Impact of the person-centred intervention guided self-determination across healthcare settings—An integrated review

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Abstract
Aim: To review the evidence of the existing literature on the impact of guided self-determination across methodologies in different healthcare settings.

Methods: An integrated five-stage review.

Results: Forty-five eligible papers were included. Guided self-determination was applied in full- or small-scale, or combined with another intervention or approach in different healthcare settings handling, for example diabetes, stroke survivorship, schizophrenia, attention-deficit hyperactivity disorder and medical disorder, gynaecological and breast cancer, endometriosis, persons with chronic pain, persons in haemodialysis and intensive care survivors. The included studies covered 12 randomised trials, 26 qualitative and seven papers of different methodology. A statistically significant effect was found in three trials. Six main themes describe the qualitative findings across papers on patients: (1) Guided self-determination reduces disease-related loneliness, (2) Insight enables integration of life and disease, (3) Reflection sheets—an appreciated but challenging tool to prompt insights and person-specific knowledge, (4) New person-specific knowledge enables person-centred support, (5) Feeling seen and believed in a new and trusted relationship and (6) Exchange of knowledge enables the development of life skills. Four themes describe the healthcare professionals’ experience: (1) Change of usual practice—a decision from above, (2) A new role—unlearning previous behaviour and need for support, (3) Reflection sheets as facilitators and barriers and (4) Discovering the benefits of changing to a person-centred approach.

Conclusion: Overall, guided self-determination proved to have a great impact on patient important outcomes and was useful and well-accepted by the majority of patients and healthcare professionals. Albeit guided self-determination is not a ‘one size fits all’ method. Continuous training and supervision of professionals are a

Study registration: OSF, https://osf.io/rjk5u

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INTRODUCTION

On a political level, person-centred care is acknowledged as an essential aspect of quality in health care. In 2018, two reports defined effective quality of care to be person-centred and responsive to individual preferences, needs and values [1, 2].

There is fairly strong evidence that most interventions promoting person-centred care lead to significant person-centredness in a consultation process and that improved person-centred care skills in staff improve patient satisfaction [3]. Patient participation has been reported to be strongly associated with favourable judgements about hospital quality and reduced risk of experiencing an adverse event [4]. However, translating research into practice comes with challenges and has been reported to be one of the most consistent failures in health research [5]. It is therefore suggested to collect all evidence about a specific matter in a review to provide easily accessible evidence to clinicians and policymakers, enabling them to make informed decisions on implementation.

The guided self-determination (GSD) method is a person-centred intervention, developed more than 15 years ago [6] and widely used in different populations [7–15], but a review collecting the evidence of GSD has never been performed. The GSD method, first developed for Type 1 diabetes (T1DM), consists of 21 reflection sheets in a predefined order, which patients fill in and bring to sessions with healthcare professionals (HCP), who use advanced professional communication skills to further support patient reflection, shared insight and problem-solving [16]. The GSD method has been used in research trials testing effect and qualitative research investigating experiences of GSD from both providers’ and receivers’ point of view.

Even though RCTs are considered gold standard regarding evidence of effectiveness, clinicians and policymakers are also interested in whether an intervention is useful to patients and appropriate in the used context [17]. Therefore, the overall purpose of this integrated review was to collect, synthesise and disseminate research covering different methodologies on the GSD method to make it easily accessible.

AIM

To review the evidence of the literature examining the impact of the GSD method across methodologies in different healthcare settings.

METHODS

An integrated review was conducted in a systematic five-stage approach developed by Whittemore & Knafli [18]: problem identification, literature search, data evaluation, data analysis and presentation. The protocol was registered in OSF 19th January 2021: https://archive.org/details/osf-registrations-rjk5u-v1

Stage 1: Problem identification

Five research questions determined the aim:

1. In which healthcare settings and populations has the GSD method been used, and in which form (content, dose and delivery)?
2. Which outcomes and effects have been reported?
3. What experiences and effects do patients describe and value when receiving GSD? Are there common patterns across populations and settings?
4. What experiences and effects do the HCPs describe and value when delivering GSD in clinical practice? Are there common patterns across populations and settings?
5. What barriers and facilitators have been reported when implementing the GSD method in clinical practice? Are there common patterns across populations and settings?

Stage 2: Literature search

A systematic search was initiated 1st March 2020 in the databases PubMed, CINAHL, PsycINFO and EMBASE in collaboration with a health professional librarian. The search was updated 23rd December 2021, see Table 1.
The GSD method delivered as full-scale or small-scale authors against the in- and exclusion criteria through 3585 papers were screened independently by the two for screening (Figure 1). After removing duplicates, Covidence (Covidence, covidence.org/) was used. Initially, 4082 papers were imported. Inclusion criteria

- Full-text peer-reviewed papers published in English, Swedish, Norwegian or Danish between 1st January 2000 and 23rd December 2021.
- The GSD method delivered as full-scale or small-scale or as part of an intervention.
- All types of methodologies investigating GSD, all types of outcomes evaluating GSD, all patients at all ages receiving GSD and all HCP professions providing GSD.

Exclusion criteria

- Studies older than 20 years, protocols, abstracts or conference contributions.

Search outcomes

The software Covidence (Covidence, covidence.org/home) was used. Initially, 4082 papers were imported for screening (Figure 1). After removing duplicates, 3585 papers were screened independently by the two authors against the in- and exclusion criteria through abstract and title. A total of 3529 were excluded, and 56 papers were full text assessed. The developer of GSD Vibeke Zoffmann was consulted as expert, and she pointed three GSD experts from Norway, Sweden and Australia. After expert consultation and a snowball search, eight extra papers were added. In total, 45 papers were included: 26 qualitative, 12 randomised clinical trials (RCTs), two mixed methods studies and five of different methodology.

Stage 3: Data evaluation

Quality was assessed independently by the two authors, and inconsistencies were discussed to reach consensus. The consolidated criteria for reporting qualitative research (COREQ) [19] were applied to the qualitative papers and the Revised Cochrane Risk-of-Bias Tool (RoB 2) [20] for RCTs. Seven papers could not be classified as qualitative or RCTs. Six derived from RCTs but investigated fidelity [21–23], feasibility [12], recruitment [24] and screening associated with the need of GSD [25]. The last was a mixed-method evaluation [26]. The papers on fidelity [22, 23], feasibility [12] and recruitment [24] did not use classical implementation or piloting designs.
why no checklists were suitable. However, the screening paper [25] could be assessed using Standards for Reporting Diagnostic Accuracy Studies (STARD) and was considered complete and transparently reported. A fidelity paper used a mixed-method design [21]. This paper and the mixed-method evaluation paper [26] were assessed by the Mixed-Method Appraisal Tool [27] and considered of good quality.

Quality assessment of qualitative papers

Each item in COREQ was rated to be of low, high or unclear quality (see results in Tables S1–S3).

Risk of bias assessment of the 12 RCTs

Eight papers were considered to have a high risk of bias [11, 14, 16, 28–32], three to have some risk of bias [9, 15, 33], and only one to have a low risk of bias [8] (see detailed results in Tables S1–S3).

Stage 4: Data analysis

First, all characteristics from the papers were entered into a matrix (available in Tables S1–S3) later converted into Table 2. The results from the qualitative papers were transferred to NVivo and analysed using thematic analysis [34]. The results from the RCTs and the papers with other methodologies were summarised.

