



# Social Justice and Diversity in Relation to Loss and Death: a Neglected Issue

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# Autoethnography

*“Autoethnography is a research method that uses a researcher’s personal experience to describe and critique cultural beliefs, practices and experiences and acknowledges and values a researcher’s relationship with others.”* (Adams/Jones/Ellis 2015:2)

Autethnographic research and writing (*graphy*) is biographical research (*auto*) from the inside out and is concerned with an reflection in my own existence in a specific historical and cultural context (*ethno*). (Hefel 2014, 269)

# Autoethnography

*“Autoethnographers often foreground the ways in which social identities influence the research process, particularly in terms of what, who and how we study; what and how we interpret our observations and experiences of cultural life.”* (Adams/Jones/Ellis 2015:19)

formation of autoethnography from 1970 by Carolyn Ellis, Art Bochner and Norman Denzin:

- ❖ new and changing ideas about and ideals for research: limits of scientific knowledge, emerging appreciation for personal narratives, stories, emotions and body
- ❖ heightened concern about ethics and politics of research practices and representation
- ❖ increased importance of social identities and identity politics (Adams/Jones/Ellis 2015)

# Autoethnography

Autoethnography treats research as a political and socially conscious act. These are writings of life and challenge accepted ways of doing research and representing others. Consequently, autoethnography is an approach that acknowledges the researcher's influence on research, rather than hiding from these matters or assuming they do not exist. (Adams/Holmann/Ellis 2022)

# Autoethnography

Autoethnographers use analytical strategies to explore the social and cultural contexts of meaningful life experiences and their implications for the present.

**Narratives reflect the experiential encounters of everyday messy life.**

(Ellis 2004, Hefel 2014, Witkin 2014)

In doing autoethnography we confront the tension between insider and outsider perspectives, between social practice and social constraint.

The research raises awareness to issues of identity, to experiences, which are partly under a taboo and neglected, about shrouded issues and to empathize with people who are labeled as different - this is highly connected to social work. (Adams/Holmann/Ellis 2022; Hefel 2014)







*„Here hatred and envy end, and all earthly suffering,  
here rich and poor, high and low are equal“*



# Diversity - treating people as a whole person

*„Social workers work toward strengthening inclusive communities that respect the ethnic and cultural diversity of societies, taking account of individual, family, group, and community differences.“* (Global Social Work Statement of Ethical Principles 2018)

*„Social workers recognize the biological, psychological, social, and spiritual dimensions of people's lives and understand and treat all people as whole persons. Such recognition is used to formulate holistic assessments and interventions with the full participation of people, organizations, and communities with whom social workers engage.“* (Global Social Work Statement of Ethical Principles 2018)



# Social Justice in loss and grief

*„Social Justice in Loss and Grief asks us to be reflective - constantly questioning ourselves about the ways that our thoughts and experiences of gender, class, race, ethnicity, and occupation influence our perceptions of those we work for and with and how such perceptions shape our care.“* (Harris 2016 xvi)

# outline of presentation

*„Since there is death, we should care for the people around us and not think that life is able to eliminate this.“* (Noll 2009, 150)

- loss, death and dying over a lifespan
- historical changes
- implications for Social Work

dtv  
Ruth Klüger  
weiter leben  
Eine Jugend  
Still Alive



*„Their secret was death, not sex. That’s what the grown-ups were talking about, sitting up late around the table. Gas chambers, that is one’s own upcoming killing as a daily topic.“ (Klüger 2001, 121)*



*„Growing up I felt that the dead were **more** present in our house than the living. You are born on their side, as if you would be layed in their arms. You can feel them, you can touch them, you are part of them.“*

*We were different because of what we had experienced. And I felt it was **we** who had had the experience, not just my mother and father. I felt I had absorbed it by osmosis in the way children can absorb what has happened to their parents.“ (Brett 2016)*



