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Overcoming new challenges for advocacy of people with intimate health conditions in Europe.

Living with an ostomy: the impact of education, the role of caregivers and the importance of research.



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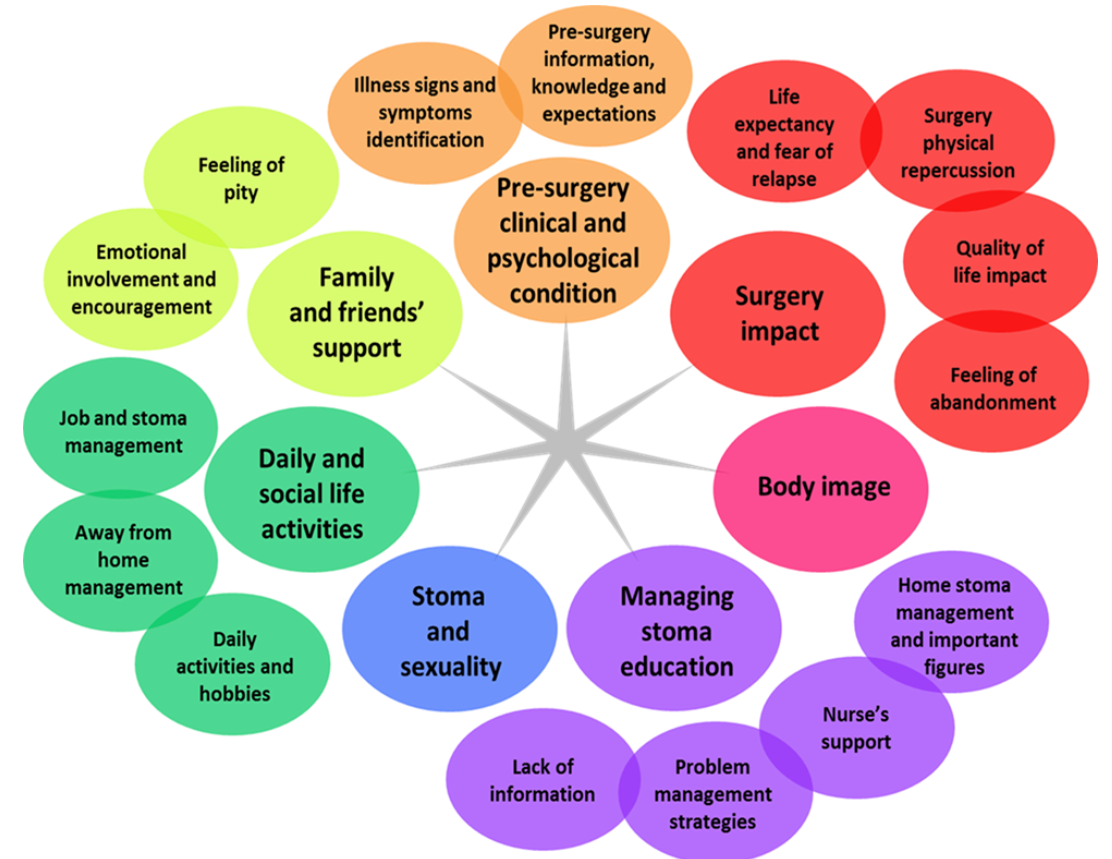
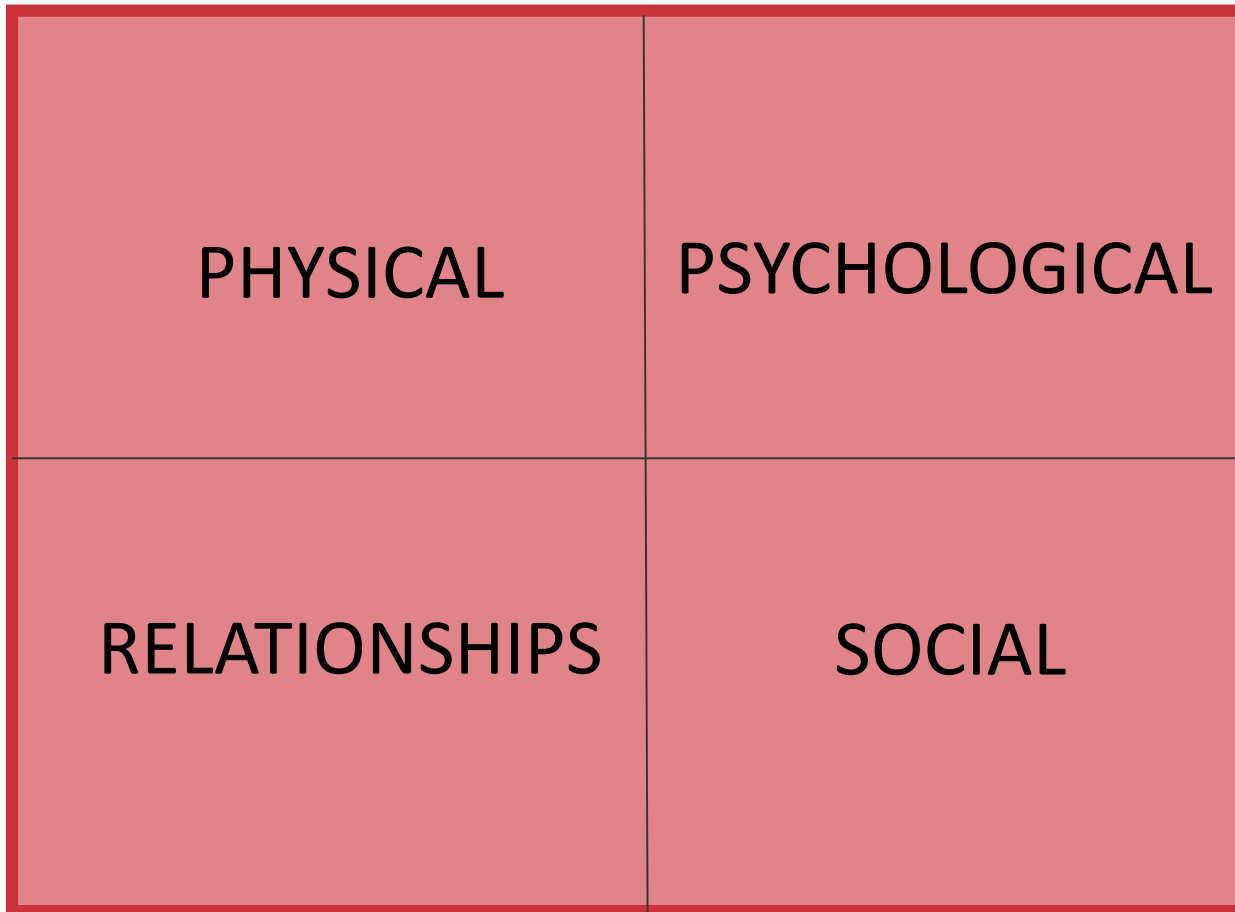
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1. The context
2. Four aspects
3. The impact of education
4. The role of caregivers
5. The importance of research