Stage 5: Presentation

Characteristics of included studies are summarised in Table 2.

RESULTS

Characteristics of studies

In total, 45 papers were included: 26 qualitative, 12 randomised trials, two mixed methods and five of
different methodology. Twenty-seven were Danish, 14 Norwegian, two Swedish and two Australian, mostly covering out- but also in-patients healthcare settings and general practices. Receivers of GSD were aged between 12 and 89 years with the following conditions or diagnosis: diabetes, stroke survivors, schizophrenia, attention-deficit hyperactivity disorder (ADHD) and a medical disorder, gynaecological cancer, breast cancer, endometriosis, persons in need of haemodialysis, persons with chronic pain, intensive care unit (ICU) survivors and relatives, and parents at a neonatal care unit. HCPs’ experiences of delivering GSD were investigated in different settings: out-patients, general practices and in-patient wards.

The GSD method, content, dose and delivery

Guided self-determination was delivered either as full-scale, with all or with a small reduction in the number of reflection sheets, as small-scale, with a significant reduction in reflection sheets, or as part of an intervention using selected reflection sheets together with other content. Advanced communication skills were used in all ways of delivery (Table 2 and Tables S1–S3). Guided self-determination was delivered by physicians, a dietician [35], diabetes educators [36], social healthcare assistants [37] and nurses [35, 37–41]. All HCPs had followed a structured training program.

Effects of the GSD method

Guided self-determination was delivered differently in the trials: small-scale with a few reflection sheets [14], as part of an intervention using reflection sheets with unfinished sentences [30, 31], as part of an intervention with use of various adjusted reflection sheets [29], stepped-care [11], a flexible approach with individual or groups sessions [15], and a full-scale GSD with approximately 20 reflection sheets distributed on 8 [16] or 10 sessions [9], or group [28, 32, 33] or individual sessions with parents participating [8]. Only three trials reported a statistically significant improvement on the primary outcome: HbA1C in diabetes patients [16, 33] and physical well-being in gynaecological cancer survivors [11] (Table 3). Two of the trials had a high risk of bias [11, 16], and one had some risk of bias [33] meaning that results should be interpreted with caution. Multiple secondary outcomes were reported but are outside the scope of this review.

Six papers reported from the trial processes. As to recruitment, high readiness to participate and a low dropout of 8% were reported in people with schizophrenia [24]. In gynaecological cancer, psychological distress seemed to predict the number of GSD conversations needed [25]. A feasibility study conducted in breast cancer found the intervention feasible and acceptable [12]. Three papers evaluated fidelity of HCPs’ delivery. In stroke, 80% of the interventions were completed within the criteria of high fidelity [22]. The trial on ICU survivors reported high intervention fidelity in relation to consistent delivery in sessions [21]. Finally, in a neonatal care unit, high intervention fidelity was reported based on a framework supporting provider training and intervention delivery [23].

Experiences of receiving and delivering the GSD method

Experiences were investigated from the perspectives of patients and HCPs, the themes are listed in Table 4.

Patient’s experiences of receiving GSD

Across all papers, working with the GSD method, patients gained retrospective insight as they became aware of how alone they had felt and realised that they had not managed to integrate the disease as a natural part of their lives previously. The reflection sheets facilitated self-insight and helped the majority of patients to communicate their challenges to the HCPs. Next, their challenges became the subject of a joint problem-solving process with a trusted HCP, who contributed with disease-specific knowledge. This process supported most patients in developing life skills dealing with their disease. The findings will be described in six main themes.

GSD reduces disease-related loneliness

Across diseases and settings, GSD broke a bubble of loneliness. Adolescents with diabetes described that GSD ‘created a sense of belonging and mitigated the feeling of loneliness’ [42]. Feeling lonely was the motivation for participating in GSD for some persons with endometriosis, and they realised they were not alone [13]. A person with schizophrenia chose to work with ‘human isolation’ in the GSD sessions because of feeling alienated and socially excluded all his life. During the sessions, this person felt understood for the first time [43]. Gynaecological cancer
<table>
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<tr>
<th>Study</th>
<th>Approach</th>
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<th>Context</th>
<th>Participants</th>
<th>The GSD method</th>
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</thead>
<tbody>
<tr>
<td>Zoffmann, V et al., 2006 [16]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To test the effect of guided self-determination (GSD)</td>
<td><strong>Setting:</strong> Hospital</td>
<td>Type 1 diabetes patients with persistent poor glycemic control  (N = 61)</td>
<td>Full scale (group)</td>
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<td><strong>Data collection:</strong> Questionnaires &amp; HbA1C in blood samples</td>
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<td><strong>Country:</strong> Denmark</td>
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<td><strong>Name:</strong> GSD</td>
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<td>Weis, J et al., 2013 [14]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To investigate the effect of the Guided Family-Centred Care intervention (GFCC)</td>
<td><strong>Setting:</strong> Hospital</td>
<td>93 families with an Infant of gestational age up to, and including, 34 weeks and 0 days  (N = 134) parents</td>
<td>Part of an intervention/ reflection sheets (parents) <strong>Name:</strong> GFCC</td>
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<td><strong>Data collection:</strong> Questionnaires</td>
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<td>Husted, G et al., 2014 [8]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To test the effect of Guided self-determination Youth (GSD-Y)</td>
<td><strong>Setting:</strong> Outpatient clinics at two hospitals</td>
<td>Adolescents between 13–18 years old diagnosed with type 1 diabetes for &gt;1 year and their parents (N = 71)</td>
<td>Full scale (individual &amp; parents) <strong>Name:</strong> GSD-Y</td>
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<td><strong>Data collection:</strong> Questionnaires &amp; HbA1C in blood samples</td>
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<td>Jørgensen et al., 2015 [9]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To investigate the effect on insight of GSD-SZ</td>
<td><strong>Setting:</strong> Assertive Outreach Teams</td>
<td>Adults with schizophrenia (N = 101)</td>
<td>Full scale (individual) <strong>Name:</strong> GSD-SZ</td>
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<td><strong>Country:</strong> Denmark</td>
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<td>Zoffmann, V et al., 2015 [15]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To test the effectiveness of a flexible guided self-determination intervention (GSD)</td>
<td><strong>Setting:</strong> Outpatient clinics</td>
<td>Younger adults with poorly controlled Type 1 diabetes (N = 200)</td>
<td>Full scale (group or individual) <strong>Name:</strong> GSD</td>
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<td><strong>Data collection:</strong> Questionnaires &amp; HbA1C in blood samples</td>
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<td><strong>Country:</strong> Denmark</td>
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<tr>
<td>Jensen JF, et al., 2016 [30]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To test the effectiveness of a post-Intensive Care Unit (ICU) recovery Program The RAPIT-study</td>
<td><strong>Setting:</strong> 10 ICUs</td>
<td>Danish-speaking adults (\geq 18) years who had been mechanically ventilated (\geq 48) h and who did not meet criteria for baseline dementia (N = 386)</td>
<td>Part of an intervention/ reflection sheets (individual &amp; relatives) <strong>Name:</strong> The individual ICU recovery program</td>
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<td><strong>Data collection:</strong> Questionnaires</td>
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<td><strong>Country:</strong> Denmark</td>
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<td>Olesen, ML et al., 2016 [11]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To assess the effect of Guided Self-Determination Gynaecological cancer (GSD-GYN-C)</td>
<td><strong>Setting:</strong> Outpatient clinic</td>
<td>Women surgical treated for ovarian, endometrial, cervical, vulvar cancers or borderline tumours without recurrence (N = 165)</td>
<td>Full scale – in a stepped care approach (individual) <strong>Name:</strong> GSD-GYN-C</td>
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<td><strong>Data collection:</strong> Questionnaires</td>
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<td><strong>Country:</strong> Denmark</td>
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<td>Mohn J et al., 2017 [28]</td>
<td><strong>Methodology: RCT</strong></td>
<td>To test the effectiveness of GSD-GT</td>
<td><strong>Setting:</strong> Outpatient clinic</td>
<td>Adults with type 1 diabetes and suboptimal metabolic control (N = 178)</td>
<td>Full scale (group) <strong>Name:</strong> GSD-GT</td>
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<td><strong>Data collection:</strong> Questionnaires &amp; HbA1C in blood samples</td>
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<td><strong>Country:</strong> Norway</td>
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| Brorsson, AL et al., 2019 [33] | **Methodology:** RCT  
**Data collection:** Questionnaires  
HbA1C in blood samples | To evaluate the effect of GSD-Y                                       | **Setting:** Outpatient clinics in three hospitals  
**Country:** Sweden | Adolescents aged 12–18 years diagnosed with type 1 diabetes >12 months earlier and starting continuous subcutaneous insulin infusion (N = 71) | Full scale (group & parents)  
**Name:** GSD-Y |
| Hjelle, E et al., 2019 [29] | **Methodology:** RCT  
**Data collection:** Questionnaires | To evaluate the effect of a dialogue-based intervention on psychosocial well-being 6 months after stroke. | **Setting:** Eleven acute strokes or rehabilitation units/primary healthcare  
**Country:** Norway | Adults who had had an acute stroke within the past month (N = 322) | Part of an intervention/reflection sheets (individual)  
**Name:** The dialogue-based intervention |
| Bohart S, et al., 2019 [31] | **Methodology:** RCT  
**Data collection:** Questionnaires | To determine whether relatives benefit from a recovery program intended for intensive care survivors. | **Setting:** 10 ICUs  
**Country:** Denmark | Participants were relatives of intensive care patients recruited through the RAPIT-study (N = 181) | Part of an intervention/reflection sheets (individual & relatives)  
**Name:** The individual ICU recovery program |
| Pickering, A et al., 2021 [32] | **Methodology:** RCT  
**Data collection:** Questionnaires | To test whether Guided self-determination used in chronic pain management could improve the health-related quality of life, patient activation and sense of coherence as a measurement of life skills in patients with chronic pain. | **Setting:** Three major multidisciplinary pain centers  
**Country:** Denmark | Patients receiving treatment in the pain centers (N = 200) | Full GSD (group)  
**Name:** GSD |
| Other methodology, n = 7 | **Methodology:** Descriptive study  
**Data collection:** Data, notes and observations from a trial | To report recruitment challenges, how they were overcome and dropout rate from a trial | **Setting:** Assertive Outreach Teams  
**Country:** Denmark | Adults with schizophrenia eligible for the trial (N = 170) | Full scale (individual)  
**Name:** GSD |

