

The Impact of Smart Sensor Technologies on the Total Care Principle in the Context of Palliative Care

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Abstract

Palliative care is a crucial component of healthcare, which has been more reliant on technology in recent years. Recently developed smart sensors and artificial intelligence have the potential to improve diagnosis and therapy. However, it is still unclear how smart sensor technologies (SST) are challenging palliative care principles and their underlying human assumptions, as well as how care can benefit from SST. The purpose of this paper is to uncover SST-related alterations and difficulties in palliative care. Furthermore, normative guiding standards for the application of SST are defined. The foundation for the ethical analysis is the Total Care principle advocated by the European Association for Palliative Care (EAPC). Drawing from this, a phenomenological lens is used to investigate its fundamental humanistic and socio-ethical dimensions. The second stage examines the benefits, drawbacks, and socio-ethical issues associated with employing SST in relation to the Total Care philosophy. The application of SST is then required to meet ethical-normative standards. First, the measurement capabilities of SST are constrained. Second, SST affect human autonomy and agency. Both the patient and the carer are concerned about this. Third, the employment of SST may push some facets of the Total Care principle to the background. In order to use SST to promote human flourishing, the study develops normative standards. It lays out the three standards that SST must meet: (1) proof and purposefulness; (2) autonomy; and (3) Total Care.

Keywords: Smart sensor technologies; Healthcare; Total care; Palliative care; Technology; Terminal illness; Psychological; Dementia

Palliative care

Smart sensor technologies (SST) have the power to completely change how patients are identified and cared for in the medical field, especially palliative care. In particular, the impact on core human assumptions and the care principles that form the basis of this profession, the use of SST in palliative care is examined in this study along with potential and difficulties that may arise. As a result, there are three normative standards to which the application of SST must conform. Patients who are suffering from life-threatening illnesses get palliative care, which aims to enhance their quality of life. This term requires explication in several places. First off, because quality of life is such a highly subjective term, it cannot be evaluated objectively from the outside [1-4]. It depends on the interaction of many different elements, not just physical ones. Second, palliation rather than cure is the main objective of therapy. Parallel to curative treatment, palliative care can be given at any point in the illness trajectory [4]. However, it is mostly used in the period following the discovery that the underlying illness is incurable. Third, palliative care is provided in a variety of environments: Family members have cared for the terminally ill and the severely sick at home for many millennia [5]. Palliative care facilities such as nursing homes, hospices, or hospitals are increasingly integrating private care into their operations [6]. However, in Germany, 89% of individuals still choose to get care at home, and from 2003 to 2017, there was a 30,7% rise in home deaths in the US [7, 8].

As digital technologies in healthcare advance, more services promote creating "Home Health Care Centres" where patients may receive high-quality clinical treatment while yet feeling at home [9]. Fourth, informal carers (family, friends, relatives, and neighbours play a dual position in palliative care that makes them particularly susceptible [10, 11]. They are both carers and individuals in need of care at the same time. Taking on care is frequently followed by a change in the role and dynamic between informal carers and patients. For example, kids may start acting as parents' substitutes as they lose more and more of their independence [12, 13]. The interaction between

J Palliat Care Med, an open access journal ISSN: 2165-7386 the team of carers and the dying patient is also characterised by a gap in experience. The distinction results from the actual experience of passing away. The shared universe of meaning between the patient and carer vanishes as a result of the palliative patient's particular experience. Even further, Martin W. Schnell asserts that participant empathy is no longer conceivable [14]. It is crucial to employ "bridges" that the patient provides of their own will instead. A shared horizon, according to Gadamer as well as understanding as speaking for an Other in front of others, is required for comprehending the other [15, 16].

