

## The need for understanding

### Potreba po razumevanju

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Whenever I meet nurses, registered nurses, in conferences and in other contexts it seems that doing a good job for the patient and being a good nurse is a general concern all over the world. It also seems that this concern, this ambition, is not easy to fulfill. The ambition can even lead to frustration, when understanding for the work and the work situation is lacking among e.g. colleagues, managers and significant others (Lindahl, et al., 2010; Jangland, et al., 2017).

Both van Manen (1997) and Dahlberg and colleagues (2008) developed research on lived experience and lifeworld. They opened up for gaining an understanding of a phenomenon as it is experienced by persons, and shared through their narratives. The lifeworld is only mine and cannot be experienced by anyone else. We can share experiences but not the lifeworld, and it is only through narratives we can get access to someone's lifeworld. Furthermore, we can only learn what they tell. Hence, the lifeworld can be described but also understood. Husserl provides an epistemological perspective on the lifeworld, a foundation for descriptive phenomenology. Heidegger provides an ontological perspective, opening up for an understanding of a phenomenon, hermeneutic phenomenology (van Manen, 1997; Dahlberg, et al., 2008).

In order to provide good care we need to understand patients' and relatives' experiences as well as nurses' experiences. We need to learn about their lifeworlds in order to be able to create caring encounters. How can we ever grasp fears, prejudices, perceptions or false expectations if we do not ask patients and relatives to tell about their thoughts and experiences. How can we ever support nurses in their challenging work if we do not ask them about their experiences and reflections.

There is a growing body of research on patients' and relatives' lived experiences to learn from, and to consider

in daily work. The meaning of living with malodorous excuding ulcers can be understood as being trapped in a debilitating process that slowly strikes one down. There is a longing for life to improve, a longing for wholeness and purity. Nurses cannot make ulcers and malodour disappear but they can provide consolation and hence contribute significantly to improve patients' lives (Lindahl, et al., 2007). According to West and colleagues (2012) the impact of chronic pain on the family is extensive. Understanding the physical, social and emotional changes opens opportunities for nurses to develop and implement strategies to better support partners/families, and strategies to involve families in e.g. assessment, education and treatment processes. A review by Larsen and Uhrenfeldt (2013) aiming to identify patients' lived experiences of having reduced intake of food and drink during illness report high satisfaction with hospital food. However, due to physical changes because of illness, experiences of reduced intake seems to be related to negative feelings during meals, such as anxiety and shame. The review points to the need for more professional assistance during meals as well as the need for guidance on how to handle specific nutritional problems. Living with arterial or mixed leg ulcers can be interpreted as "life in hell" (Lernevall, et al., 2017). Living with constant pain, between hope and despair, in an eternal battle against the ulcer means that the ulcer controls life. The findings call for individualistic holistic care where not only the ulcer is treated. Lingehall and colleagues (2015) interviewed older people diagnosed with postoperative delirium about their experiences of undergoing cardiac surgery, a one year follow-up. Their experiences were interpreted as feeling drained of viability, feeling trapped in a weird world, being met with disrespect and feeling safe. Hence, health care personnel need deeper knowledge in order to prevent, detect and treat delirium to avoid and relieve suffering

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that might be caused of patients' experiences. This sample of studies, there are of course more to be found, focus on patients' and relatives' experiences. The findings provide significant insights and knowledge for nurses who are responsible for nursing care.

Research on nurses' lived experiences is equally important to consider and to learn from. Blondal and Halldorsdottir (2009) report that caring for patients in pain is a "challenging journey" for the nurse. Reading the patient, dealing with inner conflict of moral dilemmas, dealing with gatekeepers and organisational hindrances were challenges the nurse could face. Coleman and Angosta (2016) interviewed acute care nurses about their lived experiences of caring for patients and their families with limited English proficiency in the United States of America. The nurses desire to connect, to provide care and to provide cultural respect and understanding. These findings point to the need for nurses to share their experiences and ideas for solutions, and to the need for identifying e.g. barriers and resources for communication. Identifying concerns of the bedside nurses is equally important. District nurses shared their lived experiences of meeting significant others in the home when providing advanced home care to patients (Pusa, et al., 2015). Interpretations of the findings were formulated as themes; feeling close, mediating strength and being emotionally influenced. Creating and maintaining a trustful relationship with significant others in order to illuminate and respond to their needs and desires was found to be the meaning of the meetings. It is emotionally demanding as well as emotionally rewarding being a district nurse in advanced home care. Egede-Nissen and colleagues (2017) performed interviews with minority health care providers in a dementia unit within a Norwegian nursing home aiming to examine challenges in care. Findings show that experienced challenges were related to an ethical striving for understanding the patient. Minority healthcare providers share almost the same challenges as ethnic norwegians but their work includes an extra dimension due to their cultural and linguistic experiences from their home country. The findings open up for the need of sharing experiences and supporting each other. This sample of studies focus on nurses' experiences. The findings provide significant insights and knowledge for nurses but also for managers responsible for organising work and providing education and support.