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</table>
| Weis J, et al., 2014 [23] | **Methodology**: Inspired by participatory implementation  
**Data collection**: Qualitative and quantitative data | To evaluate and adjust systematic implementation of Guided Family Centred Care (GFCC) in a neonatal intensive care unit | Setting: Hospital  
Country: Denmark | Nurses educated in GFCC and delivering GFCC during an RCT (N = 45) | Part of intervention/ reflection sheets (parents)  
Name: GFCC |
| Olesen, ML et al., 2017 [25] | **Methodology**: Diagnostic and cross-sectional analytic study  
**Data collection**: Questionnaires | To validate the accuracy of the distress thermometer (DT) to detect psychological distress on the Hospital Anxiety and Depression Scale (HADS) among early-stage gynaecological cancer survivors and whether the women’s DT and HADS scores were associated with the need of GSD-GYN-C | Setting: Outpatient clinic  
Country: Denmark | Women surgical treated for ovarian, endometrial, cervical, vulvar cancers or borderline tumours without recurrence (N = 165) | Full scale – in a stepped care approach (individual)  
Name: GSD-GYN-C |
| Saltbæk, L et al., 2018 [12] | **Methodology**: Nonrandomized Feasibility study  
**Data collection**: Questionnaires and clinical data | To test the study procedures and the components of the MyHealth intervention | Setting: Outpatient clinic  
Country: Denmark | Women treated for breast cancer (N = 25) | Full scale + patient-reported outcomes (individual)  
Name: MyHealth |
| Jensen, JF et al., 2018 [21] | **Methodology**: Multistage intervention mixed methods design  
**Data collection**: Quantitative and qualitative data | To evaluate intervention fidelity of nurses’ delivery of the RAPIT recovery program for post intensive care patients | Setting: 10 ICUs  
Country: Denmark | Danish-speaking adults (≥18 years) who had been mechanically ventilated ≥48 h and who did not meet criteria for baseline dementia (N = 386 patients and 27 nurses) | Part of intervention/ reflection sheets (individual & relatives)  
Name: The individual ICU recovery program |
| Bragstad, LK et al., 2019 [22] | **Methodology**: An explanatory sequential mixed methods study  
**Data collection**: Quantitative and qualitative process data | To evaluate to what extent a dialogue-based psychosocial intervention was delivered according to protocol | Setting: Eleven acute strokes or rehabilitation units/primary healthcare  
Country: Norway | Adults who had had an acute stroke within the past month and personnel delivering the intervention (quantitative phase: adults N = 166, qualitative phase: adults N = 14, personnel N = 17) | Part of intervention/ reflection sheets (individual)  
Name: A dialogue-based psychosocial intervention |
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| Enggaard, H et al., 2021 [26] | Methodology: A convergent mixed methods design  
Data collection: Quantitative and qualitative data | To evaluate the impact of the GSD-ADHD-MD intervention on support from nurses, support from parents and adolescents’ self-management of co-existing ADHD and MD | Setting: One outpatient pediatric clinic and one outpatient ADHD clinic  
Country: Denmark                                                                 | Adolescents aged 13–17 years diagnosed with ADHD and a medical disorder (N = 10)  
Name: GSD-ADHD-MD                                                                 |                                                                                       |

Qualitative studies, n = 26

Jørgensen, R et al., 2012 [43] | Methodology: Single case study  
Data collection: Interview and field notes | To analyse how delusional beliefs were indirectly targeted and improved by use of GSD | Setting: Psychiatric hospital  
Country: Denmark                                                                 | A 55-year-old male diagnosed with paranoid schizophrenia  
Name: GSD-SZ                                                                 |                                                                                       |