In conclusion, it is difficult to assess "quality of life". It must be continually reinterpreted in light of a terminally ill person's shifting life circumstances and a terminally ill person's care environment, which includes complicated care relationships. Total care, also known as multifaceted and comprehensive care, is necessary in response to the feeling of total pain [17] at the end-of-life phase. By taking into consideration a person's subjectivity, complexity, changeability, relationality, and embeddedness, it offers a paradigm to explain how responsive they are [18]. For the successful care of suffering and dying patients who are faced with a loss of agency and an increase in reliance, the Total Care concept serves as the foundation [19].

Palliative care's guiding idea is total care

The phrase "Total Care" is used by the European Association for Palliative Care (EAPC) to describe palliative care standards in their 2009

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guidelines [20]. The Total Care approach was developed in reaction to Cicely Saunders' Total Pain idea, which is seen as one of the originators of contemporary hospice and palliative care [21]. Total Pain, according to Saunders, depicts pain as multifaceted phenomena that encompass mental misery in addition to social and spiritual suffering [17, 22]. It also describes pain as more than just a bodily symptom. This realisation inspired her and many who came after her to develop a holistic view of healthcare that emphasises the individual as an integrated being and incorporates insights from the humanities [23]. The Total Pain paradigm and the resulting concept of Total Care specifically address the following four dimensions: the physical, psychological, social and spiritual dimension [21] (Figure 1).

Even if the structure of this study indicates otherwise, these aspects are intricately interwoven rather than independent from one another. It helps to understand them independently to organise them into distinct dimensions. They will each have their connection emphasised at the same time. Several fundamental anthropological presumptions about people underlie the Total Care principle and its four dimensions: People have bodies. 'Leib' (embodiment) and 'Körper' (body) are separate words in German: The lifeworldly, or personally and socially always understood body is what constitutes embodiment; it goes beyond the idea of a simple objective corporeality. The anchoring of the ego in society and biology, or the "zero point of orientation"[24] in the world, is the embodiment. In every interaction with the outside world, the embodiment is always "mitgegeben" (given along), which is an epistemic characteristic [25, 26]. Both experiencing and being experienced is embodiment. It serves as a conduit for the outside world while also being a human being. The one seeking for sovereignty encounters the embodiment in disease, addiction, ageing, and sexuality an experience that is uniquely its own [27]. In conjunction with developmentalpsychological, sociological, and psychoanalytical findings, the bodyphenomenological tradition has demonstrated that we as individuals always have an interpreted, indirect access to the outside world and are sensitive to ourselves. We never succeed in doing so, not even in our abstractions, where we purportedly avoid doing so since it is consistent with the natural sciences' epistemic goal. Additionally, body carvings, cardiac catheters, eyeglass frames, clothing that fits our bodies (or doesn't), and drug usage all demonstrate in different ways how the embodiment transcends simple corporeality on the inside as well as the outside. Corporeality can be understood, with Bernhard Waldenfels, as "Zwischenleiblichkeit" as a result of these intricate connections between the inner and the outside, the social and the individual, the cultural and the natural. We are the intersection of multiple biological imprintings and sociocultural traditions within our body. In this web of life, we continue to weave both physiologically and socially. The experiences of I, you, third, we, your, and you are formed in this methodically and genealogically irreparable gap. As a result, intersocial relationships

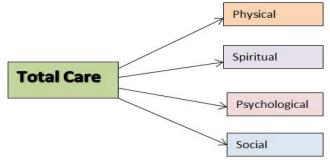


Figure 1: The total care principle.

shape and are shaped by the embodiment [28]. The second underlying presumption of the Total Care concept is congruent with this view of the human embodiment: People are responsive and relational creatures. Their interpersonal relationships have an impact on their wellbeing [29]. This interconnection of the human comes more and more into focus when treatment planning shifts away from prioritising illness prevention or control in favour of improving patient quality of life.