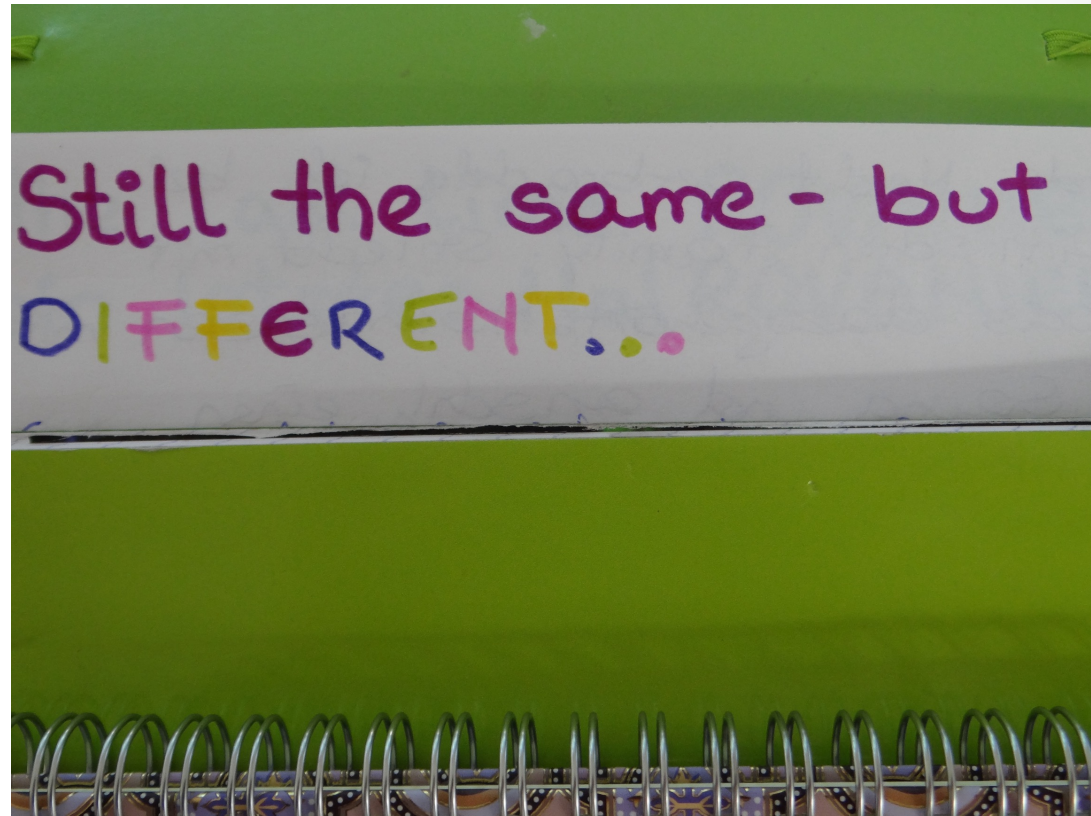


Audre Lorde „being a *black, lesbian, mother, warrior, poet*“

*„There must be some way to integrate death into living, neither ignoring it nor giving in to it.“* (Lorde 1980)

# We are ...

“It is always important to look at the past. Someone’s past, as this is always the reason why we are the way we are, our history forms us. Things that happen, the way we cope or handle them and the people we meet (and many other things) build our character. So maybe one could say the past creates us.” (journal entry)









<https://www.independent.co.uk/news/uk/home-news/number-of-homeless-people-dying-more-than-doubles-in-five-years-figures-show-a8298981.html>



# transition of death and dying

death and dying are part of life and are subjected to historical, social, political, religious and cultural circumstances and changes.