Bronken, BA et al., 2012 [53] | Methodology: Single case study  
Data collection: Qualitative interviews and observation | The aim was to illuminate how an interactive process of co-constructing stories was established between a person with aphasia and a nurse | Setting: Rehabilitation unit and participant’s home  
Country: Norway                                                                 | A 30-year-old woman, stroke survivor  
Part of an intervention/reflection sheets (individual)  
Name: A dialogue-based psychosocial intervention                                                                 |                                                                                       |

Bronken, BA et al., 2012 [47] | Methodology: A qualitative multiple case approach  
Data collection: Qualitative interviews and observation | To explore how the participants with aphasia experienced participating in the intervention and its impact on their recovery process | Setting: Hospital, rehabilitation unit, and their home  
Country: Norway                                                                 | Seven stroke survivors, one woman and six men, age range 33–72 years  
Part of an intervention/reflection sheets (individual)  
Name: A dialogue-based psychosocial intervention                                                                 |                                                                                       |

Weis, J et al., 2013 [54] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | To explore how parents of premature infants experience GFCC and to compare how parents receive GFCC vs. standard care | Setting: Neonatal intensive care unit  
Country: Denmark                                                                 | Ten dyad interviews with parents and two individual interviews with mothers  
Part of intervention/reflection sheets (parents)  
Name: GFCC                                                                 |                                                                                       |