The creation of an **ostomy** modifies person's life with repercussions on some aspects: **PHYSICAL, PSYCHOLOGICAL, RELATIONSHIPS, SOCIAL.**

The person has to adapt himself to a **different lifestyle condition**, requiring the development of **self-care skills**.

Four aspects



PHYSICAL ASPECTS

- **OSTOMY COMPLICATIONS**

- Discomfort
- Reduced sleep
- Decreased quality of life

- **SEXUAL FUNCTION**

- Organic sexual dysfunction
- Painful sexual intercourse

If the persons adapts to the new situation and manages the ostomy well, they will have a good level of adjustment and a good quality of life.

PSYCHOLOGICAL ASPECTS

- **Change or alteration** of body image
- Negative effects on the **emotional sphere**: anxiety, depression, negative view of the future, shame due to possible stigma, embarrassment
- Attitudes and **coping strategies influence illness experiences**: search for autonomy and self-care
- **Development of a new identity, new goals on life**

People who proactively face this new condition and implement a process of adaptation to the new living conditions can have high levels of self-care, adaptation and quality of life.

RELATIONSHIP – 1

- Problems related to the **sexual sphere** could be cause a negative influence on couple life
- **Effects on family life**
 - Negative. Lack of communication with partner
 - Positives. Increased understanding with partner (rediscovery)
- Importance of recreational activities for **sociability/reduction of isolation**

The physical and psychological aspects, if addressed, allow the person to adapt to the new condition; the relational and social aspects create the conditions to facilitate this.

RELATIONSHIP – 2

Importance of the **social support from family, friends and peers:**

- Support from partner and family
- Need for support from colleagues
- Support from health professionals
- Informal network support (friends)
- Mutual help groups

SOCIAL – 1

Information and **Health Education** provided by health professionals to individuals and caregivers - **key element for self-care** and activating effective coping strategies:

- Need for continuous information
- When do people ask for information? Two different moments: before surgery or after surgery (still in hospital)
- Information given by health professionals can reduce people's shame and fear of being stigmatized

SOCIAL – 2

- **Influence** of cultural aspects on perception of illness and treatment (including spirituality)
- Influence of gender on perception of illness
- **Importance of person-professional relationship** -> fundamental nurse support
- **Return to work key element** for quality of life (ability to work)

The **ADJUSTMENT** to the **new life condition** is implemented by:

1. **EDUCATIONAL PROGRAMME** to reduce the **impact of the stoma** and to promote the **adjustment do new condition** (from the preoperative phase).
2. **PARTICIPATION TO SUPPORT GROUPS / ASSOCIATIONS**

Adequate education in self-care activity, through formation, information and inclusion of family, are essential aspects in the ostomy adjustment process.

A well-educated person achieves a high level of self-care, increase quality of life and adjust better to the new condition.

Most people with ostomies are **autonomous** and do not need a caregiver.

When present, the caregiver is a fundamental figure for support, ostomy care and any issues that may arise.

Why research in this area?

To improve the person's adjustment to the new condition and to help them face the challenges that arise.

The importance of research – 2

Research efforts in this area include:

- ostomy and peristomal skin care
- new products and accessories
- innovative educational strategies
- management of complications
- identification of social and relational problems
- improving the skills of ostomy nurses
- identifying research priorities with patient associations
- AND MUCH MORE...

Further reading

Claessens, I., Probert, R., Tielemans, C., Steen, A., Nilsson, C., Dissing Andersen, B., & Størling, Z. (2015). The Ostomy Life Study: the everyday challenges faced by people living with a stoma in a snapshot. *Gastrointestinal Nursing*, 13(5), 18–25.

Colwell, J. C., Kupsick, P. T., & McNichol, L. L. (2016). Outcome criteria for discharging the patient with a new ostomy from home health care: A WOCN society consensus conference. *Journal of Wound, Ostomy & Continence Nursing*, 43(3), 269–273. <https://doi.org/10.1097/WON.0000000000000230>

urukawa, C., Sasaki, Y., Matsui, K., & Morioka, I. (2013). Health-related quality of life and its relevant factors in Japanese patients with a urostomy. *Journal of Wound Ostomy & Continence Nursing*, 40(2), 165–170. <https://doi.org/10.1097/WON.0b013e31827e8339>

Gomez, A., Barbera, S., Lombraña, M., Izquierdo, L., & Baños, C. (2014). Health-related quality of life in patients with urostomies. *Journal of Wound, Ostomy & Continence Nursing*, 41(3), 254–6. <https://doi.org/10.1097/WON.0000000000000026>

Recalla, S., English, K., Miller, D., & Gray, M. (2013). Ostomy Care and Management. A systematic review. *Journal of Wound, Ostomy & Continence Nursing*, 40(October), 489–500. <https://doi.org/10.1097/WON.0b013e3182a219a1>

Villa, G., Manara, D. F., Brancato, T., Rocco, G., Stievano, A., Vellone, E., & Alvaro, R. (2018). Life with a urostomy: A phenomenological study. *Applied Nursing Research*, 39(September 2017), 46–52. <https://doi.org/10.1016/j.apnr.2017.10.005>

Corvese, F., Giordano, V., Alvaro, R., Vellone, E., & Villa, G. (2020). Sociodemographic characteristics and self-care management knowledge of patients with an ostomy. *British journal of nursing* (Mark Allen Publishing), 29(22), S20–S26. <https://doi.org/10.12968/bjon.2020.29.22.S20>