## **Significant changes during the 20<sup>th</sup>/21<sup>st</sup> century in the western world:**

- process of secularisation - power and influence of religious authorities and traditions are diminishing
- financial and economic paradigms are becoming increasingly meaningful
- banishment from everyday life „*Society does not any longer take a break*“ (Ariès 2002, 716)
- changes and loss of traditions and searching for other possibilities

# transition of death and dying

- medicalisation „*With the exception of birth no **medical event** relates so inevitably all living people like dying*“ (Borasio 2011, 12)
- institutionalisation „*It seems that death and dying are **packed** in proper operations and thus defused as an explosive charge*“ (Gronemeyer/Heller 2014, 244)
- economisation „*The **technical** death conquers dying*“ (Illich 2007, 48)
- assisted dying - a complex tension field: desire to self-determined and dignified death in various forms up to „*assisted suicide as a service*“ (Gronemeyer 2007, 167)
- Hospice and Palliative Care

# pioneers in research, teaching and practice

Cicely Saunders (1918-2005)



Elisabeth Kübler-Ross (1926-2004)



# Cicely Saunders: pain – needs – awareness

Founder of the St. Christopher hospice in London, 1967

*„The best education was to love dying people.“* (Saunders 1999, p. 33)

## Saunders' concept of **total pain**

Multidimensionality of pain as a biopsychosocial, cultural and spiritual phenomenon requires a holistic multiperspective and interdisciplinary approach.

*„Such an approach has had a strong influence on the ability of the movement to cross boundaries of culture and resources and to flourish (...) in countries. This has rightly been recognized as a medical speciality but, because it ideally goes far beyond symptom control alone, it demands the whole multi-professional team.“* (Saunders 2001, p. 792)



# Elisabeth Kübler-Ross: model of stages

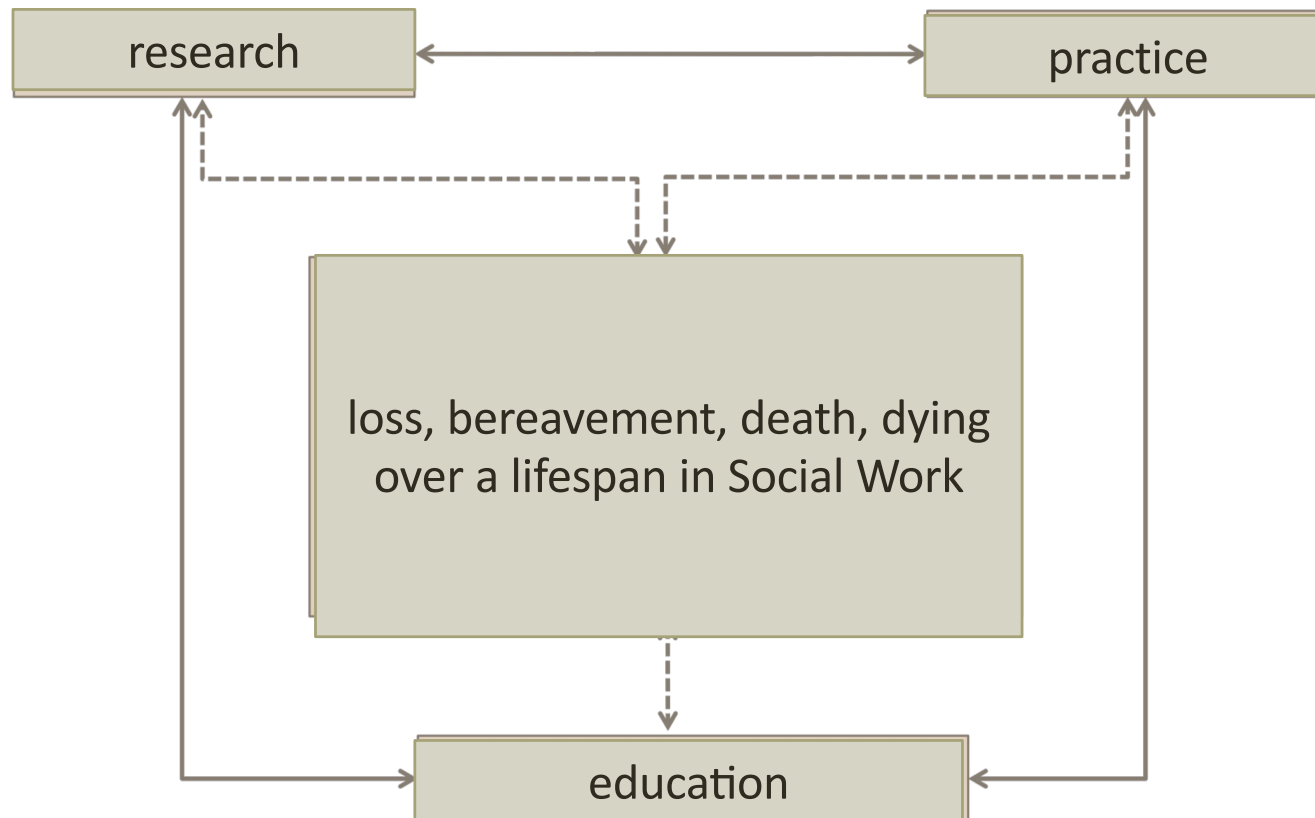
*„The book [On Death and Dying] you are about to read, or reread, is one of the most important humanitarian works on the care of the dying written in the Western world.“* (Kellehear 2009)

