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A four-step grounded theory developed in people with long-term health conditions

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Person-specific evidence has the ability to mobilize relational capacity: A four-step grounded theory developed in people with long-term health conditions

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Abstract

Person-specific evidence was developed as a grounded theory by analyzing 20 selected case descriptions from interventions using the guided self-determination method with people with various long-term health conditions. It explains the mechanisms of mobilizing relational capacity by including person-specific evidence in shared decision-making. Person-specific self-insight was the first step, achieved as individuals completed reflection sheets enabling them to clarify their personal values and identify actions or omissions related to self-management challenges. This step paved the way for sharing these insights and challenges in a relationship with a supportive health professional, who could then rely on person-specific evidence instead of assumptions or a narrow disease perspective for shared decision-making. Trust in the evidence encouraged the supportive health professional to transfer it to the interdisciplinary team. Person-specific evidence then enhanced the ability of team members to apply general evidence in a meaningful way. The increased openness achieved by individuals through these steps enabled them to eventually share their new self-insights in daily life with other people, decreasing loneliness

For affiliations refer to page 11.

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they experienced in self-management. Relational capacity, the core of the theory, is mobilized in both people with long-term health conditions and healthcare professionals. Further research on person-specific evidence and relational capacity in healthcare is recommended.

KEYWORDS

empowerment, evidence, grounded theory, guided self-determination, life skills, long-term health condition, pragmatic research, shared decision-making

1 | INTRODUCTION

Reasons for developing a theory about person-specific evidence arose from two decades of pragmatic research on the guided self-determination (GSD) method, which is one of several empowerment-based initiatives (Charles et al., 1997; Karazivan et al., 2015; Stoop et al., 2020) to provide better outcomes for people with long-term health conditions (LTHCs). Several researchers have pointed out the failure to realize empowerment in clinical practice despite good intentions of practicing it (Anderson & Funnell, 2010; Ekman et al., 2011; Mahmic et al., 2021), raising questions about whether methods used in clinical decision-making and problem-solving might lack the potential to foster empowerment. As one answer to this question, research in Danish diabetes care identified barriers to empowerment (Zoffmann et al., 2008; Zoffmann & Kirkevold, 2005, 2007) and developed GSD as an alternative method to overcome them (Zoffmann, 2004). GSD promoted empowerment in shared decision-making when people with LTHCs completed written or drawn semistructured reflection sheets in preparation for interacting with healthcare professionals (HCPs) trained in communication (Zoffmann & Kirkevold, 2012).

GSD conducts an open investigation of person-specific challenges in daily life and thus differs from comparable initiatives such as motivational interviewing (Miller & Larionov, 2011) and acceptance and commitment therapy (ACT) (Zhang et al., 2017) that focus on preselected issues such as smoking cessation or weight-management. GSD is named after one of the most thoroughly developed theories on motivation, the theory of self-determination (SDT) (Deci & Ryan, 1985), which describes a continuum of motivation moving from amotivation on one end to intrinsic motivation on the other end. SDT also identifies three basic needs—autonomy, competence and relatedness—that people must fulfill to become self-determined (Lev Arey et al., 2022). The proposed goal of GSD is to enable people to develop life skills defined as “those personal, social, cognitive and physical skills which enable people to direct their lives, and to develop the capacity to live with and produce changes in their environment” (Mullen, 1985, p. 121; Nutbeam, 1986). Life skills theory adds to SDT by differentiating between other-determined, selfish-determined, and balanced self-determined behavior, with the latter, recommended as the goal of individual health promotion (Allen et al., 1995). GSD is thus

designed to support people becoming balanced self-determined, meaning that their behavior is determined by their own needs while respecting the needs of others, an approach that leads to a coherent view of oneself in interaction with others.

Early evaluation of GSD in diabetes care was built on six sources of observation and interview data, revealing that exchanging traditional methods for GSD provided systematic cocreation of a new kind of knowledge with an ability to release a potential for change seldom seen in traditional care. Consistent with the definition of method as “a path of cognition, a planned approach to the acquisition or justification of knowledge” (Lübcke, 1992, p. 296), it is not surprising that using another method in decision-making will result in gaining another kind of knowledge. However, the difference this kind of knowledge made was remarkable. When GSD reflection sheets were used in diabetes care, diabetes nurses became aware that they got to know people in a new way, which enabled them to “better understand” them. Physicians noticed that people “proposed suggestions” and “became more active” in decision-making. People with diabetes reported that they had changed attitudes about the hospital service: “it has become clear that it [the hospital service] is here to help me.” They eventually experienced a “more open relationship with family and friends,” which they highly appreciated (Zoffmann, 2004, p. 117; Zoffmann & Kirkevold, 2012).

An integrated review of previous GSD studies was recently published (Linnet Olesen & Jørgensen, 2023). While disseminating GSD across varying LTHCs, GSD researchers became increasingly aware of the emancipatory character of the new kind of knowledge, which they assumed played an essential role in GSD's ability to realize empowerment. Its verified person-specific nature provided the rationale for calling it “person-specific evidence.” Due to its apparent prevalence in GSD interventions, the first author (V. Z.) invited the GSD researchers, as first-hand observers, to take part in a study of this person-specific evidence across the involved LTHCs. With GSD as the decision-making and problem-solving method tested in the interventions, we have the opportunity to study the creation of person-specific evidence and its importance in realizing self-determination among people with LTHCs. The purpose of this study was twofold: (1) to investigate whether the finding of person-specific evidence in diabetes was replicable across diverse LTHCs using GSD and (2) to develop a grounded

theory explaining how person-specific evidence used in mutual decision-making contributes to self-determination and empowerment for people with LTHCs.