To sum up, phenomenological research provides advantages for nursing as the findings or interpretations reveal meanings of health and illness. It also guides nurses' understanding of emotional needs/desires and impact of illness, e.g. dying, caring, comfort. Furthermore, self-understanding is included and constitutes the cornerstone to understanding. Phenomenological research is used internationally, in various contexts. The significance for nursing is that

phenomenological research reveals depth and diversity of nursing knowledge. It explicates tacit knowledge inbedded in caring and provides a foundation for caring science. Finally phenomenological research advances our knowledge and practice. When extending our knowledge and understanding creating caring encounters becomes possible and hence good nursing care can be provided.

#### *Slovenian translation / Prevod v slovenščino*

Ko na konferencah in drugje srečujem zaposlene v zdravstveni negi, se mi zdi, da sta povsod po svetu bistvena skrb za paciente in kakovostno opravljeno delo. Gre za cilja, ki ju ni lahko doseči. Kadar pa pri tem ni razumevanja med sodelavci, vodji in pomembnimi drugimi, lahko pride do frustracij (Lindahl, et al., 2010; Jangland, et al., 2017).

Van Manen (1997) ter Dahlberg in sodelavci (2008) so razvili raziskave o življenjskih izkušnjah in osebnem doživljjanju sveta. S tem so omogočili, da določen pojav razumemo bolje – tako kot ga razumejo posamezne osebe in ga delijo z drugimi s pripovedovanjem svoje zgodbe. Kljub temu je osebno izkustvo sveta le moje in ga ne more izkusiti nihče drug. Lahko si sicer delimo izkušnje, a ne lastnega sveta. Čeprav skozi pripovedovanje zgodbe dostopamo do sveta nekoga drugega, lahko izvemo le tisto, kar nam nekdo pove. Svet pa je mogoče opisati in ga tako tudi razumeti. Husserl je podal epistemološko videnje sveta, ki je osnova za deskriptivno fenomenologijo, Heidegger pa ontološko perspektivo, ki omogoča razumevanje nekega pojava in s tem hermenevtično fenomenologijo (van Manen, 1997; Dahlberg, et al., 2008).

Da bi lahko nudili kakovostno zdravstveno nego, moramo razumeti izkušnje pacientov in njihovih sorodnikov ter tudi izkušnje zaposlenih v zdravstveni negi. Da bi zagotovili srečanja, ki izražajo skrb, moramo spoznati njihove svetove. Kako razumemo strahove, predsodke, zaznavanja ali napačna pričakovanja, če pacientov in sorodnikov ne povprašamo o njihovem razmišljaju in izkušnjah? Kako lahko podpiramo zaposlene v zdravstveni negi pri njihovem težavnem delu, če jih ne povprašamo po njihovih izkušnjah in doživljjanju?

Vse več raziskav se ukvarja z osebnimi življenjskimi izkušnjami pacientov in njihovih sorodnikov, iz česar se lahko učimo in vedenje uporabimo pri svojem delu. Tako je na primer življenje z razjedo, zaradi katere pacient oddaja neprijeten vonj, mogoče razumeti, kot da je pacient ujet v situaciji, ki mu počasi jemlje moči in opravilnost. Želi si izboljšanja življenja, celostnega pristopa in čistosti. Čeprav zaposleni v zdravstveni negi razjede in slabega vonja ne morejo odpraviti, mu lahko nudijo oporo in tolažbo ter tako znatno pripomorejo k izboljšanju njegovega življenja (Lindahl, et al., 2007). West in sodelavci (2012) menijo, da ima kronična bolečina

velik vpliv na pacientovo družino. Razumevanje fizičnih, družbenih in čustvenih sprememb pomeni, da zaposleni v zdravstveni negi dobijo priložnosti za razvijanje in uporabo strategij, ki jim omogočajo, da pacientovim partnerjem zagotavljajo učinkovitejšo podporo. Tako jih na primer vključijo v procese ocenjevanja, izobraževanja in zdravljenja. Raziskava Larsena in Uhrenfeldta (2013) izpostavlja, da so pacienti, ki imajo zaradi bolezni zmanjšan vnos hrane in pijace, bolj zadovoljni s hrano v bolnišnici. Zaradi fizičnih sprememb, ki so posledica bolezni, pa je zmanjšan vnos hrane in pijace povezan z negativnimi občutji med obroki, kot sta tesnoba in sramota. Zato se kaže potreba po večji strokovni pomoči in smernicah za soočanje s specifičnimi prehranskimi težavami. Življenje z arterijskimi ali mešanimi razjedami na nogah se pogosto interpretira kot »življenje v peku« (Lernevall, et al., 2017). Živeti s kronično bolečino, med upanjem in obupom, v večni bitki proti razjedam pomeni, da bolezen upravlja pacientovo življenje. Ugotovitve kažejo na potrebo po individualni celostni oskrbi, pri kateri se ne zdravi le razjed. Lingehall in sodelavci (2015) so intervjuvali starejše paciente z diagnozo pooperativnega delirija o njihovih izkušnjah operacije srca in enoletnega spremljanja. Izrazili so jih kot občutek, da so jim bile odvzete sposobnosti za normalno življenje, da so ujeti v čuden svet, da se srečujejo z nespoštovanjem in da se počutijo varne. Da bi lahko preprečili, zaznali in zdravili delirij ter tako pacientom odvzeli ali olajšali trpljenje, ki ga izkušajo, morajo zaposleni v zdravstveni negi razviti globlje razumevanje. Obstaja več raziskav, omenjene se osredotočajo na izkušnje pacientov in njihovih sorodnikov. Ugotovitve predstavljajo pomemben vpogled in zaposlenim v zdravstveni negi nudijo novo znanje.