Kolltveit, B et al., 2014 [38] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | To gain insight into how nurses experience the introduction of a new empowerment-based approach, GSD in outpatient nurse-led group consultations among adults with Type 1 diabetes | Setting: Outpatient clinic  
Country: Norway                                                                 | Five female nurses. Average age: 47  
Name: GSD                                                                 |                                                                                       |
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| Husted, GR et al., 2014 [35] | Methodology: Qualitative realistic evaluation  
Data collection: Qualitative interviews | To explore and illustrate how the GSD-Y method influences the development of life skills | Setting: Paediatric diabetes outpatient clinics  
Country: Denmark | Thirteen adolescents, age range 13–18 years with Type 1 diabetes | Full scale (individual & parents)  
Name: GSD-Y |
| Kirkevold, M et al., 2014 [46] | Methodology: Qualitative interviews  
Data collection: Qualitative interviews | This study evaluated content, structure and process of a dialogue-based psychosocial intervention from the perspective of adult stroke survivors | Setting: Primary care  
Country: Norway | Twenty-five stroke survivors (17 men, 8 women), median age 64 (age range 33–89) | Part of intervention/ reflection sheets (individual)  
Name: A dialogue-based psychosocial intervention |
| Olesen, ML et al., 2015 [41] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | To develop and pilot test an intervention targeting the women’s psychosocial needs | Setting: Outpatient clinic  
Country: Denmark | Sixteen gynaecological cancer survivors | Full scale – in a stepped care approach (individual)  
Name: GSD-GYN-C |
| Zoffmann, V et al., 2015 [48] | Methodology: Single case study  
Data collection: Interview | The woman changes her perception of diabetes dramatically and improves glycemic control and self-reported psychosocial function. The study aims to explore how she achieved the changes | Setting: Outpatient clinic  
Country: Denmark | A 24-year-old woman with Diabetes Type 1 and 10 years of complex eating disorder. | Full scale (individual)  
Name: GSD |
| Jensen, JF et al., 2017 [51] | Methodology: A qualitative longitudinal study  
Data collection: 36 audio-recorded consultations and 68 photographs | To describe the patient experience of ICU recovery from a longitudinal perspective by analysing follow-up consultations (the RAPIT intervention) at three time-points. | Setting: 10 ICUs  
Country: Denmark | 12 ICU survivors in the RAPIT intervention arm | Part of an intervention/ reflection sheets (individual & relatives)  
Name: The individual ICU recovery program |
| Finderup, J et al., 2015 [7] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | How GSD-HD influenced the quality of relatedness between the patient and the GSD-HD nurse | Setting: Dialysis units  
Country: Denmark | Four males and nine females on haemodialysis, age range 20–78 years | Full scale (individual)  
Name: GSD-HD |
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<tr>
<td>Brorsson, AL et al., 2017 [42]</td>
<td>Methodology: Qualitative</td>
<td>To describe adolescents’ perceptions of</td>
<td>Setting: Outpatient clinics</td>
<td>Adolescents aged 12–18 years diagnosed with type 1 diabetes &gt;12 months earlier</td>
<td>Full scale (group &amp;</td>
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<td></td>
<td>interview study</td>
<td>participation in GSD-Y</td>
<td>in three hospitals</td>
<td>and starting continuous subcutaneous insulin (N = 14)</td>
<td>parents)</td>
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<td>Data collection: Semi-structured</td>
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<td>Country: Sweden</td>
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<td>Name: GSD-Y</td>
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<tr>
<td>Lie, SS et al., 2017 [52]</td>
<td>Methodology: Qualitative</td>
<td>To explore experiences with an eHealth</td>
<td>Setting: General practice</td>
<td>12 patients with T2DM – 2 women and 11 men, age range 44–73 years</td>
<td>Full scale (individual)</td>
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<tr>
<td></td>
<td>interview study</td>
<td>intervention based on GSD in general</td>
<td>Country: Norway</td>
<td></td>
<td>Name: GSD eHealth</td>
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<td></td>
<td>Data collection: Telephone</td>
<td>practice from the perspectives of those who</td>
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<td>interviews</td>
<td>dropped out.</td>
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<tr>
<td>Oftedal, B et al., 2017 [40]</td>
<td>Methodology: Qualitative</td>
<td>To describe how diabetes nurses in primary</td>
<td>Setting: Primary care</td>
<td>Four female diabetes nurses 34–54 years old</td>
<td>Full scale (individual)</td>
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<td></td>
<td>interview study</td>
<td>care experience the process of</td>
<td>Country: Norway</td>
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<td>Name: GSD</td>
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<td>Data collection: Individual</td>
<td>learning to practice GSD</td>
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<td>interviews at two points in</td>
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<tr>
<td>Rasmussen, BC et al., 2017</td>
<td>Methodology: Single case study</td>
<td>The experience of one young woman and the</td>
<td>Setting: Online platform</td>
<td>A 24-year-old woman with diabetes for 10 years</td>
<td>Full scale (individual)</td>
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<td>[55]</td>
<td>Data collection: Semi-structured</td>
<td>changes she made to her diabetes self-</td>
<td>Country: Australia</td>
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<td>Name: GSD online program</td>
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<td>interview</td>
<td>management while participating in the GSD</td>
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<td>online program</td>
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<tr>
<td>Rasmussen, BC et al., 2017</td>
<td>Methodology: Qualitative</td>
<td>This study aimed to engage young adults with</td>
<td>Setting: Online platform</td>
<td>Eight diabetes educators Eleven young adults with diabetes between 20–39 years</td>
<td>Full scale (individual)</td>
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<td>[36]</td>
<td>interview study</td>
<td>Type 1 diabetes who have self-reported low</td>
<td>Country: Australia</td>
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<td>Name: GSD online program</td>
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<td>Data collection: Semi-structured</td>
<td>motivation and suboptimal blood glucose</td>
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<td>interviews</td>
<td>control in a specifically tailored GSD</td>
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<td>online program</td>
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<td>Lie, SS et al., 2018 [50]</td>
<td>Methodology: Qualitative</td>
<td>To explore how adults with T2DM experience</td>
<td>Setting: General practice</td>
<td>Ten patients with T2DM – 6 females and 4 males, age range 39–64 years</td>
<td>Full scale (individual)</td>
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<td></td>
<td>interview study</td>
<td>using reflection sheets to stimulate written</td>
<td>Country: Norway</td>
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<td>Name: GSD eHealth</td>
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<td>Data collection: Semi-structured</td>
<td>reflection in the context of the GSD eHealth</td>
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| Karlsen, B et al., 2018 [49] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | To explore the experience of adults with diabetes Type 2 who took part in a GSD intervention. | Setting: General practice  
Country: Norway | Five men and four women with diabetes Type 2, aged 36–67 years. | Full scale (individual)  
Name: GSD |
| Kitzmuller, G et al., 2019 [45] | Methodology: Qualitative interview study – phenomenological hermeneutic  
Data collection: In-depth interviews | To gain rich understanding of the participants’ lived experience of the influence of the intervention on their adjustment process. | Setting: Community care setting  
Country: Norway | 19 stroke survivors, age range 42–83 years | Part of an intervention/  
reflection sheets (individual)  
Name: A dialogue-based psychosocial intervention |
| Lie, SS et al., 2019 [39] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews | To explore how an eHealth intervention based on the eGSD influences the patient–nurse relationship. | Setting: General practice  
Country: Norway | Ten patients with T2DM – 6 females and 4 males, age range 39–64 years | Full scale (individual)  
Name: GSD eHealth intervention |
| Oftedal, B et al., 2019 [57] | Methodology: Qualitative interview study  
Data collection: Individual interviews | Investigates GSD in an electronic format with the aim to explore what can be learned about the written form for health communication. | Setting: Primary care  
Country: Norway | Four female diabetes nurses, age range 36–56 years | Full scale (individual)  
Name: GSD eCommunication |
| Jørgensen, R et al., 2019 [37] | Methodology: Qualitative interview study  
Data collection: Semi-structured interviews and field notes | To explore mental health care professionals’ reactions to using the evidence-based intervention GSD in the care of in patients with severe mental illness | Setting: Mental health hospital  
Country: Denmark | Nurses and social healthcare assistants (N = 9) | Full scale (individual)  
Name: GSD |
Data collection: semi-structured Individual interviews and a focus group interview and use of questionnaires | To assess the implementation of GSD targeting women with complex endometriosis | Setting: Outpatient clinic  
Country: Denmark | Ten persons with endometriosis between 20 and 45 years of age | Full scale (individual)  
Name: GSD-ENDO |
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<tr>
<th>Study</th>
<th>Approach</th>
<th>Aim</th>
<th>Context</th>
<th>Participants</th>
<th>The GSD method</th>
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<tr>
<td>Thisted, LB et al., 2019 [44]</td>
<td>Methodology: Qualitative interview study&lt;br&gt;Data collection: Semi-structured interview</td>
<td>To explore how participants perceived GSD-GYN-C and how it influenced the challenges they faced during their rehabilitation</td>
<td>Setting: Outpatient clinic&lt;br&gt;Country: Denmark</td>
<td>Ten gynaecological cancer survivors between 30 and 70 years of age</td>
<td>Full scale – in a stepped care approach (individual)&lt;br&gt;Name: GSD-GYN-C</td>
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<tr>
<td>Lehmkuhl, L et al., 2020 [58]</td>
<td>Methodology: A qualitative descriptive study&lt;br&gt;Data collection: Telephone interviews</td>
<td>To explore critical care nurses’ experiences of research participation during a one-year recovery program for intensive care survivors</td>
<td>Setting: 10 ICUs&lt;br&gt;Country: Denmark</td>
<td>Fourteen trained intensive care nurses</td>
<td>Part of an intervention/restriction sheets (individual &amp; relatives)&lt;br&gt;Name: The individual ICU recovery program</td>
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<td>Dehn, P et al., 2021 [56]</td>
<td>Methodology: A qualitative interview study&lt;br&gt;Data collection: Semi-structured interviews</td>
<td>To investigate nurses’ experiences of being educated in GSD and their subsequent use of GSD in three different gynaecological settings being asked whether, and how GSD, as a new task, influences their professional role and identity</td>
<td>Setting: Outpatient clinics&lt;br&gt;Country: Denmark</td>
<td>GSD educated nurses working in a gynaecological setting (N = 16)</td>
<td>Full scale used in a stepped care approach in some of the settings (individual)&lt;br&gt;Name: GSD</td>
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<td>Paper</td>
<td>Health setting and country</td>
<td>Primary outcome + follow-up</td>
<td>Results</td>
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<td>Zoffmann, V. 2006 [16]</td>
<td>Diabetes/adults (N = 61) Denmark</td>
<td>A1C Baseline and at 3, 6, 9 and 12 months</td>
<td>A1C was statistically significant lower in the GSD group than in the control group at 12 months Mean diff. 0.41%; (p &lt; 0.0099)</td>
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<td>Weis, J. 2013 [14]</td>
<td>Neonatal care/parents (N = 134) Denmark</td>
<td>Parental Stressor Scale: Neonatal Intensive Care Unit, summary score At discharge of infant</td>
<td>No effect on parental stress was found between groups at discharge of infant Intervention group mean 2.70 (0.67) vs control group mean 2.84 (0.71) mean diff. 0.14 (p = 0.28)</td>
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<td>Husted, G. 2014 [8]</td>
<td>Diabetes/adolescents (N = 71) Denmark</td>
<td>HbA1c Baseline and every third month during the trial</td>
<td>No effect on HbA1c was found between groups at 6 months post treatment Intervention group 9.6% (0.3%) vs. control group 9.1% (0.2%) mean diff. 0.99 (p = 0.85)</td>
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<td>Zoffmann, V. 2015 [15]</td>
<td>Diabetes/adults (N = 200) Denmark</td>
<td>HbA1c Baseline and every 3 months until 18 months after intervention</td>
<td>A borderline significant decrease in HbA1c in the intervention group compared with the control group Intervention group −0.4% vs control group −0.1 (p = 0.073)</td>
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<td>Jørgensen, R. 2015 [9]</td>
<td>Schizophrenia/adults (N = 101) Denmark</td>
<td>Cognitive insight (self-reflection and self-certainty) assessed with the self-rating instrument Beck Cognitive Insight Scale Baseline and after 3, 6 and 12 months</td>
<td>No effect on cognitive insight was found between groups at 6 months post-treatment. Self-reflection: Intervention group −0.8 (4.1) vs. control group −1.0 (4.0) mean diff. −0.79 (p = 0.275) Self-certainty: Intervention group −1.2 (3.4) vs. control group −0.6 (3.3) mean diff. 0.71 (p = 0.222)</td>
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<td>Olesen, ML. 2016 [11]</td>
<td>Cancer/adults (N = 165) Denmark</td>
<td>Quality of life cancer survivors, total scale, and subscales; physical, psychological, social, and spiritual well-being Baseline, 3 and 9 months after randomization</td>
<td>Significantly higher total score and physical well-being 9 months after randomization among those receiving usual care and GSD Total scale: Intervention group 6.79 (1.10) vs. control group 6.24 (1.32) mean diff. 0.56 (p = 0.022) Physical well-being: intervention group 8.16 (1.54) vs. control group 7.35 (1.79) mean diff. 0.81 (p = 0.013)</td>
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<td>Jensen, JF. 2016 [30]</td>
<td>Intensive care/adults (N = 386) Denmark</td>
<td>Health-related quality of life with two aggregated summary scores: Physical Component Score (PCS) and Mental Component Score (MCS) Baseline and after 12 months</td>
<td>No effect on HRQOL was found between groups at 12 months PCS: Intervention group 39.06 vs. control group 37.65 mean diff. 1.41 (p = 0.35) MCS: Intervention group 51.87 vs. control group 49.95 mean diff. 1.92 (p = 0.21)</td>
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<tr>
<td>Mohn, J. 2017 [28]</td>
<td>Diabetes/adults (N = 178) Norway</td>
<td>HbA1C Baseline and 9 months post treatment</td>
<td>No effect on HbA1c between groups at 9 months post treatment Intervention group 8.9 (1.3) vs. control group 8.5 (1.1) HbA1c % mean diff. −0.15 (p = 0.316)</td>
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survivors felt lonely and abandoned after being effectively cured at the hospital, but this changed during the GSD sessions [44]. Stroke survivors also experienced loneliness after hospital discharge [45, 46]; however, the assistance to verbalise experiences helped them out of their loneliness [45, 47]. Though some stroke survivors found the GSD method redundant, not fitting their needs [45].