2 | MATERIALS AND METHODS

The study was designed as a pragmatic grounded theory (Dewey, 1933; Morgan, 2020; Strübing, 2007), building on a series of loops between grounded theory studies and interventions (Ramanadhan et al., 2021; Strübing, 2007). The theoretical development of person-specific evidence in the study presented here is the latest of many iterative theory-intervention loops in GSD research aiming to realize empowerment for people with LTHCs.

In diabetes, the systematic occurrence of person-specific evidence prompted a study of the phenomenon that led to the development of a preliminary four-step theory called “releasing knowledge” (Zoffmann, 2004, pp. 111–118). The benefit of this knowledge at all steps was obvious, as exemplified in Figure 1 describing GSD used in collaboration with a young woman who managed a bakery and was struggling with her type 1 diabetes. The nurse thought the woman was well-informed about healthy dietary habits, which she was. However, the nurse had not previously comprehended the way the woman's knowledge influenced her actions in daily life.

2.1 | GSD interventions and their theoretical underpinnings

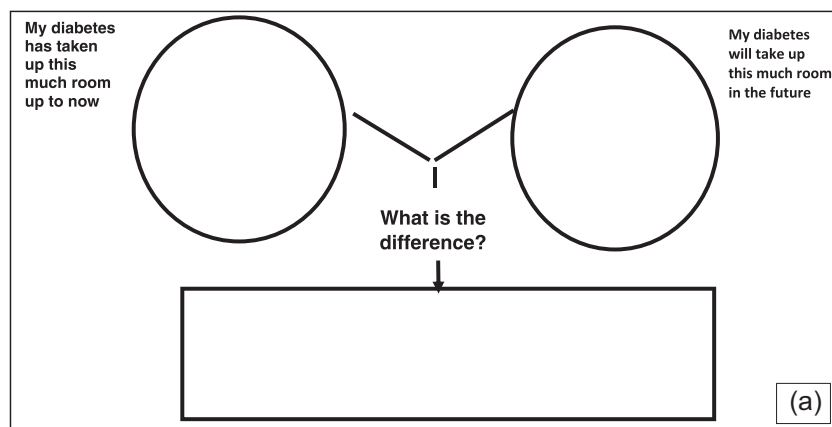
GSD is a method for reflection, collaboration, and change that invites people to take an active role in decision-making and problem-solving, supported by HCPs in the role of facilitators. This is actively promoted through a written invitation to collaborate delivered to individuals to let them know about their role in a collaborative relationship that was identified as empowering in a grounded theory (Zoffmann & Kirkevold, 2007). Moreover, a unique part of GSD is a set of reflection sheets that are completed in writing or by drawing by the person preparing for conversations with the HCP. Originally, a large set of reflection sheets was developed in diabetes care (Zoffmann, 2004) to overcome barriers to empowerment, even in deadlocked collaboration.

It is beyond the scope of the current article to provide a full description of GSD's concepts, philosophical background, ethical premises, total set of reflection sheets, various versions, and digitization. However, we aim to provide a sufficient foundation for readers to understand how GSD supports the cocreation of person-specific evidence in shared decision-making. Three GSD reflection sheets are presented in Figure 2, with the background for their development presented in Supporting Information: Table S1.

GSD facilitator skills include three advanced communication skills: mirroring (Clabby & O'Connor, 2004), active listening (Gordon et al., 1995), and values-clarifying responses (Steinberg, 1986). A full description of the original GSD is available elsewhere (Zoffmann, 2004).

GSD was used in collaboration with a young woman with type 1 diabetes who managed a bakery. The nurse thought the woman was well-informed about healthy dietary habits, which she was. Even so, the woman remarked: “I know a lot about diabetes. I do not, however, use it”. Applying GSD surfaced something new: one of her daily management responsibilities was tasting if cookies were fresh enough to be sold in the shop. While completing reflection sheets, she became aware that she did so without thinking about the effect on her blood sugar (PERSON-SPECIFIC INSIGHT IN THE MIND). She shared this insight with the nurse (PERSON-SPECIFIC INSIGHT IN A SUPPORTIVE RELATIONSHIP), who found it an intriguing discovery and later shared it with colleagues. They received this insight with humour and a respectful understanding of her person-specific challenges requiring some necessary changes (PERSON-SPECIFIC INSIGHT IN A MULTIDISCIPLINARY TEAM). The woman also shared this insight with her father (PERSON-SPECIFIC INSIGHT IN DAILY LIFE), who owned the bakery. Discussing her challenges with him greatly enriched their relationship. Her ability to talk about difficult matters enhanced the openness and understanding about challenges related to her condition.

FIGURE 1 Person-specific evidence and the changes it provided in the case of a young woman working in a bakery.



Room for the condition in daily life

Example of unfinished sentences to complete

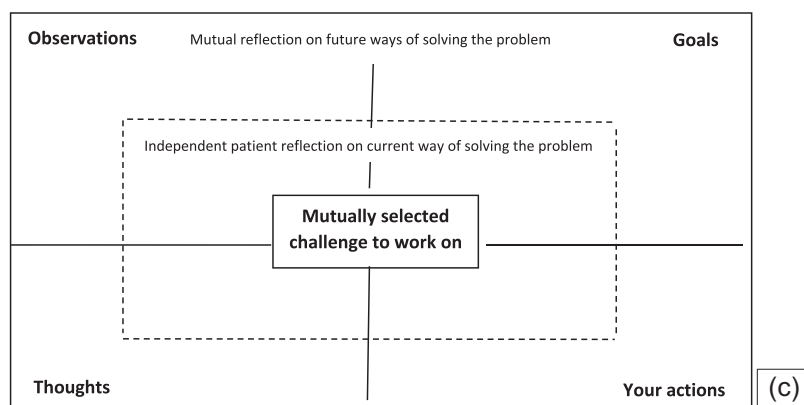


FIGURE 2 (a–c) Three examples of reflection sheets (Zoffmann, 2004). The original reflection sheets are available at https://www.researchgate.net/publication/274081690_Guided_Self-Determination_A_Life_Skills_Approach_Developed_in_Difficult_Type_1_Diabetes.