Vir znanja pa predstavljajo tudi raziskave o osebnih izkušnjah zaposlenih v zdravstveni negi. Blondal in Halldorsdottir (2009) poročata, da je za zaposlene v zdravstveni negi skrb za paciente z bolečinami zahteven izzik. Spoznati pacienta, soočiti se z notranjimi konflikti in moralnimi dilemami, z zaprtimi vrati in organizacijskimi preprekami so samo nekateri od izzivov, s katerimi se srečujejo. Coleman in Angosta (2016) sta v Združenih državah Amerike intervjuvala zaposlene v akutni zdravstveni negi o njihovih osebnih izkušnjah pri oskrbi pacientov in njihovih družin, ki imajo omejeno znanje angleškega jezika. Želja zaposlenih je, da se povežejo ter nudijo oskrbo ob razumevanju in spoštovanju različnih kultur. Ugotovitve kažejo na njihovo potrebo, da delijo svoje izkušnje, ideje in rešitve ter prepoznavajo tudi ovire in različne vire komunikacije. Prepoznavanje potreb zaposlenih v zdravstveni negi je torej enako pomembno kot prepoznavanje potreb pacientov. Zaposleni v patronažni zdravstveni negi so delili svoje izkušnje o srečanju s pomembnimi drugimi na domu, ko so izvajali napredno oskrbo pacientov na domu (Pusa, et al., 2015). Interpretacije ugotovitev izpostavljajo: občutek bližine, posredovanje moči in

vpliv na čustvovanje. Izkazalo se je, da je bil pomen teh obiskov v ustvarjanju in obnavljanju pristnih odnosov, kar pomaga osvetlili potrebe in želje ter se odzvati nanje. Poklic patronažne medicinske sestre je čustveno zahteven, a hkrati prinaša tudi čustveno zadovoljstvo. Egede-Nissen in sodelavci (2017) so z namenom preučiti izzive v zdravstveni negi intervjuvali zaposlene v zdravstveni negi, ki so predstavniki manjšin in nudijo oskrbo na oddelku za demenco v norveškem domu za ostarele. Ugotovitve kažejo, da so bili izzivi, s katerimi so se zaposleni srečevali, vezani na etično željo razumeti pacienta. Zaposleni v zdravstveni negi, ki so predstavniki manjšin, imajo skoraj enake izzive kot Norvežani, vendar jih pri delu zaznamujejo tudi njihove kulturne in jezikovne izkušnje iz domovine. Ugotovitve kažejo na potrebo po deljenju izkušenj in medsebojni podpori.

Omenjene raziskave se osredotočajo na izkušnje zaposlenih v zdravstveni negi. Ugotovitve omogočajo pomemben vpogled v delo v zdravstveni negi in oskrbi ter predstavljajo vir znanja za zaposlene v zdravstveni negi, pa tudi za menedžerje, ki so odgovorni za organiziranje dela ter zagotavljanje izobraževanja in podpore.

Povzamemo lahko, da so fenomenološke raziskave za zdravstveno nego koristne, saj njihove ugotovitve in interpretacije pripomorejo k razumevanju pomena stanja zdravja in bolezni. Poleg tega pomagajo razumeti čustvene potrebe in želje zaposlenih v zdravstveni negi ter vpliv bolezni, na primer umiranja, skrbi in tolažbe. Pomemben del razumevanja predstavlja tudi razumevanje samega sebe. Fenomenološke raziskave uporabljajo po vsem svetu v različnih kontekstih. Za zdravstveno nego so pomembne, ker odkrivajo globino in raznolikost znanja. Predstavljajo pa tudi »tiho znanje«, ki je vključeno v skrb in je temelj znanosti o zdravstveni negi. Hkrati prispevajo k napredku na področju znanja in praktičnega dela. Proses razširjanja znanja in razumevanja omogoča nova spoznanja, kar pripomore k zagotavljanju kakovostne zdravstvene nege.

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