships and therefore, sexuality and intimacy. As such, though people age and physical problems may increase, intimacy and sexuality remain active interests.

Defining key groups and integrated care.

Who are professional caregivers?

Home, community and residential care staff who receive payment for their work fall within the category of professional caregivers. Services for older people in need of care and assistance should be provided by skilled and competent workers with a decent salary and stable working conditions, and according to a manageable workload. Workers' rights should be respected and confidentiality, professional ethics and professional autonomy protected. Opportunities for continuous learning and improvement should be available to all care staff (WeDo Project 2012).

Who are informal caregivers?

Informal caregivers are most often family, however they can also include friends, neighbours and important others who provide care to an older person in need of assistance. They do not usually have a formal status and are usually unpaid.

Integrated care

The aim of integrated care is to design and implement individual care pathways, financially and administratively coordinated with a view to achieving better outcomes in terms of effectiveness and user satisfaction. The provision of appropriate care at the right moment in the most appropriate setting implies collaboration in multi-disciplinary teams, collaboration between providers and agencies, all of which should take place in collaboration with the older person in need of care and assistance and their carers (WeDo Project 2012).

Unit 1 (of 4): Long-term care

Introduction

National definitions on long-term care vary within the European Union. These variations reflect differences over the length of stay, range of benefits and the often blurred dividing line between medical (healthcare) and non-medical (social) services. Some countries, for instance, prefer to concentrate on out-patient rehabilitation treatment earlier than others, which focus more on providing care in hospitals or similar establishments (European Commission 2008).

As the European Charter of the rights and responsibilities of older people in need of long-term care notes

"The European Union recognises and respects the rights of older people who are more likely to come to depend on others for care, to lead a life of dignity and independence and to participate in social and cultural life (Charter of fundamental rights of EU, art. 25.)...Members States should develop policies that promote these rights at home and in institutional care settings, and support individuals asserting them. Advanced practice nurses are associated with improvements in several measures of health status and behaviours of older adults in long-term care settings and in family satisfaction (European Commission, 2010)."

Nonetheless, in practice it can be difficult to distinguish between recognising a right and recognising when a restriction of a right is in the best interest of the individual. For example, an individual may need medication to preserve their health, but may not accept this due to diminished capacity. In such circumstances, medicines are often administered in food or drink without the patient's knowledge, a practice known as covert or surreptitious prescribing or administration (Haw & Stubbs 2010). This is a controversial practice, as the line between acting in a person's best interest and engaging in chemical restrain can blur very easily.

While medication and medicines will be dealt with in more detail in Unit 3 of this module, as such examples highlight, there can be substantial ethical challenges in the area of long-term care. In particular, health and social care professionals may have to attempt to balance the rights, responsibilities and wishes of a range of actors, including in areas such as sexuality and intimacy.

Key messages

- Regardless of age, every individual has a need for love, intimacy and companionship, including those in long-term care (LTC) facilities.
- Health and social practitioners can empower older people to help them continue to enjoy intimacy and a healthy sex life.
- Balancing the rights, responsibilities and wishes of the range of actors involved in long-term care situations can present ethical challenges for health and social care practitioners

Learning outcomes

At the end of this unit students are expected to:

1. Appreciate that intimacy and sexuality are components of human life that change but do not diminish with age
2. Appreciate the challenges surrounding intimacy and sexuality in long-term care
3. Understand the need to balance the rights, responsibilities and wishes of a range of actors

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Responsibility and Residents' Rights

In response to the often-sensitive issue of geriatric sexual expression, some facilities have established firm policies and procedures to ensure that staff support residents' rights. Here, policies often specifically outline residents' rights to privacy, sexual expression, and intimate relationships, as well as delineating staff and facility responsibilities in upholding these rights. The rights of residents in a long-term care facility to engage in appropriate sexual activities have not always been clear cut and supported by staff. As Sisk (n.d.) notes, "Warmth, closeness, and touching with another resident can alleviate the profound loneliness that affects many elderly in long-term care". It is important to realise that residents are not necessarily seeking only sexual gratification, rather they may be "seeking comfort, companionship, and human touch to combat feelings of loss and isolation" (Sisk, n.d.).