Theoretically, GSD is a method developed to overcome barriers between the philosophy of empowerment (Funnell et al., 1991) and the overall goal of enabling people to develop skills to live with an LTHC. Important theoretical underpinnings of GSD are the grounded theories mentioned above and embedded constructs from life skills theory (Mullen, 1985), self-determination theory (Deci & Ryan, 1985), humanistic values theory (Grendstad, 1977), stages of change theory (Prochaska et al., 1997), and dynamic judgment building (Bos, 2001).

2.2 | Participants and data collection

V. Z. invited 25 researchers who had conducted GSD interventions in Denmark, Norway, Sweden, and Australia (Zoffmann et al., 2016) to

participate. GSD researchers who applied reflection sheets and advanced communication skills in intervention studies were theoretically sampled as participants because they were considered first-hand observers of person-specific evidence in their roles as researchers across LTHCs. V. Z. and all the researchers knew each other from adapting GSD to their respective areas and from GSD training run by V. Z.

The preliminary four-step theory of releasing knowledge developed in diabetes (Zoffmann, 2004, p. 112) was considered a conceptually sound foundation for a deeper understanding of the phenomenon. V. Z. thus outlined a template (Supporting Information: Table S2) for data collection based on the theory of releasing knowledge. Although she was certain about the releasing property of this kind of knowledge, V. Z. renamed the concept “person-specific

evidence" to highlight its ability to promote critical discrimination between unverified assumptions and person-specific evidence about the persons for whom HCPs provide care. In the template, participating researchers were asked whether they did or did not recognize the four steps of person-specific evidence in their study. If applicable, they were also asked to provide one or two examples of person-specific evidence that they found typical for their research area. A total of 23 researchers, including V. Z., completed templates for exemplary situations from 20 GSD intervention projects across 10 LTHCs. Two senior researchers, both nurses, participated without delivering data based on their in-depth experience with GSD. Both had followed the development of GSD for years and adjusted GSD to settings and specific conditions that were the foci of their own research.

Across projects, GSD versions were adjusted and dosed from 1 to 19 semistructured reflection sheets used in one to seven conversations, the number of which was mutually decided by the GSD facilitator and the person with LTHC according to the person's needs and preferences. The GSD versions were adapted to diabetes or prediabetes, a diagnosis or risk of chronic obstructive pulmonary disease, breast cancer, gynecologic cancer, endometriosis, fertility treatment, neonatal care, schizophrenia, end-stage kidney disease and attention deficit hyperactivity disorder (ADHD) combined with a medical disorder (Supporting Information: Table S3). In five projects (Supporting Information: Table S4, projects 3, 4, 10, 16, 19), relatives also completed GSD reflection sheets related to adolescents, a premature infant admitted to intensive neonatal care unit or a spouse after treatment for breast cancer.

GSD facilitators introduced people with LTHCs to the reflection sheets and how to complete them at home as preparation for the mutually agreed-on number of conversations. The person with an LTHC then initiated the conversation with the HCP by reading their words on the reflection sheets aloud or sharing their completed drawings. If the person found it challenging to complete the sheets in writing, for example, due to dyslexia, relatives might complete the sheets so they presented the person's point of view. Alternatively, reflection sheets were completed with support from the GSD facilitator during the conversation.

A key requirement for person-specific evidence is that it must be verified by the person with LTHC. In the template (Supporting Information: Table S2), participating researchers were asked how this had happened: "A requirement for person-specific evidence is that it is verified by the person concerned. How did the people confirm?" Completed reflection sheets were mutually discussed in all the original study cases, and a typical response to this question was: "By bringing the reflection sheets, reading them out loud and talking about them and the nurses using their communication skills to make sure they correctly understood what was explained."

Eighteen projects took place in hospital settings and two in general practice (Supporting Information: Table S3). The researchers were asked whether they used parts of GSD, even just a single reflection sheet, or a full GSD that included several sheets and an essential reflection sheet called dynamic problem-solving (Figure 2c and Supporting Information: Table S1C).

2.3 | Analysis

Due to a large number of researchers, the analysis was conducted in a stepwise fashion, which enabled the thorough, manageable, and democratic contribution of all authors' observations and ideas. First, the completed templates were read several times by V. Z. and compiled by a research assistant (CHC) into a comprehensive table of responses to the questions posed in the template. V. Z. conducted the initial analysis using constant comparison in open and selective coding as recommended by Glaser (1978). A three-part pattern was revealed related to challenging situations in which the person's values were at risk (Supporting Information: Table S4). This pattern linked values the person had discovered to (1) the person's awareness of their own actions or omissions that threatened their values, (2) the person's awareness of other people's actions or omissions that threatened their values, and (3) changes that mobilized relational capacity in support of their values. These patterns were subsequently discussed first with a small group of leading authors (V. Z., R. J., M. G., M. K.), ensuring author triangulation, and then with the entire author group to provide all researchers the opportunity to contribute.

During the analysis, it became increasingly clear that the diversity of the example situations provided across LTHCs provided a foundation for a deeper understanding of person-specific evidence. The three-part pattern described above led to including Blumer's ideas about "deficiencies" from symbolic interactionism as deductive elements to reach a deeper understanding of mechanisms embedded in person-specific evidence (Blumer, 1969, p. 64):

The fact that the human act is self-directed or built up means in no sense that the actor necessarily exercises excellence in its construction. Indeed, he may do a very poor job in constructing his act. He may fail to note things of which he should be aware. He may misinterpret things that he notes. He may exercise poor judgement. He may be faulty in mapping out prospective lines of conduct. He may be half-hearted in contending with recalcitrant dispositions. Such deficiencies in the construction of his act do not belie the fact that his acts are still constructed by him out of what he takes into account.