Insight enables integration of life and disease

During the GSD sessions, many patients realised they had dealt inappropriately with their disease by unknowingly keeping life and disease apart. This new insight was considered a prerequisite for integration of life and disease.

A young person with diabetes [48], persons with endometriosis [13] and haemodialysis [7] realised they had never accepted their disease, and making changes in their lives had been an obstacle. Adolescents with diabetes allowed the disease to be a part of their minds and not a burden, resulting in a more mature approach to manage the disease [35]. A few adolescents with diabetes and their parents did not experience the intended balanced responsibility for diabetes management [35]. Persons with T2DM described how GSD increased their awareness and reformulated diabetes from being an enemy to becoming a friend [49], but a few perceived the GSD method as inappropriate as they had no challenges in managing T2DM [49]. Gynaecological cancer survivors experienced a gap between being cured and still having to struggle with unaddressed needs, and GSD became an appreciated opportunity to address this [44]. Adolescents with ADHD and medical disorder gained a new insight into their lives with two disorders [26].

Reflection sheets—Appreciated but challenging tool to prompt insights and person-specific knowledge

Across studies, it was obvious that new insight and creation of person-specific knowledge were prompted by the reflection sheets. Across diseases, the sheets were described as a necessary tool for reflection in preparation for the GSD sessions with HCPs [13, 42, 44–47, 50]. Some mentioned the sheets’ build-in structure as an advantage [13, 47]. However, people with diabetes working with GSD as eHealth found that the sheets provided less opportunity to elaborate on their responses [50]. Topics induced by the reflection sheets enabled patients to narrate about themselves and their experiences [26, 47] and to ‘put things into words’ [46] that they were previously not aware of [13].
This led to a deepen dialogue on issues otherwise not discussed [13, 42]. In psychiatry, a person experienced the reflection sheets as a neutral zone without underlying intensions of HCPs, ‘It is the reflection sheets that give the questions and I the answers. I am not being told, repeatedly, that I am mentally ill, and it is the reason for my experiences’ [43]. Adolescents with diabetes and coexisting ADHD and medical disorder expressed that they were met with an interest in understanding their perspectives and attributed this change to their completed reflection sheets, which gave them a voice [26, 35]. ICU survivors found reflection sheets helpful in articulating what was important in recovery [51]. Some appreciated the intellectual stimulation represented by written reflection [50]. Even digital reflection sheets followed up by video conversation were found expedient, flexible and suitable by young adults who had lost motivation in diabetes management [36].

In general, patients who experienced the reflection sheets as helpful, experienced that reflection enhanced their recognition and understanding of needs [13, 44, 45]. Some frequently looked back at the reflection sheets to maintain motivation [49]. By contrast, others experienced the reflection sheets challenging. Some adults and adolescents with diabetes experienced the sheets too time-consuming [42, 50]. Additionally, some adolescents expressed difficulties in understanding the sheets and needed help from their parents [42]. Although persons poststroke experienced the topics relevant, some found them difficult to understand and use on their own due to reading troubles, difficulties in concentrating, fatigue or inability to write [46]. Persons with T2DM, who dropped out of a GSD eHealth intervention, experienced the reflection sheets abstract, and felt uncomfortable with, or pathologized by some of the questions [52]. Those, who completed this GSD eHealth intervention likewise found the sheets difficult to understand, the language ‘too academic’ and responding in writing challenging as they found the sheets repetitive and inapplicable to their current life experience and likely to create unnecessary problems [50]. Of note, some suggested that the writing would have been easier if the reflection sheets were on paper instead [50].

New person-specific knowledge enables person-centred support

Across diseases and settings, it was a common theme that GSD facilitated shared knowledge about person-specific challenges that enabled the HCPs to target support. Persons with endometriosis appreciated that the sessions focused on personal needs and preferences, ‘It has been very different I have gotten more in-depth answers and much deeper talks’; additionally, they appreciated the change of focus ‘about me as a person not just the disease’ [13]. Others emphasised that when sharing their newly gained person-specific knowledge with a HCP, they experienced that the HCP contributed with their understanding and provided disease-specific knowledge on disease, treatment and symptoms targeting their needs [7, 13, 43, 45, 47, 49, 53]. In continuation of this, some highlighted that this exchange of knowledge increased their own knowledge of disease-related behaviour [13, 50].

The shared knowledge on person-specific challenges enabled person-centred support [39, 54]. Some underlined that the HCPs’ communicative competencies [13] and disease-specific knowledge [13, 47] were important preconditions for this exchange of knowledge. Moreover, the knowledge exchanged, and personal insights enabled them to explain their disease and challenges to important others [13, 41] and initiated a process of acceptance of one’s situation [13].

Feeling seen and believed in a new and trusted relationship

Several experienced that GSD sessions enabled the parties to ‘get acquainted’, which generated trust [45, 53], confidence, understanding and partnership [39, 53, 54]. Some persons with T2DM described being seen and heard in an unjudging way, in contrast to what they usually had experienced [49]. Persons with endometriosis emphasised the importance of mutual trust enabling them to share intimate concerns [13]. Similarly, gynaecological cancer survivors experienced for the first
time an opportunity to express their fear of dying [44]. Adolescents with diabetes felt seen as a person and not just ‘as a patient’ [35].

Exchange of knowledge enables development of life skills

The exchange of knowledge and the following problem-solving process supported the development of life skills which further mediated the integration of life and disease. People with endometriosis improved on prioritising which problems to address and solve, ‘I have gained a much greater emotional acceptance of the disease... I have gone from frustrations to actions’ [13]. Similar was experienced by persons with T2DM, and acceptance of their situation improved, ‘I discovered the disease as a resource’ [49]. This is in line with gynaecological cancer survivors who acknowledged and accepted their changed life conditions [44]. Stroke survivors found their sense of psychosocial well-being improved through facilitating their expressions about their experiences in a changed life situation [47], ‘We talked about how life would proceed, what I missed and what I felt’ [45]. Furthermore, one stroke survivor described the realisation of the necessity to adjust to a new role [53]. ICU survivors started to accept the new terms of life including memory gaps [51].