Concept of total care change

How is the employment of smart sensor technology (SST) both a threat to and a support for the philosophy of Total Care, which is not only but also uniquely manifested in palliative care? SST encompass any minimally invasive or non-invasive sensor technologies intended to gather a wide range of physical data, such as perspiration, blood pressure, movements, and heart- and respiratory-rate rates [30]. It is referred to be smart since machine learning is utilised to analyse the data rather than traditional techniques. The goal of implementing these new technologies is, among other things, to gain new insights into relationships between quantifiable factors (such as respiratory rate, facial expression, etc.) and a person's inner experience - or, to put it another way, to gain a more thorough understanding of a person's general condition. This goal in relation to the Total Care approach first appears promising. In palliative care, symptom evaluation and treatment are crucial to achieving the highest possible quality of life. However, up to this point, clinical situational evaluation by healthcare practitioners has been sporadic. Touch-based monitoring methods are the norm (ECG with wires, for example). The patient may become irritated by them, and their mobility may suffer. Personal care and social inclusion are hampered by visibly present medical equipment. For instance, family members can be hesitant to touch or embrace the sufferer. As a result, although normal technologies provide a constant understanding of the patient's health, they are also burdensome for the patient and inadequate in a palliative care context. SST provide patients with unhindered movement and avoid physical limits that arise with invasive technologies since they are non- or minimally invasive in design. SST monitor continually (24/7) as opposed to health care providers' intermittent assessments. They are able to deliver long-term data as a result, all without burdening the patient. In palliative care environments, which are intended to be person-centered, as non-invasive, and pleasant as possible, these traits are particularly encouraging. Future health and palliative care will be shaped by this type of technology, maybe in conjunction with other digital applications. This essay's goal is to outline the normative precepts regarding SST usage that must be adhered to in order to fulfil the Total Care concept. The study first challenges the absoluteness and scope of measurable facts. Second, it inquires as to how SST may assist each patient's autonomy, ability to express their preferences, and ability to do so when their circumstances at the end of life change. And last, it raises the question of whether SST can fully implement the Total Care philosophy. The purpose is to demonstrate that the employment of SST often referred to as "high tech" and human corporeality their reliance on relationality in care settings often referred to as "high touch" do not have to be mutually incompatible and may even benefit one another.

Smart sensor technology

There are often 10 to 12 physical symptoms present at once in patients with severe illness. For targeted therapy to be effective and to raise quality of life, identifying their causes is essential. Palliative care, however, deals with a lot of patients who don't disclose all of their symptoms. Numerous things contribute to this. The authors Claudia Bausewein et al. cite resignation or the desire to not burden others as motivations. Another significant impact is a person's diminished capacity for speech and comprehension brought on by the advancement of a terminal illness, conditions like dementia that often accompany it, or the use of sedative medicines.

SST pledge to be of considerable assistance in identifying physical symptoms. Heart rate variability may be calculated as a possible indicator of the autonomic nervous system's balance thanks to sensors that accurately detect, for example, heartbeat. They can aid in identifying stress brought on by discomfort or other symptoms. These measurements can also be utilised as indirect indicators of the efficacy of symptom management strategies, such as when a painkiller causes a rise in HRV as an indication of reduced stress. SST can therefore serve as a sort of articulation assist or advocate. The experience of symptoms, such as discomfort, shortness of breath, and nausea, is, nonetheless, deeply unique and complicated. It is impossible to think about the interpretation of SST-produced data in isolation.

Other sources of ensuring autonomy or better "assisted freedom" must also be taken into consideration in order to contribute to the protection of patient autonomy. Setting biomarker data as absolute and resulting in paternalism is a concern. Setting data as absolute negates first the measuring instruments' subjectivity in the process of converting data into a diagnostic or medical action (this might be caused by bycatch, bias in the application of AI, or other variables). Second, it runs the danger of overlooking the Total Care principle's more comprehensive approach, which takes into account aspects other than the physical that are difficult or impossible to measure with SST. For instance, it is likely to pay less attention to the psychological and spiritual parts of care and instead concentrate on "easy-on-the-eye' physical aspects like wound management". A possible influence on the patient-professional interaction "that focuses on the data generated rather than holistic concerns of the patient" is something that Sheila Payne et al. expressly recognize. Last but not least, it must be remembered that studies with healthy people have shown that the measured data are quite likely to affect the patient's actual bodily experience.