One impact of person-specific evidence was that people with LTHCs seemed to expand and deepen what they took into account in constructing their actions. By comparing all example situations, we identified challenging situations revealed by GSD reflection sheets that made people with LTHCs more aware of important matters in their lives and specific actions or omissions. To solve conflicts that seemingly impeded or threatened their values, previously unknown or unacknowledged actions or omissions of their own or on the part of others became focal points and were further clarified through mutual reflection with HCPs.

Theory development addressed validity through constant comparison of the case descriptions, following Glaser's advice to grounded theory researchers "to visualize the total integration of"

the grounded ideas, “hence where each fits, as all ideas eventually integrate” (Glaser, 1978, p. 118). We consider the theoretical coherence of person-specific evidence strengthened through the final step of analysis in which relational capacity was identified as the core category. All patterns were theoretically linked in a cumulatively developed overall model, comprising an explanatory theory (Figure 3) that revealed a typology of relational capacity at each step of person-specific evidence (Supporting Information: Table S5).

Meetings discussing the findings were conducted as web conferences due to COVID-19. Drafts of the manuscript were written and refined following the same steps and finally included refinements suggested by external reviewers. This work was conducted from March 2021 to March 2023.

2.4 | Ethical considerations

All included research studies had been conducted in accordance with the Helsinki Declaration (World Medical Association, 2008) following local rules for ethical approval. All researchers had obtained informed consent from participants in their original research, and all data had been anonymized and managed according to local requirements.

2.5 | Findings

The theory of person-specific evidence was developed by detailing how it appeared and worked in a variety of GSD intervention projects, revealing it as situational knowledge

verified by the person it concerned. The analysis recognized the four steps of the preliminary theory of releasing knowledge described in diabetes (Figure 3).

Moreover, the analysis identified relational capacity as the core of the theory, explaining in detail how it was mobilized at each step (Supporting Information: Table S5) and included the capacity to transfer the evidence to next step of the theory (Figure 3). Person-specific evidence pertains to choices people have made in their management of situation-specific challenges and value conflicts in life with an LTHC. To clarify how relational capacity is connected with person-specific evidence, we suggest that person-specific evidence is created by using GSD, whereas relational capacity is an empowering potential it mobilizes that enables people to create change through mutuality. A central part of relational capacity across contexts pertains to people's confidence in mutual solutions and their ability to communicate constructively with others, especially in challenging situations where different points of view or power imbalances are at play.

Completing values-clarifying reflection sheets for encounters with HCPs made it easier for people with LTHCs to talk about their own actions or omissions: things they had discovered needed to change and that previously might have been unconscious, unacknowledged, dismissed or concealed. Actions or omissions could relate to difficult feelings, such as guilt or disappointment with relatives or HCPs, and it seemed pivotal that people with LTHCs opened the dialog by reading aloud their written words or explaining their drawings on reflection sheets. This person-specific evidence seemed to pave the way for an approach that, in contrast to the biomedical approach experienced in previous consultations that people with LTHCs frequently described as impersonal, focused on

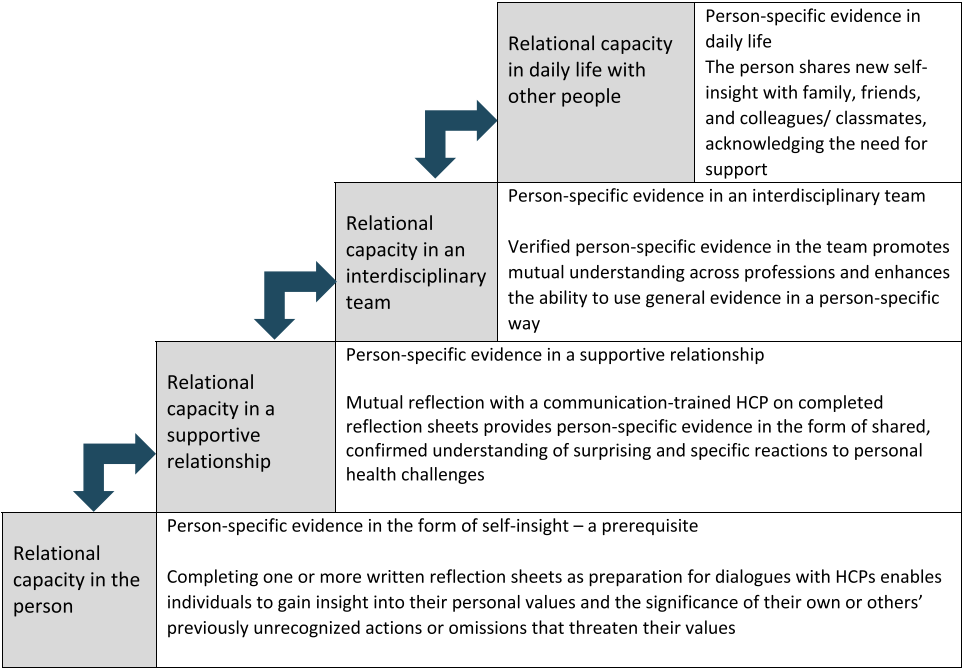


FIGURE 3 The theory of person-specific evidence with its mobilization of relational capacity at four steps.

the specific person's values and challenges in daily life with a health condition.