Case study

Ana lives in a nursing home. She is 67 years old and has regular sexual intercourse with her partner, who visits her twice a week. Because she cannot wash herself, comb her hair, change her clothes or generally care for herself, nurses help her with every day's activities. Because she has regular intercourse, nurses prepare her for it. They take care for her anogenital hygiene, wash her, change her bed sheets and position her in accordance with her partner's wishes. Ana's partner is also there to witness the whole preparation for sexual intercourse. After intercourse her partner calls the nurses, who clean Ana, dress her and change the sheets, again with Ana's partner present. Ana encourages her partner's behaviour, because he is showing extreme pleasure in watching the nurses. However, some of the nurses find this kind of behaviour inappropriate.

Discussion – Questions for the case study

1. Do you think that besides the resident's right of sexual expression, the wish of the partner (to be present at the preparation) should be acknowledged?
2. In your opinion, are the caregivers obliged to prepare the resident in front of her husband? Why/why not?
3. Do you think that with the presence of Ana's partner, at her preparation for their sexual act, the resident's dignity is being questioned? Explain your answer.

Unit 2 (of 4): Informal long-term care

Introduction

While informal carers are most frequently daughters, sons or spouses, informal carers can include siblings, neices, nephews, cousins, grandchildren or friends and neighbours. In some cases, older people themselves may be providing care to their ageing parents. Indeed, informal carers provide the bulk of care to older people in need of care and assistance (depending on the country between 70 to 90% of care needs are covered by informal carers). As such, informal carers, many of whom are family members and women aged 55 and over, provide a vast amount of the care work.

Informal carers are nevertheless a particularly vulnerable group and are at a high risk of burn out, abuse and/or social exclusion. The quality of life of the informal carer is closely linked to the quality of life of the older person in need of care and assistance. Services therefore have to consider support for informal carers as an integral part of the quality improvement process, as well as the need to improve cooperation between formal and informal care. At the same time, family members should have the right to refuse to provide informal care. Likewise, older people in need of care should have the right to refuse to receive care from informal carers (WeDo Project 2014). While informal carers are a vulnerable group, they can also be the perpetrators of abuse and it is therefore important that health and social care workers are aware of this and can recognise situations of concern.

Key message

- Informal carers provide substantial amounts of care to older people who require long-term care
- Informal carers are not a homogeous group and can be a vulnerable group, espcially in relation to burn out and isolation
- In part because of the vulnerability of both older people who require long-term care and the informal carers who care for them, relationships can become abusive

Learning outcomes

At the end of this unit students are expected to:

1. Be aware of the contribution that informal cares can and do make to caring for older people who require long-term care
2. Understand that both informal carers and older people area vulnerable groups who can require information, support and assistance

3. Appreicate that the relationships between older people in receipt of long-term care and their informal carers can breakdown and sometimes become abusive

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Case Study

"Mary" is a widow. She has lost both her legs and is wheelchair bound. Mary receives a monthly pension that is just enough to cover the basic expenses. Her son, "Bob", is her primary caregiver and he lives with her. Bob is an alcoholic. He regularly takes his mother's pension to spend on alcohol. During a regular examination, medical workers have discovered Mary has been severely mistreated and even sexually abused.

Reflective activities

1. How can caregivers interpret the signs that a person under their care is being mistreated?
2. In what way do the caregivers exchange information about the needs of the older person?
3. What could be specific activities of the caregivers for the wellbeing of the elderly?
4. Which experiences should the caregivers have to provide for the elderly?

Unit 3 (of 4): Medication (medication, addictions and alcohol)

Introduction

Many older people may be taking medicines for different conditions and so there can also be concerns around the interactions of such polymedication, which can have various side effects, particularly increasing fall risk, but also resulting in decreased libido (Hill and Wee). Moreover, as with any other group in society, older people can be at risk of developing addictions. For example, is not uncommon for older people to start to abuse alcohol and medication after the death of a spouse or after divorce, retirement or other major change in their lives. Indeed, the first signs of dependence may not arise before the ages of 70-79 years (14% men and 28% women addicted to alcohol). For many individuals retirement means a negative experience, the deterioration of social status, lower incomes and standard of living. In addition, older people can experience empty nest syndrome, health problems, loss of cognitive function, and decreased sexual desire, which can contribute to increased drinking in the elderly, although there may be no history of such behaviour in earlier years.