In diabetes, GSD inspired and supported patients to make own decisions [49, 55].

Guided self-determination enabled persons in dialysis and with endometriosis to solve own problems [7, 13]. This was supported by persons with diabetes and adolescents with ADHD and medical disorder [26, 49].

In diabetes, an increased willpower and determination in reaching goals were described [49]. Similar was found in stroke survivors, as they expressed setting goals and focus on their future life as valuable [45].

Due to increased understanding of difficulties in their life with disease, more became able to take action [7, 13, 26, 44] and stroke survivors explored different coping strategies [46].

Persons with endometriosis, in dialysis and stroke survivors increased their ability to communicate disease-related issues and needs to family and colleagues [7, 13, 45]. Cancer survivors had refrained from this, but GSD encouraged them to change behaviour and share their thoughts [44]. People with diabetes began to include family members as a resource [49]. Increased openness was also experienced by those with T2DM [50], two young persons with diabetes [48, 55]. In adolescents with diabetes, relationships and communication with parents changed to be less conflicting and mutual understanding increased [42].

Healthcare professionals’ experiences of delivering GSD

Almost no HCPs had prior experience with GSD; therefore, facilitating GSD represented a new role. Most found that the reflection sheets supported their facilitator role, yet others as a barrier. However, all HCPs experienced that GSD supported a change towards a more person-centred approach. This entailed a more positive and collaborative relationship allowing the HCPs to support patients’ management of the disease. In the following, the findings will be described in four themes.

Change of usual practice—A decision from above

None of the HCPs had prior experience with GSD, except for four HCPs who changed from face-to-face GSD to an eHealth format [40]. The rationale for HCPs to learn GSD varied between papers, for example to support internally motivated self-management [56], learning a new way of counselling to stimulate patients’ illness management [39, 40], changing traditional practice towards a more collaborative approach [35, 36, 38], to provide an evidence base for psychosocial support [41], or as part of implementing evidence-based methods into clinical practice [37]. The decision to use GSD was made by researchers or management.

A new role—Unlearning previous behaviour and need for support

Initially, most HCPs felt insecure about the new role. This was denoted as ‘in open waters’ [38] ‘groping in the dark’ [40] or hesitation in starting out with the first patient [37]. When entering the new role, some HCPs found they had to unlearn behaviour such as informing and advising [41], and coming up with solutions [36, 56]. The change of approach made some question own professional competence [56] as traditional practice was built on a ‘safe, professional and disease-specific platform’ [38]. In GSD, the HCPs had to focus on difficulties perceived important by the patients [35, 56]. The HCPs who provided written feedback in the electronic format experienced a change of their communication with patients, some expressed that the advanced communication skills were difficult to use in writing and the relationship with patients became more ‘distant’ [57]. In regard to the new role, several emphasised the importance of professional supervision of the use of GSD [56] to ensure feeling more ‘competent and secure’
[38], particularly when delivering the GSD in ways not familiar, for example eHealth with written feedback [39]. An important aspect, that supported the new role and motivated them to continue, was positive feedback from patients, as it stimulated HCPs’ ‘willingness to persevere in the process of learning to practice the method’ [40]. Some described an increased professional self-esteem [56].

The altered role also changed the professional relationship with the patients towards a more collaborative approach [36], a change that was mentioned by several HCPs as a positive mean of GSD [35, 37, 40, 56], except when GSD was delivered as pure eHealth with written communication, then a ‘more fragile relationship’ with patients was experienced due to no face-to-face contact [39].

Some HCPs participated in follow-up training [38], and some expressed a need for further follow-up training [56], and that continuous use of GSD in clinical practice was of great necessity to improve their skills [39].

Reflection sheets as facilitators and barriers

In most papers, the reflection sheets were highlighted as facilitators, but in some also as a barrier.

Most important, they were considered a tool facilitating collaboration and keeping focus on the patient’s perspective [35–39, 41, 56]. Additionally, saved online reflection sheets created opportunity for the HCPs to revisit previous conversations to ensure personalised plans [36].

The most common barrier was the reflection sheets being time- and energy-consuming [37, 38, 40], especially for the HCPs that provided written feedback [39, 57]. Nevertheless, some expressed that GSD was a ‘good investment’ [40]. Some HCPs found them ‘quite awkward’ to use [40], and some ‘too artificial’ preferring conversations without [37]. Filling in reflection sheets at home was also contemplated as a barrier, as some arrived without filled in sheets [35].

Discovering the benefits of changing to a person-centred approach

Several HCPs realised that the person-centred approach, facilitated by GSD, was necessary to empower the patients, for example ‘it is about empowerment, respect for the client’ [36] ‘it’s based on terms set by the patients’ [56], ‘it relates more to the young person’s problem than it does to my own need to inform’ [35], ‘stop giving advice all the time and instead support the patient in finding the answers himself’ [37], ‘from giving diabetes advice and information to prompting patients’ responsibility for their own health’ [57] and ‘It led to an awareness in me of a totally different way of communicating with the patient’ [40].

Furthermore, the HCPs valued and recognised the patients’ knowledge and experiences, ‘it is the whole patient now’ [56]. This entailed a shift in power to be more equal [36, 38, 40], but also an opportunity to discover the patients’ real challenges in living with their condition [35–38, 40, 55–57], which contributed to a mutual generation of new insights.

Healthcare professionals found this new and of great importance as it introduced openness [36, 40], helped HCPs to support patients’ goals being consistent with their values [35], increased their knowledge and understanding about the patient’s life [39, 40, 58], revealed different views on challenges [38], challenged their prior understandings about patients and unsolved problems at previous encounters with professionals [43] and became more sensitive to patients needs [58] enabling them to target support by combining their disease-specific knowledge with person-centred knowledge [56]. Of note, in intensive care, HCPs stated that better understanding of the patients could reduce stress and increase their job satisfaction [58].

More HCPs noticed that the characteristics of patient-challenges in GSD were different from the challenges identified in usual practice, going from being disease-specific to becoming more of an ‘emotional’ character [38] or addressing ‘psychosocial aspects’ [39, 41].

Some denoted that facilitating GSD took a ‘surplus of energy’ [38, 56] and was ‘time- and energy-consuming’ [40]. However, it was also noted that HCPs’ recognition of patients as an essential contributor to own self-management, entailed patients to take responsibility for the content in sessions [35] and arrived prepared to sessions [40].

DISCUSSION

In the trials, different primary outcomes were applied, but statistically significant effect was only reported in HbA1C [16, 33] and physical QOL in cancer patients [11].

By contrast, the qualitative themes described a positive impact of GSD experienced by both patients and HCPs. The patients gained retrospective insight working with the GSD method as they became aware of how alone they had felt and realised they had not managed to integrate the disease as a natural part of their lives previously. The reflection sheets facilitated self-insight and helped them communicate their challenges to the HCPs. Next, their challenges became the subject of a joint problem-solving process with a trusted HCP, who contributed with disease-specific knowledge. This process supported most patients in developing life skills. A smaller group did not experience any benefits from GSD.
Guided self-determination changed usual practice and introduced a new role to the HCPs. The reflection sheets were experienced as facilitators supporting the HCPs to discover the benefit of a person-centred approach including the exchange of knowledge with patients. Some HCPs experienced the reflection sheets as barriers and the method requiring a surplus of energy.