The theory of person-specific evidence clarifies how this foundation mobilized relational capacity at each step: in the mind of the person with an LTHC, in a supportive relationship with a healthcare professional, in the interdisciplinary team and in everyday life. The different types of relational capacity mobilized in each stage of person-specific evidence are depicted in Supporting Information: Table S5 and described in more detail below.

2.5.1 | Step 1: Person-specific evidence in the mind of the person with an LTHC

Person-specific evidence in the mind of the person with LTHC was a surprising and convincing self-insight that emerged for individuals completing reflection sheets. This step appeared to be a prerequisite for creating person-specific evidence and motivated individuals to discover challenging situations where important matters might be threatened by their own actions or omissions—or those of others. In all cases, relational capacity in this step was a new awareness for people with LTHCs that they might be able to make changes in mutuality with other people. GSD promotes this openness by suggesting that people complete reflection sheets enabling them to consider and write down difficult thoughts and to clarify and express what is important to them. Across studied projects, this relational capacity seemed to initiate the process of coming to terms with an LTHC. For example, one woman indicated on a reflection sheet that she had “made peace with diabetes” and another stated that she intended to “become one with diabetes” (Supporting Information: Table S4, project 20).

The relational capacity of being honest with oneself and others about one's behavior (Supporting Information: Table S4, project 14) was created at this step, along with coming to appreciate truth (Supporting Information: Table S4, projects 3, 10, 16), another important relational capacity. Adolescents often accompanied it with relief and humor. For example, after finishing a GSD group session, adolescents with type 1 diabetes left laughing together at themselves in self-deprecation about their tendency to lie to their parents, always reporting “7.5” (58 mmol/L) as their blood glucose level.

Other examples of mobilized relational capacity at this step included seeing a situation from someone else's point of view (Supporting Information: Table S4, project 16) and seeing one's part in an issue (Supporting Information: Table S4, project 2). A man with schizophrenia became aware of his unfulfilled need for close relationships and realized that he had been the one to end relationships with his family and friends years ago. This awareness enabled him to re-establish contact with his family, a connection he was maintaining a year later.

Supporting each other through a difficult time (Supporting Information: Table S4, projects 4, 19) also exemplified relational capacity, particularly when relatives were involved in completing reflection sheets. For example, a mother and father of a preterm

infant admitted to a neonatal intensive care unit learned about each other's thoughts by sharing their completed reflection sheets. They realized they had not been supporting each other, solving a conflict caused by different points of view. They also discovered that they needed time alone, which was inhibited by too many visits from friends. Together, they found a good way to tell their friends, who received it well, that they needed time on their own.

Another example was observed in the case of a woman treated for breast cancer whose husband was also sick. He accepted an invitation to attend a GSD conversation, completing a reflection sheet in preparation. The couple had considered themselves able to tell each other everything, but the conversation guided by the reflection sheets enabled them to have a new and deeper dialog. The facilitator noted the husband's unconditional support for his wife:

Well, he came with a walker, he smells like urine, he could hardly drag his legs with him, he spent all his energy on coming [to take part in the encounter and support her] and almost the only thing he has written [on the sheet with unfinished sentences] is: “I think she [his wife] should live her life, I think she should get well, I do not think she should be stuck with me.”

After becoming convinced of her husband's support during the GSD conversation, the woman began “to live more,” proceeding with things she had not previously allowed herself to do.

In the first step of person-specific evidence, people with LTHCs became aware that it was counterproductive to keep their disease a secret or avoid involving others in their disease-related challenges. People with diabetes, cancer, endometriosis and end-stage kidney disease, as well as parents of neonates in intensive care, discovered these tendencies while completing reflection sheets. They became aware that keeping their health conditions and its challenges secret and handling everything themselves isolated them and prevented them from getting necessary help or support from others. They realized a connection between not sharing their concerns with others and feeling lonely or unable to solve problems. For some, relinquishing the idea that they ought to be able to handle an LTHC on their own required hard work. A young woman with diabetes finally realized how detrimental trying to handle everything alone had been for her and exclaimed, “It's not just a disease. It's a life!” Taking control of her condition while sharing her difficulties with other people empowered her to subsequently fulfill her dream of becoming pregnant and to complete the pregnancy with minimal diabetes-related stress.

2.5.2 | Step 2: Person-specific evidence in a relationship with a supportive HCP

At the second step, people with LTHCs read their reflection sheets aloud or explained their drawings in a relationship with a supportive healthcare professional. This enabled professionals to ask questions

about the person's reflections using advanced communication skills. An important relational capacity at this step was the verification or rejection of HCPs' previous assumptions, as observed by the researcher in project 20 (Supporting Information: Table S4), who pointed out that HCPs had been previously relying on unverified and "mostly wrong" assumptions about each person's situation, making it difficult for them to provide individualized support. Unverified assumptions had been accompanied by a biomedical focus, which people with LTHCs unanimously described as limiting because it did not focus on them or their daily lives with their health conditions. Person-specific evidence promoted mutual understanding of previously undiscovered issues that were both challenging and important to share to establish a reliable mutual foundation for shared decision-making and problem-solving. HCPs acknowledged that person-specific evidence increased the relational capacity they needed to support people with LTHCs as individuals.

When people had comorbid health conditions, HCPs had often neglected the fact that they had two health conditions and needed to understand how they were connected in daily life to manage both. For example, a boy shared a discovery he had made about a connection between ADHD and incontinence: being easily distracted due to his attention disorder, he often failed to reach the toilet in time. Thus, individuals' daily challenges with family, friends or colleagues were revealed and shared in mutual reflection, enhancing for this boy a mutual understanding of how these challenges affected his situation. Moreover, mutual reflection increased his willingness to follow his parents' personal hygiene requests (Supporting Information: Table S4, project 16).