Kübler-Ross spoke **WITH** people and their relatives and friends rather **ABOUT** them.

*„Shortly before death, patients have very specific needs that can be fulfilled, if we take our time to listen to them and to figure out. We have to verify and reflect our own conception of death and dying thoroughly before we can sit serene and without fear near the patient.“* (Kübler-Ross 1969, p. 150)

Kübler-Ross' model of five stages of loss and grief:  
denial, anger, bargaining, depression, acceptance (not linear but a circular process)

# interdependency



# Social justice and diversity

*“All intersect with a host of other dimensions of experience or identity.”*

(Fowler 2008, 57)

Addressing diversity and social issues in death education *“many of the ‘lesson taught’ are still based on studies of predominantly middle-class, white population.”* (DeSpelder/Strickland 2005, 536)

- privilege and power
- alliances
- stereotyping
- prejudices and discrimination
- disenfranchised grief and suffocated grief
- socially just practice
- language

# language and daily Social Work

Language – essential in Social Work

linguistic difficulties in every day life come about

- insinuations
- encryptions
- silence
- vague statements
- reticence to talk about loss, grief and death
- encountering and confronting frightening and shameful subjects
- resistance
- refusal
- power of discourse (*Foucault 1994*)



# language in University

oriented, established and often uncritically adopted by the vocabulary of economics

- students are considered as customers
- studies are labeled products
- image of lecturers as service providers
- individualism
- discourse of effectiveness (do the right things) and efficiency (do the things right)
- Universities must self-display on the market and withstand the competition with excellent products (Hefel 2014, Mautner 2010)

*„Social Work is about relationships, the collective, the social, and stands against the dominant individualism that has characterized neoliberalism.“* (Ife 2017)

# language matters

*“Dying and caregiving, death and grieving are all situated in, mediated by, and filtered through cultural, social, and historical contexts.”* (Fowler 2008, 55)

- language barrier provokes confusion, misunderstanding
- monitoring the framing of the language
- learning and engaging in an open respectful dialogue
- widen the different perspectives of social and cultural background and bring these debates and insight into conversation
- think more widely about loss, grief, bereavement and death and take into account the diversity of service users
- uncover the power of discourse and provide alternative

(Fowler 2008, Harris 2016)

# ressources and strategies to infuse diversity and social justice themes into Social Work

- remove the taboo from loss, bereavement, death and dying over a lifespan
- transformative power of mutual learning
- enhancing diversity awareness through reflected personal sharing, experimental learning