When it comes to alcoholism in older people there is a lack of comparable studies. Most studies have been performed in the United States for instance. But addiction is not the only problem the elderly face when dealing with intimacy issues. For example, people often attribute a lack of libido with advanced age, when in reality it can be contributed to many different factors, including drugs prescribed by a doctor that are used appropriately. Camacho and Reyes-Ortiz (2005) point out that, although aging and functional decline may affect sexual function, when sexual dysfunction is diagnosed, physicians should rule out disease or side effects of medications first.

The odds of being polymedicated also increase with advanced age and common medication interactions tend to occur more often in the oldest old. More importantly perhaps, patients may believe any new symptoms are a result of old age and may not report the occurrence to their physician. Unless the health and social care practitioner enquires, common side effects of any given medication, may be overlooked. As such, health and social care practitioners should keep in mind that new symptoms such as decreased libido, lack of lubrication or ED may result from medication use (Camacho & Reyes-Ortiz 2005).

Decreased libido is not the only problem. Older patients may complain to their physician about a new symptom, which is actually a side effect of their medicines. If they visit another specialist, who is not acquainted with the exact medication the patient is receiving, they may prescribe new medicine, which can create a dangerous cycle.

As the report of the European Monitoring Centre for Drugs and Drug Addiction states, a particularly vulnerable group when it comes to the issue of drug abuse, are elderly people. Older adults are frequent users of prescription and over the counter drugs, which is due to the fact that the aging process is often associated with social, psychological and health problems.

Key messages

- Older people can often require different medications and these can have negative effects, particularly falls.
- Upheaveals that can accompany ageing, such as loss of a spouse, retirement or empty nest syndrome can lead older people into becoming addicted to drugs or alcohol.
- Both medicines and alcohol have impacts on libido and this needs to be considered by health and social care practitioners when dealing with older people.

Learning Outcomes

At the end of this unit students are expected to:

1. Be aware of the complications that can surround medication use for older people.
2. Appreciate that upheaveals can make older people vulnerable to addiction to drugs or alcohol.
3. Be aware that medication and alcohol can impact physically and psychologcially on older people in relation to intimacy and sexual health.

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Case Study

“Ruth” has been known as an exceptional beauty in her younger years. People have been complimenting her looks since she could remember. But with age the compliments got fewer and when she retired she fell into depression. Because of the nature of her depression her relationship with her husband became brittle as she was upset with her own body and thus unable to share intimacy. She began taking antidepressants, but they did not help, with every day her depression got worse and the medication prescribed by specialists got stronger. The medication decreased her libido further and impacted negatively on her interactions and intimacy with her partner. In the end her family physician proposed visiting

an Alcoholics Anonymous group as no other support group was available in her town. She and her husband, who was supporting her every step of the way, joined the support group. With the step by step programme that helped people cope with addictions, she got rid of her depression and is now able to lead the life she led before her retirement.

Reflective discussion

1. Older people are often polymedicated by different specialists. Do you think that as different prescription drugs have different side effects, a pharmacist should be included in the decision making?
2. How would you animate an older person to openly speak with the medical staff about the lack of libido associated with prescription medicine (especially barbiturates and drugs for high blood pressure)?
3. Ruth found a way out of her depression by using a step by step programme. What kind of other activities could you suggest people use in such situations before resorting to stronger medication?