In both breast cancer and gynecologic cancer, cocreation of person-specific evidence made HCPs aware that they had underestimated the challenges experienced by women with less advanced illness. They realized that their fixed assumption that less advanced illness meant fewer problems should be replaced by the intentional cultivation of openness and respectful curiosity (Supporting Information: Table S4, projects 7, 19).

2.5.3 | Step 3: Person-specific evidence in the interdisciplinary team of HCPs

After these conversations with people with LTHCs, HCPs had confidence in person-specific evidence, which encouraged them to transfer it to a specific colleague on the interdisciplinary team to shed light on questions, hypotheses, or ideas for solutions. Thus, in step 3, person-specific evidence into the person's daily challenges in living with an LTHC was spread to other professionals on the interdisciplinary team (Supporting Information: Table S4, projects 12, 14, 15). This step became central to enabling team members to contribute positively to a specific person's health because the shared person-specific evidence revealed which general evidence they should include in the specific situation (Supporting Information: Table S4, projects 12, 14, 15). For example, person-specific evidence in the interdisciplinary team was important in fertility treatment

when a woman had depressive symptoms that nearly caused her to stop treatment. The nurse hypothesized that these symptoms were side effects of treatment and discussed her hypothesis with the physician, who changed the medication. The woman's symptoms disappeared.

An impeding action that adolescents with LTHCs experienced was the tendency of their parents and HCPs to converse above their level of comprehension, preventing them from participating in decision-making. When they were the central persons completing reflection sheets, this tendency disappeared as parents and HCPs discovered that they had underestimated the adolescents' resources.

Person-specific evidence also made it possible for the supportive HCP to openly share with a colleague that a specific professional behavior needed to change because the person perceived it as disempowering (Supporting Information: Table S4, projects 3, 10, 14). A woman with type 2 diabetes confided to the nurse that she had previously perceived a stigmatizing attitude from one of the physicians. The nurse shared this evidence with the physician, who received it well. He then also made sure that a discovery the woman made about a connection between her tendency to take on the role of the strongest family member and her binge-eating habits was recorded in the journal.

2.5.4 | Step 4: Person-specific evidence in daily life with other people

With their new openness in relationships with HCPs, it became easier for people with LTHCs to share their new discoveries with relatives and other people in their daily lives. Relational capacity at this step was the ability to confide in family, friends, or colleagues about one's difficulties (Supporting Information: Table S4, projects 1, 3, 6–11, 14, 15, 18–20). This was accomplished with or without sharing completed reflection sheets. For the relatives of people on dialysis or with diabetes, ADHD or schizophrenia, these changes in relational capacity might represent a complete transformation in communication. Instead of being rejected as they had been before, they now received an honest response when they asked how the person was doing with the LTHC (Supporting Information: Table S4, projects 3, 6, 16). For example, the woman with binge-eating habits described above became more open with her adult daughter, which decreased her burden related to living with diabetes (Supporting Information: Table S4, project 14).

Some people with early-stage cancer who had previously tried to express their needs to relatives had been met with impatience or a lack of interest because their relatives felt that all problems had been addressed. Reading the reflection sheets, HCPs became aware that discussing certain issues was still important for the person, even years after treatment, and supported the person in finding the courage to resume important conversations with relatives or friends (Supporting Information: Table S4, project 7).

In one case, this prepared a woman with early-stage cancer who lived alone with her son to make an agreement with a friend to adopt the son if she did not survive.

The ability to maintain close relationships and still take care of her LTHC (Supporting Information: Table S4, project 13) was a new relational capacity for a woman who had recently moved in with her boyfriend but had also become aware that the move was ill-timed. She was still overwhelmed by her diabetes and needed to move back to her parents' home to be close to her usual HCPs for a while. However, she also very much wanted to maintain her relationship with her boyfriend. Together, she and the nurse reflected on a good way to tell him. Her boyfriend supported her, and they kept in contact. Conversely, the ability to end a relationship when lack of support was not acceptable (Supporting Information: Table S4, project 5) was also a relational capacity, as in the case of a young woman with type 1 diabetes who realized how detrimental the lack of support from her husband was to her self-concept and self-management. She decided to leave him to prioritize caring for herself and her diabetes and transformed from being known by others as appearing cross to blooming in her attitude to other people and to life.

In an intensive psychiatric unit, a woman who had been living with schizophrenia for decades told the HCP that completing a single GSD sheet with unfinished sentences helped her tell her story for the first time in her life. Her spontaneous reaction was: "Where were those sentences when I as a young person was diagnosed with a psychiatric condition? They would have helped my young self a lot!" The benefit she found in this experience made her start providing altruistic support (Supporting Information: Table S4, project 17) to young people newly diagnosed with psychiatric health conditions.

Resuming activities important to one's identity (Supporting Information: Table S4, project 15) was a relational capacity observed in fertility treatment when a woman learned that eliminating activities that were important to her identity, such as playing tennis, unnecessary. Embarking on new activities with other people (Supporting Information: Table S4, projects 1, 6, 18, 19) was also seen as a relational capacity. After a woman told her adult daughter about challenges with her health condition, they began hiking together. Another woman began eating lunch with her colleagues after telling them she had type 1 diabetes, which she previously had kept secret.

Accepting support and being persistent in getting help from others to reach a goal (Supporting Information: Table S4, project 6) was observed when a man needed a bigger apartment to begin home hemodialysis, a goal which HCPs previously considered unlikely that he would reach. To get a new apartment, he was sent from one office to another until he reached the right one, and he patiently waited in a telephone queue for hours to talk with a specific clerk. His new persistence came from the realization that home hemodialysis would "give him a life" (Supporting Information: Table S4, projects 3, 7–9, 12).