Considering noteworthy impact of GSD described in the qualitative studies, it is surprising that this was not the case in the trials. This might be because the benefits described qualitatively, such as life skills, are not captured by the outcomes used. Or that the HCP did not have any experiences with GSD ahead of the trials, and some might not have been confident in using the GSD method or collaborate on challenges with patients, as described in the qualitative results. Future trials call for instruments capturing the essence of the patient experienced impact and a generic instrument eligible across settings and conditions which would enable a meta-analysis. To our knowledge, a GSD-specific instrument is under development [59].

Another important finding was that GSD reduced disease-related loneliness. Loneliness has been defined as ‘a subjective feeling of the absence of a social network or a companion’ and has been negatively associated with cardiovascular and mental health outcomes [60]. In cancer survivors [61], stroke survivors [62] and diabetes [63], loneliness has impacted health outcomes negatively. We found that reducing loneliness was related to the reflection on challenges prompted by the reflection sheets both individually and in groups. This suggests loneliness not only to be a subjective feeling of absence of a social network or a companion but also absence of comprehending one’s current situation and challenges.

The Person-centred Practice Framework (PCPF) is a mid-range theory describing constructs important to provide person-centred care [64]. The framework describes five key person-centred processes: working with the person’s beliefs and values, engaging authentically, sharing decision-making, being sympathetically present and working holistically. The findings in this review illustrate how most patients and HCPs experienced GSD to systematically facilitate dialogue, collaboration and shared decision-making focusing on understanding the patient’s world view, beliefs and values, thereby illustrating how GSD underpin many of the person-centred processes described to be necessary to create connections between persons in the PCPF [64]. Guided self-determination also supported nurse’s clarity of own beliefs and values which is described as a prerequisite for person-centred practice [64].

One of the five key person-centred processes engaging authentically and its significance for nurse–patient relationships has been investigated in a scoping review [65]. Four themes were described as follows: (1) the complexity of relationship building, (2) getting to know the patient as person, (3) the patient’s voice and (4) important nurse characteristic and behaviour, under which communication to understand and build trust was found to be important [65]. These aspects of engaging authentically are in line with our findings where both patients and HCPs described how GSD supported relationship building and especially how the reflection sheets gave the patient a voice, provided insight, facilitated understanding, and enabled the nurse to deliver precisely the individualised disease-specific knowledge the patient needed. In the scoping review, authentic connection and relationship building were reported to provide mutually beneficial satisfaction and well-being [65]. This is supported by our findings where patients were satisfied and felt supported, and some nurses described increased professional self-esteem and renewed job satisfaction.

The positive impact of GSD experienced by patients can be understood in relation to the self-determination theory that states that humans in order to thrive have three basic needs that must be met: relatedness, competence and autonomy [66]. Regarding relatedness, a different relation with HCPs and improved relational and communicative competencies increased their ability to communicate their situation. This increased their experience of relatedness by supporting their ability to engage in good and trusted relationships [66]. Regarding competence, patients improved own competence in managing consequences of health challenges. They were supported in developing life skills described as increased competence to make decisions, solve problems, set goals and take actions. Regarding autonomy, these life skills are compatible with an increased sense of freedom to make personal decisions. Taken together, the patients described GSD as being supportive in facilitating meeting the three basic human needs.

These needs might also explain the findings of the HCPs. Their relationship with the patients changed to be more positive, improving the feeling of relatedness. Succeeding in learning to use GSD and adapting to the new role increased their understanding about the patients enabling them to qualify the care, which improved some HCP’s feeling of competence and increased their job satisfaction. Most HCPs did not actively choose to work with GSD which might have been experienced as a decreased sense of autonomy affecting their experience and learning of GSD negatively. In future implementation of GSD, it is of great importance to support internal motivation of the nurses to be trained in GSD. This is in accordance with implementation science highlighting HCPs’ values and beliefs playing an important role in implementing evidence-based interventions in real-world healthcare settings [67].
Additionally, the findings from the HCPs highlight that the GSD method requires follow-up training and continuous supervision in clinical practice to make GSD part of everyday care. This is supported by the literature stating that translating evidence-based practice into effective and sustained implementation is a challenge [68] and that underutilization of new interventions may be related to poor training and lack of supervision [69].

An important finding is that GSD is not ‘one size fits all’. Some patients found the method inappropriate, and some HCPs found the GSD method difficult to learn, time and energy consuming and artificial. This is in line with a recent discussion paper which highlights that person-centred care interventions might have possible disadvantages [70]. Not all patients wish to be included in their care and some have limited capacity to make informed decisions [70]. The focus on person-centred care is mainly on the patient and therefore might diminish the value of the HCPs as autonomous persons, moreover person-centred care might also increase the risk for compassion fatigue due to overload of tasks and engagement in patients [70].

Implications for practice and research

Eight of the 12 RCTs were assessed to have high risk of bias, mainly due to the chosen strategy of analysis, missing outcome data and participants’ knowledge of the assigned intervention. More robust use of RCT methodology is therefore required in future GSD trials. Additionally, outcomes targeting the qualitatively described impact of GSD should be considered as future primary outcomes to enhance the quality of evidence regarding the effectiveness of GSD. We did not find any cost-effectiveness analysis of GSD, why it should be investigated in future studies. To ensure sustainability in the use of GSD in clinical practice it is essential for implementation programs to cover follow-up training and continuous supervision, though further research is needed to decide frequency and duration.

CONCLUSIONS

Overall, the GSD method proved to be useful and accepted from the perspective of most patients and HCPs. Albeit guided self-determination is not a ‘one size fits all’ method. There was a significant effect of GSD in three out of 12 randomised trials. However, numerous qualitative evaluations indicate that GSD has a great impact on patient important outcomes that is not covered by traditional outcome measures.

Continuous GSD training and supervision of the HCPs are necessary during implementation to enhance adoption and sustainability in clinical practice. Finally, it is important to pay attention to advantages and disadvantages when implementing, practicing, and researching person-centred care interventions.

Strengths and limitations

The RCTs were of poor quality due to the assessment of risk of bias. However, all RCT studies were included in the review, as the purpose of an integrated review is to gather, evaluate and overview scientific evidence within a specific field and the synthesis of findings is the major activity. The integrated review is not a systematic review, but uses a systematic approach [18].

This review was limited to English and Scandinavian languages which may have led to omission of important papers published in other languages.

AUTHOR CONTRIBUTIONS

Both authors made equal contributions to the process and writing of the manuscript.

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CONFLICT OF INTEREST

Both MLO and RJ have authored papers included in the review and have been researching the GSD method. The developer of the GSD method, professor Vibeke Zoffmann has supervised both during their PhDs, and they still have a professional relationship. However, the GSD method is a public domain without copyright, and it does not provide any financial outcome.

ETHICS STATEMENT

No formal ethical approval was required for this review.

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REFERENCES


SUPPORTING INFORMATION
Additional supporting information can be found online in the Supporting Information section at the end of this article.