The patient's medical condition and diagnosis are closely tied to their psychological condition. Here, the body as Leib is once more pertinent: One's own bodily perception and interpretation have an impact on how they perceive themselves, the world, and others. The state of the body distorts how we see the outside environment. Physical pain perception and psychological component interrelate with one another. Additionally, characteristics that might weaken during a terminal disease, such social involvement, have an impact on mental health. Many patients receiving palliative care have clinically severe psychological distress symptoms, as do their family members. About half of palliative care patients experience a clinically diagnosable mental condition during the first year after their diagnosis. As previously said, the goal of SST is to develop a more thorough picture of a person's overall health by connecting non-invasively observed physical measures to interior psychological moods. As we take into account the psychological dimension and translate it into quantifiable measures, the difficulty of describing the pertinent features increases. For standardised psychological evaluations, in addition to the dialogue between the patient and the healthcare provider, questionnaires and self-descriptions are typically utilised. One such tool is the Beck Anxiety Inventory (BAI), which consists of 21 self-reported questions. SST measures exterior bodily reactions that offer indications of interior states in order to promote self-assessment. Other than heart rate variability, measures of emotions might include breathing rate, perspiration, body movements and positions, and mimicry.

However, occasionally the self-report and the observable and

quantifiable physical reaction are not the same. Mark Purdy et al. cite an experiment by Paul Zak that shown that there are differences between what individuals say and how they unconsciously feel or are emotionally invested when watching Super Bowl advertisements to support their argument. SST may turn into a paternalistic tool if this discovery is generalised with the adage "People lie, their brains don't" and seen as something that reveals the truth. Human autonomy and self-determination would be at peril if the SST's conclusions and recommendations were made inflexible. The SST is vulnerable to bias since emotions and bodily conditions are both highly subjective and culturally dependent.

Conclusion

What may SST be used for in an evidence-based manner? Which dimension is the usage of SST appropriate and reasonable?. SST place a strong emphasis on acquiring quantifiable data, which leaves the four total care elements of body, mind, social, and spirit, in the dark. Not all factors important to the Total Care philosophy can be measured by SST. Narrative information, life experiences, personality traits, and values, for instance, are likely to be omitted when drawing inferences about suffering on the social or spiritual levels. Additionally, not every patient group benefits from technology in the same way. Bias and distortion must be taken care of for SST to be used responsibly. SST can, however, assist the patient in articulating certain operationalizable components.

However, if the SST outcomes are not specified in an absolute manner, it will be unable to support the patient's articulation and autonomy. As a result, the second query Is SST inclusive of additional sources of information regarding a patient's health? serves as a reminder that SST must be embedded in a social context. SST must give patients and their loved ones a place to express all facets of their wellbeing. The final query focuses on the unintended implications of SST implementation: Does SST inhibit the application of any aspect of the Total Care principle? The significance of this question is demonstrated by three instances. First off, it is more probable that somatic characteristics will end up being the only factor considered when making medical decisions if SST solely measures those parameters. It is more probable that the other crucial elements of the Total Care principle psychological, social, and spiritual suffering will be ignored. Therefore, utilising evidence-based operators, the SST must attempt to quantify psychological, social, and spiritual pain where appropriate. Finding quantifiable indicators for the psychological, social, and spiritual aspects of care, however, is extremely subjective and open to prejudice. Second, while "high touch" and "high tech" (SST) are not mutually incompatible, they do need to complement one another. Third, SST must protect the privacy required for providing spiritual care. The answers to these three questions are crucial requirements for a responsible use of SST that takes into account the circumstances and difficulties of the care scenario in palliative care.

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Conflict of Interest

Author declares no conflict of interest.

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