## **Ability and willingness to ...**

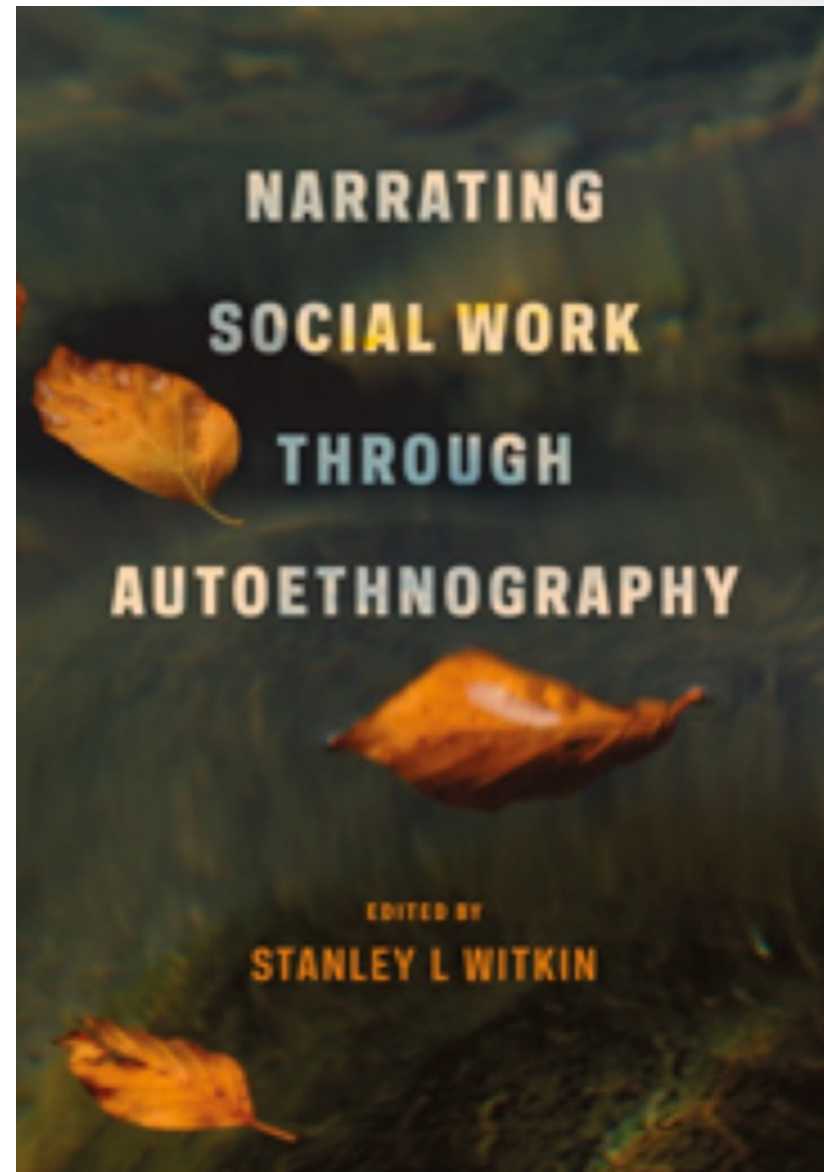
- learn about diversity, complexity and manifoldness of life, loss, bereavement, death and dying over a life span
- perceive and accept the transience of life in all fields of Social Work
- be aware of different standpoints and multiple understandings of loss, death, dying, grief and bereavement in a global diverse world
- be aware of ambivalence, contrasting coping strategies
- reflect personal fear, anxiety, experiences, prejudices and attitude
- be aware of personal vulnerability and empower others by sharing instead of keeping in secret (providing another discourse)
- reflect on life transitions and impact in being/working with others
- reflect within professional and personal growth

Johanna Hefel



# Verlust, Sterben und Tod über die Lebensspanne

Kernthemen Sozialer Arbeit am  
Beispiel österreichischer Fachhochschulen



Hefel, Johanna (2014): **“Will You Be with Me to the End? Personal Experiences of Cancer and Death.”** In: Witkin, Stanley L. (Ed.) (2014): *Narrating Social Work Through Autoethnography*. New York: Columbia University Press. p. 197-230.

# integration – death is part of life

we are mortal

Integrating loss, dying, death, anxiety, grief and bereavement in a broad diverse spectrum into everyday life, opens up doors to ourselves and others and enables a conscious and differentiated view of the values of life.





THANK YOU

GRACIAS

ISALIN

NAA GODE

bedankt

HVALA

OBRIGADO

شکشاارا

弹壳 [彈  
殼]

DEKUI

CAM ON

MERCI

KIITOS

DANKE

شکرا جزىلا

TESEKKÜRLER

OSE

GRAZIE

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