3 | DISCUSSION

The two-fold study purpose was to: (1) investigate whether the finding of person-specific evidence in diabetes was replicable across diverse LTHCs using GSD and (2) develop a grounded theory explaining how person-specific evidence used in mutual decision-making contributes to self-determination and empowerment among people with LTHCs.

Constant comparison of example situations from 20 intervention studies demonstrated that the finding of person-specific evidence in diabetes was replicable through the use of GSD across all the LTHCs. Arguably, three aspects of the GSD approach systematically yielded person-specific evidence: (1) a written invitation to collaborate delivered to the person, (2) one sheet or a set of reflection sheets completed in writing by the person as preparation for encounters with HCPs, and (3) HCPs' advanced communication skills that facilitated the process.

A strength of SDT is its thorough empirical research foundation showing the need for developing autonomy, competence, and relationship with others to become self-determined. However, ideas for realizing SDT in practice are less well described. In search of a solution, integrating SDT with motivational interviewing (MI), developed from the bottom up, has been attempted with limited success; flaws in autonomy were observed (Deci & Ryan, 2012). Developers of MI have pointed out that MI can easily change during dissemination (Miller & Rollnick, 2009), which may be due to its intuitive foundation. The replicability of person-specific evidence across all 10 LTHCs may indicate that GSD tends to be stable, likely due to its foundation in grounded and general theories and use of reflection sheets.

The second purpose of the article was to explain how person-specific evidence used in mutual decision-making contributes to self-determination and empowerment among people with LTHCs, highlighting the importance of collaborating with the individual person with an LTHC. Moreover, the stepwise movement of person-specific evidence with mobilization of relational capacity at its core showed the broad impact of increased relational capacity not only in the person with an LTHC, but also in the supportive HCP, in the interdisciplinary team of HCPs and in people in the person's daily life. Robust knowledge about the people they care for has been an enduring aim in nursing, for example, proposed by Radwin as *knowing the patient* (Carper, 1978; Radwin, 1995, 1996; Rycroft-Malone et al., 2016). Thus, introducing the theory of person-specific evidence and ways to accomplish it in nursing and other health professions seems timely. It also appears to be consistent with the aims of health literacy, advancing people's "ability to interact and express personal and societal needs for promoting health" (Nutbeam & Muscat, 2021, p. 1382). The fundamental step of person-specific evidence in the person's mind highlights the importance of prompting self-reflection and self-exploration, as suggested by life skills approaches (Mullen, 1985) in preparation for dialogs with HCPs (Carper, 1978).

Person-specific evidence in a supportive relationship with an HCP indicates the importance of having a secure relationship with an HCP with advanced communication skills with whom people can share their new discoveries for the first time (Mullen, 1985). Shame, guilt, and fear of stigma (Hamann et al., 2017; Loughlin et al., 2022) may play major roles in the relationship between the person with an LTHC and the HCP, and these apparently diminish during steps one and two of cocreating person-specific evidence and step four of making life changes. For HCPs, the ability to distinguish critically between unverified assumptions about a person and person-specific evidence verified by the person it concerns seems central to their readiness to share the evidence with the interdisciplinary team. At the team step, person-specific evidence appears to have two advantages: (1) it suggests specific team members involve in problem-solving and (2) it makes it easier to specify general evidence that is meaningful in a specific situation. Person-specific evidence thus contributes to existing shared decision-making models (Bomhof-Roordink et al., 2019; Légaré & Witteman, 2013; Mulley et al., 2012) by providing a way to avoid “the silent misdiagnosis of patients’ preferences” (Mulley et al., 2012, p. 1). The ultimate fourth step of person-specific evidence, sharing the evidence with other people in everyday life, had been participants’ major challenge for many years and was a major breakthrough in developing life skills to self-manage their conditions (Allen et al., 1995).

Researchers developing a theory about integration in diabetes have identified a knowledge called “science of one” (Deshaias & Hernandez, 2011; Hernandez, 1995; Hernandez et al., 2016) that has similarities with person-specific evidence. It was achieved by only few persons with diabetes (“specialist patients”) and, remarkably, without help from HCPs. After passing a turning point, these individuals stopped jeopardizing their health and started living with their condition. The findings reported here show that HCPs can support people’s integration of LTHCs when person-specific evidence is used in shared decision-making (Hernandez, 1996). Decreased loneliness, which appeared to be a clear effect of starting to accept support from others, was an important finding (Supporting Information: Table S4, projects 10, 12, and 20). Indeed, its importance can hardly be overestimated due to the consequences of loneliness for physical and mental health and, equally important, the ability to manage illness and treatment (Hawkley & Cacioppo, 2010).

Increased relational capacity suggests that person-specific evidence paves the way for open communication. Along with trust and mercy, open communication is a sovereign expression of life in the Danish philosopher Løgstrup’s view of interdependence as a basic ontological condition for existence (Løgstrup, 1956, 1972; Rabjerg, 2014). In contrast, “encircling internal thoughts and emotions” tend to close people off from fellow human beings and life itself, whereas the sovereign expressions of life direct people towards human beings and life. An example of this appears in the case of a gynecologic cancer survivor who asked a friend to adopt her son if she died, even though she felt fine (Supporting Information: Table S4, project 7).

This openness will likely accomplish changes that can be visualized by the Johari Window model of self-awareness (Sutherland, 1995), which consists of four quadrants: an open quadrant known to all, a quadrant known to oneself but unknown to others, a quadrant unknown to oneself but known by others and a quadrant unknown to all. Person-specific evidence gained by writing or drawing on reflection sheets seemed to increase the readiness of people with LTHCs to allow HCPs behind facades they had maintained for years, reducing the extent to which they were unknown to themselves and to both themselves and others. Accordingly, the quadrant which was known both by themselves and others enlarged considerably (Ramani et al., 2017).