Unit 4 (of 4): Changes in sexual practice and intimacy

Introduction

The need for intimacy is ageless. Studies confirm that no matter a person's gender or age, they can enjoy sex for as long as they wish. Naturally, sex at 70 or 80 may not be like it is at 20 or 30—but in some ways it can be better. As an older adult, people may feel wiser than they were in their earlier years, and know what works best for them when it comes to their sex life. Older people often have a great deal more self-confidence and self-awareness, and feel released from the unrealistic ideals of youth and prejudices of others. Moreover, with children grown and work less demanding, couples can be better able to relax and enjoy one another more without the same life distractions.
Nonetheless, it is not uncommon for many adults to worry about sex in their later years, and end up turning away from sexual encounters. Some older adults feel embarrassed, either by their aging bodies or by their "performance," while others are affected by illness or loss of a partner. Without accurate information and an open mind, a temporary situation can turn into a permanent one. People can avoid letting this happen by being proactive. Whether they are seeking to restart or improve their sex life. Thus, it is important to be ready to try new things, and to ask for professional help if necessary. There is much people can do to compensate for the normal changes that come with aging. With proper information and support, people's later years can be an exciting time to explore both the emotional and sensual aspects of their sexuality (Block et. al., 2016).

Key messages

- The desire for intimacy does not decrease with age, and there is no age at which intimacy, including physical intimacy, is inappropriate.
- Disorders and emotional changes that often occur with aging can interfere with developing and maintaining an intimate relationship. Aging can also change the way intimacy is expressed.
- Age-related changes: Levels of sex hormones decrease, causing changes (eg, vaginal atrophy) that make sexual intercourse uncomfortable or difficult. Libido may decrease.

Learning outcomes

At the end of this unit students are expected to:

1. Be aware that the desire for intimacy and sexual expression may change for older people, but does not diminish with ageing

2. Understand that older people may face particular barriers to discussing initmacy and sexual health with health and social care practitioners.
3. Be aware of considerations that can be discussed with older people to help empower them to enjoy intimacy and sexual health

Content

Tips for enjoying a healthy sex life as people get older

Sex can be a powerful emotional experience and a great tool for protecting or improving health, and it is certainly not only for the young. Sex over the age of 50 can present challenges and people may feel discouraged by issues connected with the aging process, but these problems are not insurmountable. With better understanding and an open mind, people can continue to enjoy a physically and emotionally fulfilling sex life, since it is not a question of age, but of desire.

Accept and celebrate who you are

- **Reaping the benefits of experience.** The independence and self-confidence that comes with age can be very attractive to a spouse or potential partners. No matter a person's gender, they may feel better about their body at 62 or 72 than they did at 22. Moreover, it is likely that they now know more about them-self and what makes them excited and happy. In addition, experience and self-possession can make their sex life exciting for both them and their partner.

- **Looking ahead with a positive approach.** As people age, they often have negative expectations around their sex life and how it may change. This can be undermining and people may need reminding that if they enjoyed an active sex life in younger years, there is no reason for that to change, unless they want it to. A positive attitude and open mind can go a long way toward improving older peoples approach to intimacy and their sex life.

- **Love and appreciate the older self.** It is nature for peoples' bodies to change as they age. While this is obvious and should not be unexpected, for some people it can challenge their feelings of self-esteem and self-worth.

- Naturally, your body is going through changes as you age. You look and feel differently than you did when you were younger. But if you can accept these changes as natural and hold your head up high, you'll not only feel better, you'll also be more

attractive to others. Confidence and honesty garner the respect of others—and can be sexy and appealing (Block et. al., 2016).

Communicate with your partner

As bodies and feelings change over the age of 50, it is more important than ever to communicate thoughts, fears, and desires with partners. Encouraging older people to communicate with their partner is therefore of vital importance. Speaking openly about sex may not come easily, but improving communication can help both partners feel closer, and can make sex more pleasurable.

Talking about sex
Broaching the subject of sex can be difficult for some people, but it should get easier once people begin. For example, they may find that just talking about sex can make them feel sexy. The following strategies can help older people to begin the conversation.

- **Be playful.** Being playful can make communication about sex a lot easier. Use humour, gentle teasing, and even tickling to lighten the mood.
- **Be honest.** Honesty fosters trust and relaxes both partners—and can be very attractive. Let your partner know how you are feeling and what you hope for in a sex life.
- **Discuss new ideas.** If you want to try something new, discuss it with your partner, and be open to his or her ideas, too. The senior years—with more time and fewer distractions—can be a time of creativity and passion.
- **Modernize.** You may belong to a generation in which sex was a taboo subject. But talking openly about your needs, desires, and concerns with your partner can make you closer—and help you both enjoy sex and intimacy (Block, et. al., 2016).

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