Drawing on Blumer’s symbolic interactionism theory (Blumer, 1969), people do not necessarily exercise excellence in construction of their actions; this point makes it easy to understand the tendency among people with LTHCs to conceal such actions. However, awareness of one’s values at the first step of person-specific evidence appears to enable the person to share their considerations beyond what they may perceive as weaknesses or shortcomings. We attribute this to the values-clarifying mechanisms of GSD’s reflection sheets, especially the unfinished sentences, and the associated communication skills, especially values-clarifying responses.

The theory of person-specific evidence elaborates on the concept of relational capacity, which was identified as the core concept. Two decades ago, Hartrick (1997) challenged mechanistic models of human relating, suggesting relational capacity as an alternate approach that enables nurses to make a profound difference in peoples’ health and healing experiences. However, Hartrick only addressed nurses’ ability to engage in caring relationships, whereas the theory of person-specific evidence encompasses relational capacity as the core concept in relationships with oneself, supportive HCPs, the interdisciplinary team, and daily life with others.

As a pragmatic grounded theory (Strübing, 2007), person-specific evidence is both intervention-informed and intervention-informing. In general, person-specific evidence may contribute to bridging the gap between evidence-based and person-centered care and inspire a broader perspective on evidence (Harvey, 2013; Rycroft-Malone et al., 2004). It appears that person-specific evidence also clarifies which general evidence should be used in specific shared decision-making (Dopson et al., 2010). For example, if person-specific evidence had not been interpreted as signs of depression in the young woman in fertility treatment, the formal evidence that these symptoms were a possible side effect of a specific drug might not have led to the medication change that enabled her to continue treatment. Person-specific evidence may also decrease gaps between the person who needs healthcare and the HCP who delivers it and between HCPs with different educational backgrounds, traditions and interests (Rycroft-Malone et al., 2016). The latter was recently reported as an experience of nurses taking part in a GSD intervention in gynecologic cancer (Dehn et al., 2022).

Person-specific evidence seems to be more easily generated when people prepare for encounters with written GSD reflection

sheets. Notably, only one sheet might be required, as was seen even in the complex area of intensive psychiatric care where a single sheet with unfinished sentences sufficed. Incomparable interventions, such as therapeutic writing (Bolton, 2008) and guided imagery (Menzies & Jallo, 2011), people with LTHCs also represent their thoughts by writing and drawing. The value of reflection in accomplishing person-centeredness has been studied primarily in terms of HCPs' reflection but has been emphasized in recent studies as important to people's reflection-based narratives (Kober et al., 2018; Mann et al., 2009; Zwart et al., 2017). Similarly, our study strongly suggests the need to study the benefit of reflection conducted by people with LTHCs. Person-specific evidence seemed to connect people by eliminating the resistance of people with LTHCs to talk about difficult matters and the reluctance of HCPs and relatives to focus on them.

It appears that person-specific evidence can be accomplished if new approaches such as GSD are used in decision-making in clinical practice. However, as stressed by Burton et al. (2019), an implementation must also include understanding how to de-implement traditional ways. It is important that "the insight used to inform practice has been subject to scrutiny" (Rycroft-Malone et al., 2004). Although HCPs across disciplines agree that evidence-based approaches are pivotal to high-quality care, researchers still debate what counts as evidence (Rycroft-Malone et al., 2004) and how to optimally combine different kinds of evidence (Sackett, 1997). The four-step theory of person-specific evidence with its ability to mobilize relational capacity adds constructively to this discussion.

3.1 | Strengths and limitations

We regard the findings in this study as strengthened by the fact that the same potential for person-specific evidence was observed in 10 very diverse LTHCs and 20 GSD intervention projects across LTHCs in Denmark, Norway, Sweden, and Australia. Moreover, the theoretical foundation of person-specific evidence is built on 20 years of pragmatic grounded theory that enables the well-respected theories of self-determination and life skills to be translated into the care of people of all ages with diverse LTHCs. The grounded theory methodology applied in pragmatic research is a strength due to its documented ability to reach interpretive explanation (Sandelowski & Barroso, 2003). The validity of the theory was enhanced by the identification of relational capacity as its core.

However, the study has also limitations. Our understanding of person-specific evidence is based on data from a single approach, GSD. Further studies may reveal details about person-specific evidence related to the various approaches applied in future research. Moreover, all researchers were trained in the use of GSD by V. Z., which can be both an advantage in terms of fidelity of the method but may also have influenced their likelihood of identifying person-specific evidence in the examples they provided. GSD was originally designed to be delivered at a high dose to pave the way for collaboration even when deadlocks of varying intensity exist. It would

strengthen the implications of person-specific evidence and its ability to mobilize relational capacity if future research investigates its potential in GSD at lower doses and as an effect of various approaches across LTHCs. It was beyond the scope of the current article to provide a full description of the ability of specific GSD tools to provide person-specific evidence. A limited description of GSD was provided to enable readers to understand how GSD supports the cocreation of person-specific evidence in shared decision-making.

4 | CONCLUSION

The finding of person-specific evidence in a GSD intervention in diabetes was replicable across diverse LTHCs. Moreover, it presents a four-step grounded theory of person-specific evidence that explains how this type of evidence can mobilize an empowering relational capacity when used in shared decision-making. The theory of person-specific evidence will likely contribute to the debate in LTHCs about what counts as evidence and increase HCPs' critical awareness of the limitations of unverified assumptions as the foundation for shared decision-making. The theory suggests that the foundation of shared decision-making should include person-specific evidence. Increasing the awareness of this kind of knowledge in LTHCs may increase HCPs' ability to support people across LTHCs and inspire researchers to create and compare additional ways to gain person-specific evidence.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

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